

**HIV PSYCHOSOCIAL CARE AND SOCIAL WORK PRACTICE:
ETHICAL, PROFESSIONAL AND
PRACTICAL ISSUES**

**Comprehensive
Guide for
the Care of
Persons
with
HIV Disease**

Module 6
**Psychosocial
Care**

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DEDICATION

This module is dedicated to the memory of David Kelley, a member of the Canadian Association of Social Workers Ad Hoc Committee on HIV/AIDS, and to all the social workers who have died of AIDS.

David Kelley died on April 25, 1996, after a courageous battle with AIDS, surrounded by friends, family and his life companion, Tom Stewart.

David had a long history in the social services. In Ottawa, he worked for the Youth Services Bureau. When he moved to Toronto, he worked for the Ministry of Community and Social Services, most recently with the Office of Child and Family Service Advocacy. Committed to gay and lesbian youth, David was a co-founder of Positive Youth Outreach and the Toronto Counselling Centre for Lesbians and Gays.

After David learned he was HIV-positive, he found many ways to make life better for people living with HIV. He served as a project officer with the AIDS Bureau in the Ontario Ministry of Health, as executive director of the Toronto PWA Foundation and as co-chair of the Ontario Advisory Committee on HIV/AIDS. Wherever he was, David used his own story of being an HIV-positive gay man to enrich others. He served as a member of the CASW Ad Hoc Committee on HIV/AIDS because he believed that, as a person living with HIV who had been involved in social services, he had something to offer.

Although David never earned a degree in social work, in his work and his life he embodied social work values. Supportive, warm and compassionate, David was an inspiration to all who knew him. We are much richer for having known him, and he is greatly missed.

David chose the following from a poem by Edwin Markham for his funeral program. It captures his approach to work and life.

*They drew a circle that kept me out.
Heretic, rebel, a thing to flout.
But love and I had the wit to win.
We drew a circle that included them in.*



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FOREWORD

Dear Colleague,

This module, HIV Psychosocial Care and Social Work Practice, is the culmination of two and a half years work. Since 1994, the Canadian Association of Social Workers (CASW) Ad Hoc Committee on HIV/AIDS has been working to develop information for social workers and others who provide psychosocial care for people living with HIV.

As a first step, the committee developed a statement on the impact of HIV, which was endorsed by CASW and now guides our practice in this field. The next phase involved extensive research with 299 social workers in Canada active in HIV. The results of the research were analyzed and compiled in this report, *Social Workers and Practice and Practice Wisdom in the Field of HIV/AIDS*. The committee then developed a booklet on working in HIV/AIDS designed to encourage more social workers to get involved. Finally, the committee prepared this module, which describes the ethical, professional and practice issues in HIV, and provides practical information and advice. It is a compilation of the experience that social workers have gained over the past 15 years of the epidemic.

I would like to congratulate the members of the committee for their fine work. I believe they have given us the tools we need to continue to provide high quality, effective psychosocial care for people living with HIV and for those affected by the disease. Social workers have a great deal to offer in this field, and we expect the profession will continue to play a vital role in HIV care. We hope you find the module interesting and useful.

Julie Foley, MSW, CSW
President
Canadian Association of Social Workers

ABOUT MODULE 6

This module attempts to capture social work practice wisdom, and to demonstrate how best practice can be used to meet the psychosocial needs of individuals, partners, families and communities affected by HIV. It also tries to provide the information and support that social workers and others need to respond effectively to people with HIV.

The information in these pages is based on our collective experiences in HIV/AIDS. Many of us have been involved in the field for years. Some of us are relatively new. Some people work on the front line, while others are in teaching, administration, policy development, program development, advocacy and government. We have very different interests in the field and different skills. Many of us have multiple roles. We work, we volunteer and we sit on committees or participate in the community. That is part of what makes this work so rich.

Anyone who works with people with HIV will, at some time, feel personally and professionally challenged. The ethical issues can be daunting. The following pages discuss professional and practical issues associated with providing psychosocial care and describe interventions that social workers have found effective. They cover the social worker's role in:

- providing psychosocial care for people who are infected
- working with society to support those living with HIV and to prevent new infections.

For social workers who have worked for years in HIV and those new to the field, the guide will affirm their practice, answer some of their questions and provide valuable advice and support. The range of knowledge and expertise social workers need to help someone with HIV (e.g., human rights, legal issues, insurance, social assistance, drug coverage, housing, community resources, future planning) may seem overwhelming, but it can be learned and mastered, and there are many who are willing to act as mentors.

One of the challenges of writing about working in HIV is conveying the emotional aspects without sounding maudlin or over dramatic. Passion, joy, laughter, tears, sadness, grief are all part of the work. Throughout the module, we have used quotes from people with HIV, social workers in the field and others. The quotes were taken from a variety of sources. As some people did not want to be identified, the quotes are not directly attributed to anyone.

People often wonder how we can work in a field where people are always dying and still find hope. In this work, it is vital to be able to see the strengths in everyone, and honour each person's ability to cope. Our wish for those who read this module is that you will take the time to grow in HIV work, to listen to your clients and to meet the challenges. It is not an easy task, but it can be extremely rewarding.

CASW Ad Hoc Committee on HIV/AIDS

PREFACE

An Asian-Canadian woman was diagnosed with HIV. The rest of her family was tested and everyone — her husband and two daughters, ages 1 and 3 — tested positive. The husband is trying to keep the family's HIV infection secret. Although the family has a large circle of relatives and friends near by, they are calling on no one for help or support. He has refused any kind of assistance, including home care for his wife and daycare for the children.

A gay man who was not out to his family or employer tested positive for HIV. He retreated into alcohol, and his drinking began to affect his work. The employer had to let him go and he lost all his benefits, including access to long-term disability.

A married woman, pregnant with her third child, was tested for HIV without her consent and tested positive. She had to decide whether to terminate the pregnancy and cope with the anxiety of having her husband and other two children tested.

A young man who is in psychiatric care, uses cocaine, and has sex with men and women for pleasure and to support his cocaine habit, has been diagnosed with HIV. The public health authorities have issued an order instructing him “not to engage in unprotected sex” but, given his psychiatric problems, he may not be capable of understanding the order or acting on it. He is being discharged from a rehabilitation facility with no follow-up.

A baby who was failing to thrive, and whose parents were injection drug users, tested positive for HIV. Both parents then tested positive. The parents loved the child dearly but, because of their substance use, were having trouble caring for the baby.

An aboriginal man with AIDS developed dementia and became delusional. Convinced he had won a \$2 million lottery, he went on a spending spree. His family was left to cope with his actions.

A gay man in the later stages of AIDS asks the social worker for help with an assisted suicide.

HIV is an extremely complex illness. What begins as a health problem can quickly create serious psychological, ethical, social, cultural and financial issues.

This module, one in a series prepared to help professionals provide care for people living with HIV disease, deals specifically with psychosocial care. The module has been written by social workers for social workers, but the authors recognize that social workers are part of a larger team. In many cases, volunteers and non-professionals as well as other professionals provide a significant amount of social support and psychosocial care for people living with HIV. The Canadian Association of Social Workers hopes that others will find this module useful.

SOCIAL WORK PRACTICE AND HIV: SOME BACKGROUND

Social workers, like other professionals, are bound by a Code of Ethics that guides their practice. According to that Code, the goal of the social work profession is to create a society that is more responsive, accepting and compassionate. To do that, social workers strive to achieve social justice for all — a goal unique to the social work profession. Creating a just society involves working with individuals to help them resolve any “private troubles.” However, many private troubles can only be resolved

... social workers in Canada already possess fundamental knowledge and skills through training and practice that must be used in responding to HIV.

Statement on the Impact of HIV
Canadian Association of Social Workers, 1995

through social change. So the profession also works with the larger community and with those who shape public policies and attitudes, advocating for changes that will lead to a healthy, supportive society.

Fundamental to social work practice is the ability to function as part of a multidisciplinary team, which works to give clients access to the full range of services and resources they may need. Part of the social worker's role on the team is to ensure that clients and their families receive care that is provided with dignity and in a way that respects the values of acceptance, self-determination and individuality. Social workers have an obligation to bring these values to the team.

We must act with our clients to change the environment, help prevent HIV infection and provide the care and support people living with HIV/AIDS, their caregivers, and communities may need.

Given the profession's commitment to social justice and to care for the most vulnerable in society, social workers should be active in the HIV field. And they have been. Social workers have

been providing psychosocial care for people living with HIV from the first days of the epidemic. From as early as 1983, professional social workers have been:

- advocating on behalf of people with HIV/AIDS
- helping them find the services and supports they need
- providing emotional support
- helping to organize peer support initiatives
- working with people with HIV and those at risk to help prevent the spread of HIV
- trying to change laws, policies, practices and attitudes that lead to discrimination against people with HIV.

To fulfill their professional obligations under the Code of Ethics for competency in service delivery, social workers in all areas of practice need some understanding of HIV. To help the profession develop and maintain its competency, and respond to the individual and social needs created by HIV, the Canadian Association of Social Workers (CASW) has offered ongoing support, education and information. In November 1990, CASW developed *Preparing for HIV and AIDS*, a brochure and resource kit designed to introduce social workers to the complex psychosocial issues associated with HIV.

Since that time, more social workers have entered the field, and many of the issues and needs have changed. In the fall of 1995, CASW conducted research with social workers working in the field of HIV. Who are their clients? Have they changed? Have their needs changed? What have social workers learned? What wisdom have they gained? What constitutes “best practice” in the psychosocial care of people living with HIV? What type of information and support do social workers need to help them in their work?

RESEARCH INTO HIV SOCIAL WORK PRACTICE

According to the research findings, social workers are active in the field of HIV work in a variety of settings, including: volunteer community-based organizations, hospitals, community social service agencies, out-patient clinics, community health clinics, hospices, advocacy organizations, non-profit organizations, private practice, government departments, and colleges and universities. Some focus on providing direct psychosocial care, others on preventing the spread of HIV in the community, and others on developing policies that will help create a more supportive environment for people with HIV.

A client means:
a person, family, group of persons, incorporated body, association or community on whose behalf a social worker provides or agrees to provide a service
i) on request or with agreement of the person, family, group of persons, incorporated body, association or community or
ii) as a result of a legislative responsibility ...

Social Workers Code of Ethics
Canadian Association of Social Workers 1994

Most people with HIV are between 30 and 39 — although social workers report they are seeing younger clients all the time. Most are men whose risk factor for acquiring HIV was having sex with men, but social workers find that they are now seeing more heterosexual women, more injection drug users and more aboriginal people. In general, their client base has become much more ethnoculturally diverse.

People being infected and diagnosed with HIV in the 1990s also tend to be poorer and more isolated. More have complex psychosocial needs, such as addictions or mental health problems, that complicate their efforts to cope with HIV.

Clients’ more complex needs can also lead to more complicated interventions. According to the research, social workers working with people with HIV are facing more ethically demanding issues, such as end of life decisions, decisions about pregnancy and their own professional responsibility when clients put others at risk.

Building on Social Work Knowledge and Practice to Meet the Needs Created by HIV

In their training and work experience, social workers develop the knowledge, skills and values needed to support people as they cope with stresses, changes and crises — including those triggered by illness and marginalization — and find new hope. Social workers have a professional responsibility to:

- seek out the knowledge they need to overcome any fear or apprehension they may have — either of HIV or the people affected
- apply their social work skills to help people living with HIV and those close to them
- advocate for a supportive social environment for people affected by HIV.

HIV is about death, sex, sexuality, blood and drugs — all the taboos.

Social workers have the necessary skills to provide psychosocial care for people with HIV, but they should be aware of the factors that make HIV “different” from other life-threatening illnesses and of how the illness and the needs it creates have changed over time.

The chart on the following pages describes the factors that make HIV different and their implications for social work practice and for psychosocial care.

The Implications for Social Workers — Or Putting Our Own House in Order

According to the profession’s Code of Ethics, social workers *believe in the intrinsic worth and dignity of every human being and are committed to the values of acceptance, self-determination and respect of individuality.*

Social workers are dedicated to the welfare and self-realization of human beings; to the development and disciplined use of scientific knowledge regarding human and societal behaviours; to the development of resources to meet individual, group, national and international needs and aspirations; and to the achievement of social justice for all.

Most social workers enter the profession because of a commitment to the “intrinsic worth and dignity of every human being,” but working in HIV can challenge our personal values.

HIV infection raises aspects of sexuality, drug use and death that may make some of us uncomfortable. The stigma associated with HIV, the secrecy, social isolation

Stigma

The most significant difference between HIV and other life-threatening illnesses is the stigma associated with the disease. The virus is linked in many people’s minds with homosexuality, injection drug use, sexual activity and the sex trade — behaviours that make many people feel uncomfortable and challenge their attitudes and values. Although HIV cannot be spread through casual contact, many people still have an irrational fear of infection, and avoid anyone who is infected.

The stigma of HIV affects every aspect of life for someone who is infected. Some people internalize the stigma, and feel a deep sense of shame or guilt, which affects how they relate to a social worker and to everyone else. The stigma is disempowering.

Because of the stigma, people living with HIV are often denied the comfort and support our society usually gives to those who are ill. They are marginalized and left to cope with the stresses of an illness within a hostile social environment. The situation is even worse for those, such as gay men, injection drug users and people who are homeless, who were marginalized or stigmatized before they became infected with HIV.

Disclosure is often more difficult for people with HIV than it is for those with more “accepted” illnesses, such as cancer. As a result, people living with HIV often choose not to tell friends, family members, employers or co-workers, and isolate themselves from others who might provide support.

Social workers are dedicated to respond to the needs of people in society who are marginalized or oppressed. Yet the stigma of HIV can also affect social work practice. It may cause social workers to become isolated in their work and to treat clients with HIV differently than other clients. The stigma has led some social workers to believe that “we are the only ones who can deal with these issues,” so they don’t reach out, help others learn about HIV, refer clients to other services or take advantage of other expertise in the community — as they would with other clients.

Social work practice, which has always been based on building a network of services and supports for clients, will suffer if social workers allow fear and stigma to drive good practice. Instead, social workers must ask themselves: what needs to be different for this client? what can be the same? Given the complexity of issues and needs, social workers must continue to work collaboratively with other professionals to help people help themselves.

Client confidentiality, a social work value, is a crucial issue in HIV practice. The client’s concerns about confidentiality may, at times, hinder social workers’ efforts to help clients get the resources they need or to refer clients to other services. Social workers need to work with their clients to find the fine line between confidentiality and secrecy, and between confidentiality and confidence.

The Stage of Life of People Infected

Most people diagnosed with HIV disease are between the ages of 20 and 40. Becoming infected with HIV at a relatively young age will radically change people’s expectations for their future, at a time in life when they would normally be establishing their independence, relationships, careers and lives separate from their families. According to Erikson’s individual life cycle (1963), these are the adolescent and young adult years when people first struggle to establish a sense of identity, and then leave home and begin to establish intimate ties with other people through marriage, collaboration or other important intimate relationships. It is not a stage of life when people expect to deal with a life-threatening illness, and they may not have the emotional, social or financial resources to do so.

In their practice, social workers must recognize that HIV dramatically disrupts the individual life cycle. People who are not able to move naturally through these life stages may feel purposeless, isolated or lonely, and their psychosocial care must address these issues as well as others associated with life-threatening illnesses.

The Nature of the Illness

People with HIV are living with a chronic, progressive illness — a life-threatening illness over a long period of time — with all the associated psychosocial stresses, such as gradual disability, job and income loss, the loss of independence, an increase in physical symptoms and the gradual need for ongoing care. Many long-term survivors have now lived 12 years and longer with HIV, but their prognosis is still gradual physical deterioration and death. A growing number of people with HIV are now living long enough to develop neurological problems, which can complicate their ability to relate to others and to manage their lives. They may need chronic care, but these services are not always available.

HIV also causes more stress because it can be passed between sexual partners, among people who inject drugs and from a mother to a child (during pregnancy, childbirth and breastfeeding). Before blood screening programs were in place, some people were also infected through transfusions of blood or blood products. People who are infected often say that they feel “unclean.” They must deal with the fear or guilt of infecting others and with the difficult process of changing sexual and other behaviours to protect others and to safeguard their own health. The sometimes real risk and sometimes irrational fear of infection also creates stress for sexual partners, family members, caregivers and friends.

Because HIV can pass from one person to another, both partners in a relationship, one or more parents and several children in a family may be infected. Within the gay community, men report that they have had as many as 40 friends and acquaintances who are either infected with HIV or have died of AIDS. They are coping with cumulative losses that leave them in a continual state of grief and bereavement.

The medical aspects of HIV will greatly influence clients’ psychosocial needs. To help clients, social workers must know something about HIV infection, how it affects people and their physical and mental health, and available treatments. Social workers cannot — and do not need to — become medical experts, but they should know something about the disease and be able to help clients find information and get answers to their questions. Social workers may need to develop a good working relationship with a physician who can help them build a knowledge base, or they may need some training.

Social workers should also be willing to ask clients (who may be extremely knowledgeable about their medical care) what is important to them and to see the clients as resources or teachers, as long as this does not place unreasonable demands on the clients.

At the same time, social workers must be aware of the psychosocial implications of medical care, and be prepared to help clients cope with associated stresses, such as starting on drug therapy, the high cost of drugs, the need for housing and/or financial assistance, and the need for support and care at home.

Recognizing the large number of losses in the HIV community and the impact that HIV can have within families, social workers are also struggling to develop more skills in grief work and to find new ways to help their clients — and themselves — cope with multiple losses.

Changing Expectations and Client Relationships

Many people with HIV have extremely high expectations of their caregivers, want to be actively involved in their own care, and make conscious choices about the services they use. For example, it is not unusual for clients to seek out social workers who have a similar orientation or life experience. Social workers may be asked: are you gay? are you HIV positive? are you aboriginal? are you a member of my ethnocultural group? And their answers may influence whether clients decide to come to them for psychosocial care.

Many people with HIV are also extremely knowledgeable about the illness and will often know more than the social worker about the medical aspects of the disease.

People with HIV are also actively encouraged to “get involved,” serve on boards and participate in planning, evaluating and delivering programs. A client who the social worker sees in the office in the afternoon may be sitting around the same board table that evening. People with HIV may be friends and colleagues, as well as clients, and they may be working to shape policies and programs, and to encourage community development.

Social workers who are accustomed to working with vulnerable groups may find it difficult to relate to more informed clients with high expectations. They may have to change their assumptions, adjust their practice, or reinforce role boundaries in order to work effectively with clients who are part of well-organized communities, who can speak for themselves and who may not rely heavily on the social worker for support.

The Changing Face of HIV

In the early days of HIV disease, about 95 per cent of the people infected were men who have sex with men. HIV occurred at a time when the gay population was organizing, developing a sense of pride and becoming a potent political force in shaping public policies and attitudes. Many of the men who were infected in the first wave were articulate, well-educated middle class white gay men. Strong activists and advocates in their own right, their expectations of the system and the professionals who help them were very high, and they spoke out about their concerns. As a result of their efforts, HIV/AIDS has become both well-known and highly politicized.

The majority of people infected (about 80 per cent) are still men who have sex with men, but there has been a steady increase in HIV infection in more vulnerable populations, including:

- bisexual men and younger men who have sex with men, who often do not identify themselves as gay. These men are often not integrated into the gay community and may not have the information, support or skills to protect themselves, cope with diagnosis, keep others from becoming infected, or advocate for services they need
- people who share needles to inject drugs, including steroids
- women infected through sex, injection drug use or their work in the sex trade
- infants and children who were infected perinatally (in utero, during childbirth and/or breastfeeding)
- aboriginal people
- people from more varied ethnocultural backgrounds.

Anyone who is having unprotected sex or injecting substances is at risk of acquiring HIV, but the people in our society who are most vulnerable — such as street youth, marginalized women, people who are poor and people in correctional facilities — may not have the information, self-esteem, resources, skills or motivation to protect themselves from this illness. Some may also have had difficult previous encounters with the health or social service system.

Social workers accustomed to working in the HIV field and used to a relatively homogeneous and skilled client group with strong social supports must adjust their practice to meet the more complex and diverse needs of people now being diagnosed.

HIV is affecting a growing number of people who are extremely vulnerable and have little or no community support. They may already have other serious psychosocial needs, such as addiction problems, a history of abuse, psychiatric problems and practical needs. This has serious implications for social work practice, for peer-led programs, and for the volunteers who often form such a vital part of the psychosocial team.

Social workers accustomed to working with motivated, white, middle class gay men may find the responses and behaviour of people with substance use problems very difficult. To meet the needs of all clients with HIV, social workers will need extensive information on addictions and substance abuse, medical treatments and alternatives, interventions for women, and cultural diversity, and they will have to make connections with people who already work in those fields. The more vulnerable people now becoming infected may not have the skills or resources to help with HIV work without extensive training, and peer-led programs may be more difficult to organize for these clients. In addition, people who volunteered to help gay men with HIV may not be as comfortable helping an injection drug user or street youth, and social workers may find it more difficult to develop and maintain a strong volunteer base. Family members may be a source of volunteer support.

and homophobia also add an element that may not be present in most social work jobs. HIV infection raises legal and ethical issues, and may force us to make choices that we may not face in other fields of practice.

For that reason, it's important to put our own houses in order. We must examine our attitudes towards sexuality, safer sex practices, drug use and harm reduction, and our comfort in talking openly about sex, sexual activities and illegal drug use. We must guard against homophobia, racism and any form of labelling.

The First Days in HIV/AIDS Work

When I got involved with this work, I thought it would be challenging, but I never dreamed of the different areas it would strike in me. I've always prided myself on being empathetic and on the same wavelength as my clients, but with HIV/AIDS the process is different.

HIV/AIDS so totally encompasses people's lives that every issue ...comes to the forefront. Working in this field seems to do the same thing. As a white, middle class, heterosexual, drug-free, healthy woman, I felt a strong need to prove myself worthy to work with these people. Sound funny? It wasn't. I felt as ignorant as I had my first year out of school. I worried about my terminology and knowledge of HIV/AIDS and also about orientation issues, lifestyle, decision-making and boundaries.

Working in this field has made me redefine myself and my beliefs. One of the bottom lines for me remains RESPECT. People will always know if you respect their pain, dreams, choices and lives. I had to go through a process of self acceptance before I could work healthily in this field.

Professional Responsibilities vs Personal Issues — When a Social Worker Can't Identify With a Client

Practice Issue

When a Client Asks: "Are you gay? Are you HIV positive?"

What should a social worker do if clients ask these questions? The social worker should:

- understand the concern behind the question — are you like me? will you understand what I'm feeling? how can you help me?
- realize that the client is testing the social worker's attitudes and values
- recognize that clients are taking more control and challenging all care providers
- try to deal with the clients' underlying issues
- explain what you can offer and the skills you have
- recognize that lying or skirting the question may have a negative impact on the client relationship
- acknowledge that clients have the right to choose their care providers and accept their choices.

Social workers have an ethical and legal responsibility to deliver adequate and non-discriminatory services to their clients. The CASW Social Work Code of Ethics (1994) states explicitly that social workers "shall not discriminate against any person on the basis of race, ethnic background, language, religion, marital status, sex, sexual orientation, age, abilities, socio-economic status, political affiliation or national ancestry." This professional obligation is absolute. In addition, most provinces and territories have laws that prohibit any form of discrimination. Social workers must also be sensitive to any systemic homophobia in the workplace, and strive to overcome it.

Working in the HIV field can raise personal

issues, but the social worker has a responsibility to examine these issues and work beyond them. Social workers must be clear about their own beliefs and potential biases. When social workers cannot identify with a client and feel their attitudes or biases are interfering with the clients' ability to receive good service, they have a responsibility to act. A social worker in this situation should discuss the issues openly with a supervisor or colleague and try to resolve them. In some situations, it may be appropriate to transfer clients to other colleagues, but the social worker would still be expected to take whatever steps are necessary to fulfill her/his professional obligations.

If You Are Going to Help Me

Please be patient while I decide if I can trust you.
Let me tell my story, the whole story, in my own way.
Please accept that whatever I have done, whatever I may do, is the best I have to offer.
I am not a person, I am this person, unique and special.
Don't judge me as bad or good, right or wrong. I am what I am and that is all I've got.
Don't assume that your knowledge about me is more accurate than mine.
You only know what I've told you.
Don't think that you know what I should do. You don't. I am still the expert on me.
Don't place me in the position of living up to your expectations. I have enough trouble living up to my own.
Please hear my feelings, not just my words. Accept all of them.
Don't save me. I can do it myself. I knew enough to ask for your help.

Help Me to Help Myself
Learning Together About HIV
Caring Together Federal Demonstration Project 1994

In small communities or organizations, when there is no one else to refer to, the organization must recognize the need for staff education, and help staff develop supportive links with resources, such as the AIDS Clearinghouse, the provincial AIDS hotline and people in other centres.

In many cases, education and information can help people deal with any personal biases. For example, a social worker who finds it difficult to identify with a gay client may find it helpful to understand the history and context of gay and lesbian issues and learn the community's language. In the past, in psychiatric classifications, homosexuality was considered pathological. Although this is no longer the case, many gay people have had terrible mental health experiences because of this view. Talk to gay health care providers and other gay friends and colleagues. Listen to your clients.

Advice from gay people:

- use our vernacular sexual language and get comfortable with it
 - help us rebuild our broken self esteem where we have been isolated and battered for our differences and our sensitivities
 - encourage us to continue with the struggle of coming out
- question the structures and laws that condemn us
 - support us as we struggle through our relationships.

As a gay social worker, my attitude has been not to "flaunt" my orientation, but not to deny it. I see my orientation as a quality of who I am, but not as the only thing that defines me. I am a man first, with inalienable rights and responsibilities. My gayness clearly pervades everything I think about and how I see the world. Ironically and privately I see it as a gift, because I am standing outside the walls of the pervading culture and I can see through it.

There is a political dilemma for gay social workers and their clients because some people argue that we maintain the "power of the closet" by not self

disclosing immediately. A conference of HIV clients in Denver a few years ago encouraged HIV counsellors to disclose their orientation and status to their clients because they had enough to deal with without struggling with “can they trust this counsellor?”

I’ve decided that open disclosure should be purposeful, which is a guiding principle I use when exploring with clients when and how to disclose their status to others. When I disclosed my status early in a counselling relationship with a man who I did not know was bisexual, I created tension and avoidance rather than trust.

When men ask me if I’m gay, I now interpret it as a very positive step for them rather than a threat to me, because generally they want to open up to talk about sexual matters. This signals to me they are ready to honour who they are, and are embracing hope rather than despair. They are trying to make sense out of the rules of safer sex.

I don’t interpret the question as invasive but as part of the trust building process.

A Guide to Ethical Decision-making

In many aspects of their work, social workers may find themselves in the midst of ethical dilemmas. This is often an inherent part of the process of starting where the client is and working with the client for social justice. In making ethical choices and decisions, social workers must go through a personal process of discernment. The following questions may help guide that process:

- How do I know when I am respecting someone, and not taking charge of them?
- How do I feel when I’m respecting someone? How do I feel when I take charge? (Tension in the body can be a useful indicator.)
- What are my own values? Are they in line with the guidelines or ethical standards of the organization where I work?
- How do I consult my conscience?
- Who is my client? Do I have any obligations beyond my “official” client?
- Whose interest does my decision serve, the client’s or mine? How can I know?
- Will my decision do any harm?
- Does my decision leave me feeling at peace with my own conscience or inner self — even though carrying out my decision may cause me emotional or practical difficulties?

Potential Ethical Dilemmas

In working with clients with HIV, social workers will face serious ethical dilemmas, such as:

- trying to protect clients’ confidentiality and still get them the services they need
- supporting clients who are in the process of making decisions about disclosure and recognizing their responsibility to protect others from harm
- supporting the client who may knowingly put others at risk
- dealing with requests for assisted suicide
- managing conflicts between clients’ natural families and partners, chosen families or support network
- balancing the client’s needs against those of his or her caregivers.

The following chapters will discuss issues and dilemmas the clients and social workers may experience with HIV, and possible strategies and approaches social workers can use.

THE IMPACT OF THE CURRENT POLITICAL/SOCIAL/ ECONOMIC ENVIRONMENT

HIV/AIDS is the best example of how private trouble and public issues link. From the experience of clients with HIV we can see how important it is to resolve public policy issues — such as racism, sexism, homophobia, income security and housing — because of the effect they have on people's lives.

Given the current economic environment of cuts and downsizing in health and social services in almost every part of Canada, there will be more people needing care and support, and less money to provide that care. The stresses on people with HIV and their families will increase.

Recent cuts to health care, welfare and social service budgets are having a severe impact on people with HIV, who often need expensive care over a long period of time, may not be able to afford that care and, because of the current political and economic climate, may not have the social safety nets they need.

How Policy Affects Care

The policies developed by different levels of government, by health and social service organizations, by employers and by insurance companies can have a direct impact on people's care and their ability to get the services they need. In their efforts to create a more just society, social workers must strive to change policies that have a negative impact on people with HIV.

Many social workers may not feel they are in a position to influence policy. But front line social workers know how policies directly affect their clients and their quality of life, and they have a responsibility to speak out, advocate on behalf of their clients, and support clients who are willing to speak for themselves. Social workers who cannot change policies or alleviate the negative impact policies have on clients may become professionally and personally frustrated and experience burn-out.

Social workers who cannot make changes in their own work environments can be active in other places and eventually have a direct impact on quality of care, quality of life and client empowerment. For example, social workers can be active in provincial committees, local AIDS service organizations, community organizations and committees where they can have an influence on policy decisions, lobby for changes and offer their unique perspective on the rights and needs of people with HIV. This not only helps clients, but gives social workers the chance to affect the larger community or society.

How Organizational Structures and Practices Affect Care

Organizational structures and practices should respect the dignity of all people and their right to confidentiality, be sensitive to client needs, and make it as comfortable as possible to use the services. As agents of social change, social workers should lobby in their own workplace and other settings for client-sensitive practices.

Some people are very open about their HIV status, others are not. Organizations and social workers know their clients and will use their own judgement but, to establish practices that protect the most vulnerable, it is often wise to err on the side of discretion. All practices should be open to discussion with clients. The following is a guide to client-sensitive practices:

Communication Practices

- encourage the workplace to include the values of respect and self-determination in its mission statement and reflect them in all its practices
- train everyone who answers the phone to be sensitive to people's need for confidentiality (Some people who call don't want to have to mention words like "AIDS" in case someone can overhear their part of the conversation. It's important to ask questions or give information in a way that they do not have to say anything that will breach their confidentiality.)
- establish guidelines for messages left on telephone answering machines and voice mail. Will it be helpful or stigmatizing to mention HIV in the message?
- mail out information on HIV in plain envelopes, rather than ones that identify that it comes from an HIV-related organization, and make sure that others can't readily see into the envelope
- make it a policy to have all first-time clients meet briefly with a social worker who can tell them about the services he/she can provide and make them feel more comfortable calling/using those services in the future
- ensure clients have appropriate access to professional interpreter services (see next page).

Waiting room practices

- when the HIV program shares space with other programs and services, take steps to protect people's right to confidentiality (For example, display HIV materials in a display rack with other health brochures and avoid using signs that might make people feel stigmatized.)
- train staff how to greet clients in the waiting room, so that clients do not inadvertently disclose their status in public (e.g., staff can avoid asking questions such as "how are you today" which might lead someone to answer in a way that discloses he or she has HIV)
- be sensitive to any discomfort that newly diagnosed asymptomatic clients may feel when seeing people who have more advanced disease by either arranging for them to wait in a separate area or preparing them for what they may encounter in the waiting room
- provide alternatives for someone who is particularly anxious about attending an HIV clinic including, for example, arranging to see the person initially on

Working with Interpreters

When working with people from other cultures, social workers may be accustomed to working with interpreters. However, people diagnosed with HIV may, for reasons of confidentiality, be fearful of using interpreters. The interpreters themselves need special training or preparation to help them deal with any biases they may have and to communicate the person's real issues. It is not their role to act as counsellors, but to help the process of communication, and it's important that they understand the difference. Most people who have been trained as interpreters understand this but those who are acting as translators because they know the language may not. To ensure interpreter services are sensitive to the person's needs:

Recruitment

- Avoid using a family member or friend of the client to interpret. Clients may be unwilling to talk openly about some things, such as sexual activities or orientation, in front of a family member or friend. People who are too close to the client may also come with their own biases or issues. In their desire to "protect" the person, they may not always interpret exactly what you say. There is also the risk that, because of their relationship and their lack of training, they may breach the client's confidentiality, and discuss information shared in a counselling session with others.
- Try to find people who have been trained as interpreters, understand their role and know the expectations for confidentiality in a health or social service setting. If you have a budget for these services, contact professional interpreter services. If you don't have a budget, contact cultural organizations in the community that may be able to provide volunteers who have been trained as interpreters.
- Look for people with some basic AIDS knowledge/training. Local AIDS service organizations may have done some interpreter training and have a list of volunteer interpreters.

Training

- Even if the people you use as interpreters have already been trained, provide some on-site briefing. Cover the goals of the interviews, the range of questions you are likely to ask and any issues that may arise.
- Make sure the interpreters are familiar with concepts and terminology that may be used during the interview, such as drug names, dosing schedules and ways to finance drug costs.
- Review your organization's expectations for confidentiality and any other policies or procedures that may affect their work.
- Discuss with the interpreter how to handle a situation where the client and interpreter know each other socially.

Procedures

- Discuss using an interpreter with the client, and get the client's permission before inviting the interpreter to attend an interview.
- Before the interview, meet with the interpreter to review any concerns the client may have about confidentiality in his/her community.
- Whenever possible, use the same interpreter with a client. This helps build trust.

Support

- Provide regular opportunities to "debrief" interpreters, talk to them about their work and whether they are being used effectively, and listen to any problems or difficulties they may have.
- Remember to acknowledge their work and contribution. Send thank you cards or invite them to special events at your organization.
- If possible, provide an honorarium or some form of remuneration for interpreters, and budget for this in your program.

non-clinic days. (However, it is also important not to get drawn into a “back door” approach that may, in itself, increase the stigma associated with HIV.)

Referral practices

- discuss with clients all referral practices, and get their explicit permission before making any referral
- develop a means to refer people to the services they need without having to disclose that they have HIV
- whenever possible, complete employment insurance and other work-related forms without disclosing the person’s HIV status.

When the social worker knows the client ...

It is not uncommon, particularly in small communities or in the lesbian and gay community, for social workers to know clients socially. In these situations, the organization may adopt a policy of offering the client a choice of social workers (if possible) and ensuring that clients understand that social workers are bound by their professional ethics to protect clients’ confidentiality. In this situation, the client and social worker should also agree that they will not talk about their professional relationship when they meet socially.

A DIFFERENT PERSPECTIVE ON HIV

Living with HIV is like walking on a tightrope. Each day I wonder if this is going to be the day I fall.



Almost every guide written on HIV begins with the **medical** history of the illness, starting with diagnosis and progressing through the asymptomatic patient and the symptomatic patient to death. The person’s physical well-being is measured in terms of frequency of medical appointments, CD4 counts, viral load, opportunistic infections, and the beginning of anti-retroviral treatments and prophylaxis (treatments designed to keep people from developing a serious illness). The person experiences intense periods of medical activity that require many visits to doctors or clinics.

With the **psychosocial** history of HIV, the times of intense need and activity may be triggered by changes in the client’s physical health (e.g., the first symptom, starting anti-retroviral treatment, or the first hospitalization). But they can also be triggered by changes in other parts of their lives, such as when clients decide to tell other people about their HIV, when a friend dies of AIDS and when clients decide it is the appropriate time to stop working.

People face serious psychosocial issues when they realize that they may be at risk, when they decide to be tested, and when they go for pre-test counselling and wait for test results. People with HIV will likely experience stress the first time they go to a clinic where there are other people with HIV, each time they disclose their HIV status to others, when they begin the process of consciously living with a chronic,



life-threatening illness, and the first time they are hospitalized. At different times, they will be coping with intense feelings of anger and isolation. Throughout the course of HIV disease, they will go in and out of phases of loss and grieving, and the sense of loss — of health, of future, of job, of friends, of relationships — may always be there. Some may go through periods of acceptance, where they live comfortably with their HIV. When aggressive treatment is no longer possible and when they become palliative, people with AIDS then face the highly emotional issues involved in dying, including grief, bereavement and possible thoughts of euthanasia and assisted suicide.

Every person living with HIV has a unique personal journey, and for most it is an ongoing process of crisis and coping.

Searching for Hope in the Midst of Stress

At the same time that HIV causes immense stress, it can be a powerful source of hope. Many people who come face to face with HIV often begin a process of examining and reshaping their lives and what matters to them. Life is stripped to its bare essentials.

Helping people get what they need: Information and resources

Don't assume that all people with HIV need or want counselling. Some people who attend an HIV clinic will not want to see the social worker or to participate in psychosocial programs or services, but they will want easy access to information. Some people who go to a non-HIV setting for counselling may not wish to spend a lot of time discussing HIV. To help them, social workers should keep useful materials on hand, subscribe to treatment newsletters, display materials prominently and keep a bulletin board of community newsletters, events and activities.

Some people discover the strength to deal with misfortune and adversity. It is not unusual to hear some people say that "HIV is the worst thing and the best thing that ever happened to me." They face unresolved issues, and report that they grow as a result, develop more meaningful relationships, explore new interests and live life more fully.

Scientific and medical developments are also cause for hope. When people with HIV are diagnosed early (before they develop symptoms of illness), they have a better chance of benefiting from treatments that prevent the

infections associated with HIV, anti-retroviral drugs and protease inhibitors (that inhibit the destructive action of the virus) and other therapies (vitamins, complementary therapies, rest, exercise) that can protect their health.

The challenge for social workers is to support clients as they deal with stress, search for hope and work to develop a new sense of themselves and their opportunities with the reality of HIV.

There are not a lot of right answers with HIV. It's a process of exploration with the client.



To support people with HIV as they walk the tightrope, social workers have a responsibility to:

- recognize and respect clients' skills and abilities
- empower clients to hope, find meaning in life, and develop a greater sense of control over their lives and their choices in the midst of a chaotic illness
- respond to the needs that clients express
- stay informed about medical developments that may shape the course of the disease, as well as their clients' perception of his or her illness
- help clients find the information, resources and services they need
- help clients with practical things, like filling out applications
- advocate on clients' behalf — if they cannot do so on their own — with other agencies and services
- advocate for social justice and other changes that will reduce the stigma associated with HIV.

To do this, caregivers must make thoughtful use of themselves, apply best practices, and make effective use of the full range of social work tools, including:



Building Partnerships

Because the needs of people with HIV are so complex, social workers must be prepared to call on other partners who can provide valuable services, including:

- medical personnel, including nurses, nutritionists, physicians/specialists, psychiatrists, dentists, ophthalmologists, occupational therapists
- addiction and mental health services
- community counselling services, such as the local family counselling agency
- legal and financial advisors (including insurance specialists who can provide information about life and disability insurance)
- pastoral care services
- home care specialists
- respite and palliative care services
- practitioners of complimentary therapies (depending on the client's wishes).

Social workers should develop a network of other professionals who they trust to treat their HIV positive clients with dignity and respect. This may involve educating other professionals about HIV-related needs and issues.

Resources

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1 DECIDING TO BE TESTED

I decided to be tested because I thought I was negative. I knew that, as a gay man, I was part of a high risk group, but I thought I was okay. I hadn't had that many partners. I had rarely engaged in anal sex. For the past few years, I had been careful and had been involved in only safe activities. Friends who took more risks than I did had tested negative. I guess I was looking for reassurance — and approval for having been good. I would get my negative result, and then I could get rid of that anxiety that all gay men must feel. Compared to many people I've talked to, I think I had a pretty good experience. The person doing the test took the time to explain everything to me, to ask me questions and to talk about safer practices. I already knew most of it, but I felt they were being thorough. I didn't worry a lot waiting for the result, because I was sure it would be negative. I was so confident that I just stopped in on my lunch hour to get the results, and that's when I learned I had HIV. I know the person tried to talk to me and give me a lot of information, but all I remember is "You're HIV positive." I just wanted to get out of there, call my partner and find some way to deal with it.

Stages in Deciding to be Tested

Deciding to be tested is a complicated and anxiety provoking process that may take many years and involves the following steps:

- making assumption's about one's antibody status based on perceived similarity with people who are infected or ill
- weighing the pros and cons of knowing one's antibody status
- debating whether or not to be tested with partners and friends
- having physical signs of illness or contact with someone who is ill
- talking to someone who helps focus or channel the anxiety
- making some assumptions about the test results before being tested.

Adapted from Shelby RD. *People with HIV and Those Who Help Them*. Harrington Park Press. 1995.

When people choose to be tested for HIV, they are taking a critical step in dealing with their fears and past behaviours. Some people are fairly certain they are infected and are looking for formal confirmation or access to treatment. Some may have done something risky, worry that they may have been exposed to HIV and hope to be assured that they are healthy. Some people struggle with their concerns and fears for some time before they go to a testing centre or talk to a professional about being tested.

Tom had thought about being tested for several years. He knew there was a good chance he was infected. Several of his friends had tested positive. A couple had died from AIDS. Still he debated with himself. Maybe he would be the lucky

one. He hadn't lived as wild a life as many of his friends. He was scared to find out. What good would it do? He was practising safer sex now. His partner (a relatively recent relationship) began to suggest that they go and be tested together. Other friends were also pressuring him to go. He had a cold he couldn't seem to shake, and he began to worry that it was HIV. He knew he should be tested. He was already seeing a social worker about other issues. Over the course of several months, the social worker helped

channel the debate and defuse some of his anxiety. Tom made two appointments to be tested and cancelled them. The third time he went for the test.



Risk Assessment

The purpose of a risk assessment is to:

About the HIV Antibody Test

HIV testing is a two-stage, highly accurate process that tests for antibodies to HIV, not for the virus itself. Blood samples are first tested using an overly sensitive screening test. All samples that test positive on the screen are re-tested with a screening test. If the test is still positive, a confirmatory test that rules out everything but HIV infection is done.

A borderline or indeterminate result is extremely rare. It may indicate a recent exposure, where antibody levels are too low to register a positive reading. Indeterminate results may also be related to injection drug use or pregnancy. Anyone with an indeterminate test result should be encouraged to retest within a few weeks time (the required waiting time may change as the tests become more accurate), and advised to practise safer sex and not to donate blood.

Because of the time required to process requests both at the laboratory and at the clinic where the test was ordered, results generally take two weeks. Results can be obtained more quickly — within 48 hours — for people who may have an AIDS-defining illness, such as *Pneumocystis Carinii pneumonia* (PCP).

- help clients identify and understand the factors that put them at risk (such as having unprotected sex with someone who has had other partners who may have been at risk)
- help clients look realistically at their behaviour and determine whether they are at risk of HIV infection
- help clients decide whether to be tested
- reinforce any changes they may have to make to reduce risky behaviour, irrespective of test result.

The goal of a risk assessment is to help people who may underestimate their risk or who perceive themselves to be at no risk make the link between their actions and HIV transmission. (See Appendix I.)

When people decide not to be tested

Some people decide that they can cope better not knowing their HIV status or that they are not yet ready to be tested. Social workers can help clients who decide not to be tested by:

- discussing the barrier to testing
- discussing strategies clients can use to reduce risk
- encouraging them to seek medical attention if there is any indication they need it
- leaving the door open for future testing.

Sometimes people have good reasons to delay being tested. However, a client's decision to delay testing may create a dilemma for social workers who believe that early diagnosis, treatment and prophylaxis can greatly improve the person's health and longevity. It's important to give clients the time they need to make their own decisions. Social workers can play a key role helping clients assess their risk and work through some of the issues around testing positive before they go for testing. In some cases (e.g., an adolescent) the social worker may go with the person to the test site.



RECOMMENDED APPROACH TO TESTING

A positive HIV test result can be psychologically and emotionally devastating. To help reduce the impact, social workers have advocated since 1985 that people be tested only when they are ready, have given informed consent and been offered pre- and post-test counselling. People who receive high quality pre- and post-test counselling are better informed and better able to cope with the test results.

Right now, about 30 per cent of people tested for HIV receive no or inadequate pre- and post-test counselling. This gap has dramatic implications for their psychosocial well-being and their ability to receive appropriate care or adopt practices that will reduce risk. When people are not given their test results in a caring, compassionate way, they may act out, be verbally or physically angry, or become depressed. It's common to see people who have reacted by drinking steadily for six months or longer. With the advent of home testing kits (over-the-counter kits that allow people to take their own blood and send it for testing), the potential psychosocial distress caused by testing without counselling will increase.

The Role of the Social Worker in Test Counselling

Social workers are not necessarily directly involved in pre- and post-test counselling. They are more likely to be called in to help pick up the pieces when people receive either no or poor pre- and post-test counselling. For this reason, it is important for social workers to work with people who are doing testing to improve the quality and consistency of their pre- and post-test counselling and to ensure they assess clients' psychosocial needs and make appropriate referrals. Effective test counselling programs should include the following:

Working with someone who was tested without consent

I was asked to work with a man who was the victim of a brutal gay bashing and was brought to the hospital in a coma. While he was in the intensive care unit being treated for the beating, the surgeons tested him for HIV, and he was positive. He was in traction when he was told, and he wasn't discharged for another three months. He didn't have the energy to deal with everything. I didn't know whether we should start with his HIV status or the trauma.

Listening to him helped a lot. We talked about the violent incident for several sessions and gradually moved to the HIV. Two years later, he's doing fine. He broadcast his story for a documentary, told his family and is getting on with his life. He doesn't blame the surgeons for testing him nor is he angry at how he was told. He accepts the reality that it was a trying time for everyone who was working to do the best for him.

Informed Consent

People should be tested only when they have given their "informed consent" or voluntarily agree to be tested. To give informed consent, a person must:

- have been told about the benefits and risks of being tested and of not being tested
- understand the implications of a positive or negative HIV antibody test result
- be given the opportunity to ask questions
- be asked if he/she wants the test.

Some physicians and test sites ask people to sign consent forms, but this is not legally required. It is enough to note on the person's chart that he/she was told about the benefits and risk and consented to be tested.

Test counsellors should not recommend testing to anyone who:

- does not understand testing and its implications
- has a questionable capacity to comprehend the process or is unable to give informed consent
- appears to have been coerced into being tested
- seems emotionally unable to deal with the test results (e.g., discloses that he or she will commit suicide if the test result is positive).

Test counsellors should be aware of whether the client is drunk or high. That may be the only way the person can get up the courage to be tested. The person may still be able to give informed consent.

Age is not necessarily a factor in giving informed consent — although the laws vary from province to province. If an adolescent asks to be tested and appears to be competent and understands the consequences of being tested, the counsellor should document the client's competence and provide testing, unless provincial laws prohibit this. However, if the young person does not have the capacity to understand the process or seems to have been coerced, then the counsellor should not provide testing and should refer the person to an appropriate agency.

Test counsellors should be sensitive to any requests for testing made by a third party, such as a husband asking to have his wife tested, or parents bringing in a child for testing. If there is any indication of family violence or abuse, the counsellor should contact the appropriate agency.

Pre- and Post-Test Counselling

Pre- and post-test counselling is part of the process of preparing for a positive test result. Done properly, it is the first step in a biopsychosocial assessment, and it helps clients understand and assess their risks and identify how they will cope with the diagnosis. Most pre- and post-testing counselling is done by physicians, nurses and counsellors. Some people will have talked with friends or received some preliminary pre-test counselling over the phone from a community-based group, health unit or hotline. When testing is done at an anonymous test site or in an STD clinic, the client is likely to see the test counsellor two or three times — before the test, to get their results and, if the test is positive, at possibly one other meeting. Test counsellors in these centres do not provide ongoing care and support, but refer clients who test positive to other services.

To be able to prepare clients for testing, social workers should know recommended best practice for pre- and post-test counselling. (See Appendix II.) Effective pre- and post-test counselling is done one-to-one and in person.



TESTING AND WOMEN

After her family doctor had dismissed the notion of testing her for HIV, Maria contacted the local AIDS service organization (ASO) . She was concerned about her contact with a previous partner who she now heard was into drugs. She was in a new relationship and didn't want anything to spoil it. Although she knew little about her current partner's sexual history, she was quite convinced he was "safe."

The social worker at the ASO helped her do a risk assessment and counselled her about HIV antibody testing. She also discussed with her what she would do if the test result was negative. Would she then practice safer sex with her new partner to protect herself? Would she ask her partner about being tested? The social worker then referred her to a clinic where she could be tested, and arranged to follow up with her after she received her test results.

Because most people with HIV are men, women have often had trouble getting an HIV test. This is gradually changing, but health care providers may still minimize women's risks and discourage them from being tested. Even when women present with symptoms of immune deficiency, health care providers may rule out a number of other causes before considering HIV. This attitude, combined with a tendency on the part of some women to underestimate their own risk, means that women are often diagnosed later, when they have already developed symptoms.

While some women have trouble getting tested, a large group — pregnant women — should be routinely offered HIV testing. Recent findings show that treatment during pregnancy can significantly reduce the risk of the virus being passed from an HIV-positive woman to a child during pregnancy or childbirth. Physicians in many parts of Canada are now being advised to counsel all women who are pregnant or considering pregnancy about the risk of HIV being passed to a child and the benefits of being tested, so they can assess their risk and make an informed decision about whether they and their partners should be tested.

While it is extremely important for women to have this information, this is a highly vulnerable time for them. A positive test result has serious implications for the family, and women may benefit from discussing HIV testing with a social worker. (For more information, see Women, Pregnancy and Their Reproductive Choices on page 72.)

With the stigma of HIV, just the circumstances of being tested can be isolating and alienating. People do not necessarily want their friends, neighbours or co-workers to know they are being tested. If they cannot be assured confidentiality — if they have any fear that someone might recognize them or betray a confidence — they may avoid going for testing. In some cases, simply having had a test can lead to discrimination. For example, a number of people have been denied life or disability insurance because they were once tested for HIV — even though they tested negative. The risk is real.

Confidentiality is a particularly serious concern for people who live in smaller centres, rural areas, aboriginal communities or smaller ethnocultural communities in larger centres. Both geography and culture can affect access to testing services that people perceive to be “safe.” People will often travel to other or larger centres for testing rather than risk having people in their home communities know. In many cases, aboriginal people do not go for testing because of concerns about confidentiality. Even when clinics have been established to provide HIV testing on reserves, people often avoid the clinics and go to a doctor in a nearby community where they feel they will have some anonymity.

Many clients may need help finding what they consider a safe place to be tested. Some clients will go willingly to a physician with whom they have a good relationship. Others will prefer a walk-in clinic or anonymous test site. Social workers should be able to explain the different testing options in or near their community, and help clients choose the appropriate setting for them.

Testing in Controlled Settings

It is extremely difficult to protect confidentiality in prisons and correctional facilities, closed settings where secrets are hard to keep and where people do not necessarily have the option of going elsewhere to be tested. Those working with prison inmates should advocate for voluntary and anonymous HIV testing in prisons (i.e., no link between the person’s name and the test) and for having the pre- and post-testing counselling done by an outside community-based agency, with testing done by a physician associated with the group. Social workers should also be willing to help clients advocate for confidential or anonymous testing options, and to speak out whenever a client’s confidentiality has been violated. Depending on the policy of the institution, the services available and the person’s symptoms, the social worker may counsel inmates to wait until they are “outside” to be tested.

Testing and Reporting

Not only does the testing service have to be confidential, it has to be perceived to be confidential. Some jurisdictions provide confidential testing service, but require that positive test results be reported to public health authorities. The purpose of reporting is to collect information on incidence, age, sex and risk factors that will help epidemiologists understand the spread of HIV. In most cases, the person's name is not reported. However, many people, because of bad past experiences with "authorities" or their sense of marginalization are extremely apprehensive about having any information about them reported.

The Social Worker's Role in Reporting and Confidentiality

Social workers, like many other professionals, have a legal and ethical responsibility to help safeguard client confidentiality. However, that professional responsibility must be balanced against legal requirements in some jurisdictions to report positive HIV test results and/or AIDS cases. Depending on where social workers are employed, they may be required to report or be part of an organization that is required to report. They should be aware of their responsibilities and develop procedures that allow them to provide the required information and still safeguard client confidentiality.

Practice Issue When a Client Refuses to tell a Partner

Paul is a 27 year old heterosexual male. He was referred to a social worker because he recently discovered that he was HIV positive. Paul did not request the test and never thought that he might have HIV. His physicians ordered the test without his informed consent as part of routine blood screening. Paul has been in a three-year relationship with a woman which whom he is exclusive. They do not cohabit. She is using oral contraceptives, so they do not use condoms as a form of birth control. He does not wish to disclose his HIV status to her.

In this case, the social worker would work with the client over time to help him resolve and deal with this issue. The process could include:

- explaining that the partner has a right to be protected and eventually to know that she may have been exposed to HIV
- explaining that it is particularly important in this situation because his partner does not consider herself at risk and so is not using condoms or other precautions
- supporting Paul in dealing with his own reaction to the diagnosis, and giving him the time he needs
- encouraging him to identify other possible sources of support
- helping him work out how to protect his partner until he is ready to tell her
- discussing how best to tell her
- discussing her possible reactions and how he will handle them.

Partner Notification

In most provinces, people with sexually transmitted diseases are required by law to either tell past or current sexual partners or provide the partners' names so public health authorities can contact them. In the case of HIV infection, people who test positive for HIV are asked to help notify both sexual and drug use partners.

The purpose of partner notification is to warn others who may have been exposed to a disease so they can seek care and treatment. It is one of a number of strategies used to control the spread of communicable diseases. Partner notification creates what is known in the health promotion field as a "teachable moment." People who are notified about a possible exposure are likely to act on the information to protect their own health and to prevent transmission to others. There is also some indication in the literature that people who are notified appreciate being told.

In cases where people have had many anonymous contacts, it is probably not possible to identify and contact everyone, so other approaches — such as community education and health promotion — are used to encourage everyone to take precautions.

Although official partner notification programs never disclose the name of the contact, many people fear that their identity will be disclosed. In fact, if their contacts have had few partners, it can be difficult to keep the person's identity confidential.

Social workers have no responsibility for partner notification. However, because there may be a perceived conflict between an individual's right to privacy and the responsibility to protect public health, social workers may have a role in supporting people with HIV through the process of partner notification. A client's ability to notify past and current partners depends on many factors. For most people with HIV, partner notification is extremely difficult and stressful.

WHEN PEOPLE KEEP BEING TESTED

Gunter has been tested for HIV seven times in the last nine years. Sometimes he goes to his physician, sometimes to an anonymous test site. Counsellors at the test site explored his reasons for retesting. Had he recently had unsafe sex? Is he in a situation (partner of an HIV-infected person) that might increase his risk? Is he in a situation where it is difficult to protect himself? Is he looking for reassurance?

Practice Issue To Test Again?

One of your clients has been tested five times in the past year for HIV. When you talk to him about his sexual and drug use practices, he reports that he is trying to be safe. His partner of eight years is infected and is now in the later stages of AIDS. Three of his other friends have recently been diagnosed. He appears to feel guilty about being well and anxious about his status. He is convinced that he must be positive and doesn't trust the test results. He has become extremely anxious and calls you in a panic. What do you do? Do you recommend that he be tested again? What other social work strategies could you use?

It is unlikely that being tested again will help your client deal with his anxiety. In this case, you could refer him to another mental health professional or counsel him yourself if appropriate.

Repeat testers are often people whose partners or friends are infected. Some may continue to engage in risky behaviour, and use the test to validate that behaviour. Some may have trouble believing that, given what has happened to their friends, they are not infected. "Why him, and not me?" They may become overwhelmed by and obsessed with HIV. Some may be in an abusive relationship and unable to practice safer sex, and use the test for reassurance. Some may use the test to get attention. A small number may be trying to become infected.

Over time, a significant number of repeat testers will seroconvert (go from being negative to positive), which indicates that — despite repeated testing and

counselling — they are continuing to engage in risky behaviour or are in a situation, such as an abusive relationship or heavy drug use, which limits their ability to protect themselves. The challenge for the social worker is to help retesters enhance their self-esteem and other skills to the point where they can take more control over their lives, overcome barriers and integrate the prevention messages.

Social workers can play a role because we have the ability to probe for the reasons behind re-testing. We had a recent incident where the same fellow phoned the nurses daily and even arranged chance encounters with them. We arranged for him to meet with a social worker to develop a plan to help him deal with his anxiety. Such a plan could include referrals to another professional.

When Testing Might Not Be Necessary ...

Nick had a brief affair with a woman who works in his office. He feels guilty about the affair. Although he used condoms, he is concerned that he might have been infected with HIV or another sexually transmitted disease, and that he might pass the virus to his wife.

Of the over 1.7 million voluntary HIV tests done in Ontario since 1985, only 1 per cent were positive. In Alberta, between 1 and 2 per cent of the people tested each year test positive. The proportion of positive test results is likely similar in other parts of the country. Of the many people who test negative, some may have been involved in risky behaviour, but many will have been drawn to the test because of an underlying concern, fear or guilt.

In a risk assessment, the counsellor may discover that the person's anxiety is out of proportion to his or her risk. To help ease the anxiety, the social worker will:

- feed back a realistic assessment of the person's risk (e.g., it's unlikely you were infected because you used condoms/dental dams)
- clear up any misunderstandings about HIV transmission
- explore other problems, such as marital difficulties or problems at work, that may have triggered an unrealistic fear of AIDS
- help the client see the problem as a health fear.

However, no one should be denied HIV testing. If the person has not been tested before, testing may be appropriate.

WHEN TESTING IS MANDATORY

Despite ongoing efforts to advocate that no one be tested without informed consent, a significant number of people — including people who donate blood, people applying for insurance and others — are still tested without their complete knowledge or understanding, and without appropriate discussion of what the test results might mean. In some cases, such as the blood collection system, mandatory

testing is justified because of the risk to others. In others, the risks may not be sufficient to justify violating the individual's right to give informed consent. Unfortunately, the practice of mandatory testing, which raises complex legal and ethical issues, does not become an issue until someone tests positive and is faced with the diagnosis without any preparation.

In some cases, social workers may work for agencies that require clients be tested. In this situation, the social worker should advocate for changes in the agency policy. Social workers must continue to educate health professionals about the psychosocial impact of testing and advocate with organizations to ensure they recognize the value of counselling and the patient's right to give informed consent. Social workers must also be prepared to support people who are tested without their knowledge. Their reaction to diagnosis is likely to be compounded by the lack of pre- and post-test counselling. In many cases, people who find out their HIV status in this way did not suspect they were infected and were not prepared for the result.

Ethical Dilemma Social Work Values in the Workplace

You are a hospital social worker. Someone who was tested by a surgeon in the hospital without informed consent and diagnosed positive is referred to you for counselling. Informed consent is a value of your profession, but hospital policies and practices challenge that value. You become the target of all the person's anger. What do you do?

The social worker can:

- counsel the person, support him as he deals with the diagnosis and any other unresolved issues
- provide the test counselling he should have received
- help him identify/develop his support network
- advocate within the hospital to change policies and practices that threaten people's right to give informed consent
- educate other hospital staff about the psychosocial impact on patients who are tested without their knowledge or consent
- ensure physicians are aware of the Canadian Medical Association guidelines for HIV antibody testing, which state clearly the need for pre- and post-test counselling and informed consent (see resource list).

Resources

- “Anonymous HIV-antibody Testing,” in *HIV/AIDS in Prison Systems: a Comprehensive Strategy*, a brief from the Prisons with HIV/AIDS Support Action Network (PASAN) to the Minister of Correctional Services and the Minister of Health, June 1992.
- Beevor AS and Catalan J. “Women’s Experience of HIV Testing: the Views of HIV Positive and HIV Negative Women” in *AIDS Care* 5(2)/1993; 177-1986.
- Counselling Guidelines for Human Immunodeficiency Virus Serologic Testing* Canadian Medical Association. 1993.
- Dawson J, Fitzpatrick R, McLean J, Hart G, and Boulton M. “The HIV Test and Sexual Behaviour in a Sample of Homosexually Active Men,” in *Social Science and Medicine* 32(6)/1991; 683-688.
- HIV Antibody Test Counselling Checklist for Physicians*, HIV Update, Ontario Ministry of Health. 1990.
- Ontario HIV Seroconverter Study*, Central Public Health Laboratory, Ontario Ministry of Health. 1994-1996.
- Shelby RD. *People with HIV and Those Who Help Them*. New York: Harrington Park Press. 1995.
- “Testing and Confidentiality,” in *Legal and Ethical Issues Raised by HIV/AIDS: Literature Review and Annotated Bibliography*. Montreal: Canadian HIV/AIDS Legal Network. 1995.
- Center for Disease Control. “U.S. Public Health Service Recommendations for Human Immunodeficiency Virus Counseling and Voluntary Testing for Pregnant Women,” in *Morbidity and Mortality Weekly Report*, July 7, 1995, v. 44, No. RR-7.

2 TESTING POSITIVE – DIAGNOSIS

When Claude was told that he had tested positive, he felt strangely calm. He thanked the doctor politely, went to a payphone, called his partner and told him. He hung up and began to walk aimlessly until he suddenly realized he was crying. He had to return to work, where he pretended that nothing was amiss. At home that night, he talked about it with his partner but couldn't come to any sense of resolution. For a couple of weeks, he seemed to be coping well, taking long walks, trying to joke about it with his partner. Then, at work one day, he overheard a co-worker make a casual remark about AIDS, and he suddenly felt violently ill. That evening he began to drink more heavily and seemed withdrawn. His partner noticed the change, but thought it would pass. It didn't. Several weeks later, Claude was still drinking heavily and refusing to talk about it. He was regularly late for work, and didn't seem to be able to cope with any kind of minor aggravation. His partner began to worry that he was becoming suicidal. Eventually Claude chose to get some help. His physician referred him to a social worker.

Diagnosis is a defining moment. When people are told they have HIV, their lives suddenly change. From that point on, they will view the world from the perspective of someone with HIV, and the diagnosis will begin to shape their lives.

The dynamic of diagnosis can be explained using the crisis theory model.

Applying the Crisis Theory Model to HIV

1. Hazardous event	a stressful occurrence that initiates a chain of actions and reactions. For some people, the hazardous event or diagnosis may be anticipated or predictable; for others, it is unanticipated and that can help shape the crisis. Even if the person anticipated a positive result, any change in health is stressful.
2. Vulnerable state	the emotional reaction to the hazardous event. This includes the person's reaction to the test results when he or she receives them and later on. People's reactions are influenced by their perception of the event, their coping mechanisms and their support systems. With a positive test result, a person may respond with a variety of emotions (e.g., fear, anger, sadness, anxiety, shock, relief) and use a variety of coping mechanisms (e.g., crying, venting, talking it out, seeking information). However, because of the strong stigma associated with HIV, usual coping mechanisms may not work. The person may be hesitant or unable to "talk it out" or ask for information. Some people may use ineffective coping mechanisms (e.g., drugs, alcohol, denial and running away). Some people, who have been living with a great deal of stress over a long period of time, describe themselves during this stage as just waiting for the next bad thing to happen.

Applying the Crisis Theory Model to HIV

3. Precipitating factor	the event that upsets the person's ability to cope. This is sometimes described as the "straw that broke the camel's back." With someone who has tested positive and is trying to cope, the precipitating factor may be something major, such as the onset of symptoms or having a doctor prescribe multiple medications, or something minor, such as a rude or thoughtless remark that pushes him or her into a full-fledged period of crisis. For some people, the diagnosis itself may be the precipitating factor.
4. Active crisis	a time-limited period (usually from four to 10 weeks) when the person feels unbalanced and unable to cope. During this time, the person may be emotionally, physiologically, cognitively and behaviourally upset. His coping mechanisms don't work. She can't manage the demands of her job or of daily living. He may feel that things are out of control, and may act in a manner that is out of the ordinary (e.g., running away, crying, drinking, anger, withdrawing, partying, attempting suicide). However, people can't stay at this level of high anxiety and turmoil for long, and they will return to some kind of balance with or without help. The job of the social worker is to help people get through the crisis so: <ul data-bbox="560 825 1429 940" style="list-style-type: none">• the diagnosis doesn't control or destroy their lives• they maintain some sense of power in a disempowering reality• they can regain a quality of life and hope that is at least equal to what they had before the diagnosis.
5. Reintegration	an extension of the state of active crisis when anxiety gradually subsides and the person is able to function again. The person adjusts to the positive diagnosis and integrates it into his/her life. To do that, people must: <ul data-bbox="560 1056 1458 1318" style="list-style-type: none">• come to some understanding of why this has happened (i.e., balanced cognitive perception), which can be difficult if that involves self-blame, guilt or a sense of retribution for "past sins" (as is often the case with HIV)• express and deal with the emotions that surface because of the diagnosis (i.e., manage affect)• develop new coping patterns to replace old ones that were either ineffective or no longer work — perhaps by connecting with others who are HIV positive.

Many events in the process of living with HIV can trigger a crisis (e.g., the first prescription for an HIV-specific drug, the first AIDS-defining illness, the first hospitalization, leaving work, having a friend die from AIDS, shifting from aggressive treatment to palliative care, and so on). These events may not happen sequentially, and a number may occur at the same time. Crisis theory can be applied at any of these times.

In the case of Claude:

- the hazardous event was the positive diagnosis
- the vulnerable state was his reaction: his calmness and crying indicated a need to deal with the diagnosis
- the precipitating factor was the casual comment about AIDS by a co-worker
- the state of crisis was the physical distress that Claude experienced, including being emotionally distraught, drinking, being short-tempered and being unable to commit to or focus on his work
- reintegration was his decision to seek help and take the first step in re-establishing a sense of balance in his life.

THE ABILITY TO COPE WITH DIAGNOSIS

The ability to cope with diagnosis varies greatly. The extent to which clients will go into crisis and work through it depends on a number of factors, including but not limited to:

- whether people were tested knowingly and voluntarily
- their own sense of whether they are at risk/infected
- the quality of pre-test counselling
- who the person was before the diagnosis – self image and sense of identity
- past coping skills/mechanisms
- social support networks
- other unresolved personal issues or stresses (e.g., relationships with biological family, sexual orientation, abuse)
- any pre-existing psychiatric condition
- any pre-existing addiction
- the person's socio-economic status/sense of security (i.e., job, income)
- the client's physical health (stage of illness)
- access to good quality health care
- access to credible sources of information about HIV and the ability to assimilate it
- the community's reaction to HIV.

To assess a client's ability to cope and his/her need for support, the social worker will do a biopsychosocial assessment. Based on that assessment, the social worker

may then consider the following interventions:

- crisis intervention, if needed
- counselling
- strengthening support networks
- case management
- referral.

Making Sense Out of Something that Doesn't Make Sense Applying the Crisis Theory to HIV Practice

When diagnosis is the precipitating factor that pushes someone into crisis, the social worker will help the client:

Crisis Without Support

A woman, living in a poor inner city hotel, was diagnosed with HIV and given no support to work through the diagnosis. After hearing the test results, she got drunk and was hit by a car. She was taken to hospital with a broken leg. Her care focused on the injuries from the accident, not the crisis precipitated by the diagnosis.

When she was released, her needs were complicated by the broken leg: she lived in an upstairs hotel room, was unable to get around or get food, so she lost weight. She was left to manage both the physical disability and the psychosocial impact of the diagnosis on her own.

Only when the situation became extreme did a social worker become involved. She was able to refer the woman to services she needed to cope with her injury, and to give her the information and support she needed to deal with the diagnosis. Had this support been available at the time of diagnosis, the woman's response, the accident and the injuries might have been avoided.

Come to some understanding of why this has happened by:

- reviewing the events that have occurred (testing, disclosure)
- helping clients deal with any sense of blame/shame or responsibility for having exposed someone else to the virus
- clarifying the client's understanding of next steps
 - get appropriate medical care by locating either a specialty clinic or practitioner and understanding the services available there
 - understand next medical steps (e.g., tests physicians may use to determine the stage of infection; different prophylactic treatments physicians may prescribe)
 - connect with critical/relevant supports, such as AIDS service organizations, peer support, group supports and information (resource centres, bookstores, 1-800 numbers)
- reinforcing/reiterating all that has been discussed by providing appropriate written materials (e.g., clinic brochures, business cards, selective handouts).

Express and deal with the emotions that have surfaced by:

- preparing client to expect a broad range of emotional responses
- giving the client an opportunity to vent and talk about the diagnosis (Some people will have to tell their story and talk it out many times before the emotions have been expressed sufficiently so the social worker must respect the client's pace and not rush them through the process.)

Levels of Crisis Intervention

	<i>First order intervention psychological “first aid”</i>	<i>Second order intervention crisis therapy</i>
How long?	minutes to hours	weeks to months
By whom?	front line caregivers	counsellors and therapists
Where?	in the community, where the crisis happens	at counselling centres
Goals?	re-establish immediate coping, give support, reduce tension, reduce lethal risk, link to helping resources	resolve the crisis, work through the crisis, integrate the crisis into the client’s life, prepare for the future
Procedures?	make psychological contact, explore dimensions of the problem, explore possible solutions, assist in taking concrete action, follow-up	ensure physical survival/well-being, facilitate the expression of feelings related to crisis, assist in cognitive mastery/understanding of crisis, develop effective coping mechanisms/effect necessary life changes

Principles of Crisis Intervention

- Begin with the precipitating factor.
- Involvement is time-limited and focused on the present.
- Services are easily accessible and available to the person in crisis.
- The social worker is active. There is no need for build-up or relationship building. The social worker may use dramatic means to focus on the issue at hand.
- The social worker is more emotionally involved.
- There is no need for insight-oriented therapy.
- The involvement is not limited to regular counselling sessions.
- The goal is not to solve life problems, but to help the client achieve an adequate level of functioning.

Steps in Crisis Intervention

Listening:

- defining the problem from the client’s point of view
- ensuring client safety by minimizing any physical, emotional and psychological danger
- providing support, by demonstrating through words and body language a caring, positive, non-possessive, nonjudgmental acceptance.

Acting:

- examining alternatives and the wide range of choices that may be available to them (Different ways to think about alternatives include situational supports, coping mechanisms, and positive and constructive thinking patterns.)
- making plans based on what the client wants to do
- obtaining a commitment from the client to act on the plan
- making a referral to other health professionals if appropriate (i.e., the client is actively suicidal).

- giving the client permission to cry, be angry or to laugh, and to grieve
- encouraging the client to seek out a trusted person who will help him/her cope (Because of the stigma of HIV and the risk of alienation, this person may not be part of the client's biological family or usual support system.)
- helping the client link with others with HIV who may have experienced the same emotions.

Biopsychosocial Assessment

In 1989, Tiblier, Walker and Rolland developed the biopsychosocial stages and phases theory of HIV/AIDS. According to that theory, "to look at AIDS through a biopsychosocial lens leads to two separate but interrelated perspectives:

First one can describe the psychosocial issues associated with illness at each of the medical stages from wellness to death including:

- 1) the worried well
- 2) diagnosis of HIV
- 3) symptoms of HIV
- 4) diagnosis of AIDS
- 5) death and bereavement
- 6) family reorganization.

Second, all chronic and life-threatening illnesses can be described in terms of three time phases: crisis, chronic and terminal. Each phase has its own developmental tasks and requires different coping and adaptation skills from the family."

Although the understanding of HIV infection has changed since 1989, the concept of stages and phases is still a useful way to assess clients' issues and tasks. However, good social work practice should not be driven only by the developmental stages described in this model. Each person living with HIV will have unique issues that can only be understood within the context of that person's life, his or her family and the larger community.

Tiblier KB, Walker G, Rolland JS. "Therapeutic Issues When Working with Families of Persons with AIDS" in *AIDS and Families*, ed. E. Macklin. 1989.

Develop new patterns of coping by:

- identifying any other needs or issues that may keep the client from taking charge (e.g., cultural issues, homelessness, poverty, addiction problem)
- countering the perception that HIV is an immediate death sentence
- talking about the medical advances that have been made (e.g., new approaches in early treatment and combination therapies) and about alternative and complementary therapies
- providing phone numbers clients can call any time they have a question about treatments or complementary therapies
- stressing that there's a lot people can do to help their bodies actively fight the virus
- issuing an "invitation to self-care/love" and talking about things that the client can do to take control, including good nutrition, exercise, stress reduction/relaxation and less substance use, as well as helping the client get necessary information and professional advice
- recognizing that a client's ability to take charge will depend on his/her situation (e.g., people who are homeless or living in poverty may be less able to take the necessary steps to protect their health).

Find hope and look at new possibilities by:

- when the client is ready, helping him or her find a new focus for hope by reframing goals for the future
- encouraging clients to look at the diagnosis as an opportunity to make changes or to deal with previously avoided issues, including:

Finding new ways of coping and hoping

A social worker involved with the aboriginal community was working with an HIV-infected gay man. In the biopsychosocial assessment, the social worker identified the client's low sense of self worth as one of his main issues, and the one that led to self abuse (e.g., alcohol abuse and unprotected sex). The social worker turned to aboriginal culture to offer the client a different view of himself. The social worker talked about the traditional aboriginal view of gay people as "two-spirited." Within the culture, two-spirited people were traditionally honoured and revered. They were often the medicine men, wise ones and healers. They were considered to be gifted with humour and were often the tricksters.

When aboriginal people were exposed to Euro-Christian traditions and ways, they were taught that this view was wrong and that now colours their attitudes towards sexuality, homosexuality and bisexuality. However, the culture is now seeking out the old ways and teachings, which are helping to shape and change attitudes.

Exposed for the first time to traditional ways, the young man began to use them to help him deal with his issues and to give his life meaning. He now goes to healing circles, sweats and smudges, and spirituality is becoming more important in his life.

- a new job or skill upgrading (The social worker should work with clients to make sure that, in changing jobs, they don't lose benefits, such as long-term disability and insurance, that might later help them deal with the effects of HIV. If they can't "afford" to change jobs, they may want to do something else hopeful with their lives, such as volunteer work or courses. Some clients may choose to change jobs in spite of the possible "losses.")
- new relationships (i.e., abandoning ones that have been non-productive and seeking out new friendships)
- new ways of thinking (e.g., "living for today," "taking things as they come," "one step at a time" and "planning for the future" in a different way)
- embracing who they really are and dealing with issues of sexual orientation
- if the client wants to, exploring existential questions (e.g., why am I here? what is left to do?) and, if appropriate, referring clients to a spiritual counsellor.

DEALING WITH DIAGNOSIS IN COMPLEX CIRCUMSTANCES

Other physical conditions — such as illness or pregnancy — will make it more difficult to cope with an HIV diagnosis.

Advanced stage of illness

Although more people at risk of HIV are being tested early, a significant percentage are not diagnosed until they present at the emergency department with advanced signs and symptoms of illness. At this stage, the client is dealing with diagnosis and illness, and this compression of events creates more stress. In this situation, counsellors should remember that "in the face of greater complexity ... keep it simple."

The first step is to set some concrete, instrumental priorities, based on the client's medical and personal needs, and deal with them, such as:

- the person’s need for drugs to treat the illness and any financial issues that this may create
- the person’s need for financial assistance, if he/she is unable to work or support him/ herself, beginning first with employment insurance sick benefits and social assistance, then disability insurance
- homelessness and the need for a place where the person can live and get care and support when released from hospital.

Practice Issue Keeping It Simple

I recently worked with a woman whose HIV positive daughter came home having injected heroin for several years. I discussed four tasks at once:

- *getting a family doctor*
- *registering with home care*
- *getting social services and long-term disability*
- *getting connected with the outpatient clinic and having her eyes checked.*

She started with home care but was told she had to have in-province health care. (With new rules in some provinces, people have to be resident for three months before they qualify for health care. However, newcomers can start the registration process in a new province within the first three months of their arrival and, in the meantime, be eligible for home care and continue to have their medical costs covered by the province where they used to live.) The first few family doctors she tried had “closed their practices.” When she tried the eye clinic, she was told the family physician clinic had to refer her. She couldn’t do it directly.

When I saw her the next day, she was pretty discouraged. In hindsight, I wish I’d only discussed one thing at a time so she could have done it and succeeded. In my anxiety, fed by the family’s, I tried to get them doing too much at once.

Dealing successfully with these issues will establish trust. The client may then be ready to tackle other issues, and the social worker can then apply the traditional crisis intervention model.

Pregnancy

Because there are now treatments that reduce the risk of mother-to-child transmission, many jurisdictions encourage pregnant women to be tested for HIV. As a result, a growing number of women will find out they are HIV positive when they become pregnant and begin routine pre-natal care. The psychosocial impact of a positive diagnosis at this stage can be devastating.

A married woman, Kate, pregnant with her third child, was tested for HIV without her knowledge or consent. (The HIV test was ordered along with a battery of other blood tests.) When the results came back positive, she was then faced with deciding whether to terminate the pregnancy, the anxiety of having her husband and other two children tested, and having to persuade her husband to practice safer sex within her marriage.

Kate’s husband, who was ambivalent about the third pregnancy, didn’t want to take a chance that the baby would be infected and favoured terminating the pregnancy. Kate struggled with the decision. She and her husband both met with a social worker, who invited Kate to attend a support group for women who were HIV positive when they were pregnant.

“It just happened,” said the social worker, “that the day Kate attended the group, all the women there had given birth to babies who were uninfected. After much discussion, Kate realized she had options.”

Kate decided to continue her pregnancy. She took AZT, and the baby was eventually found to be uninfected. (Because infants of HIV-infected women are born with their mother's antibodies, it takes some time before parents know for sure whether their child is or is not infected.) The other members of the family were all HIV negative, but the couple went through some extremely stressful times and needed ongoing support.

Women diagnosed in early pregnancy may be faced with a decision about whether to continue or end the pregnancy. To make that decision, they will need accurate information on the risks of transmission to the child and on the impact of pregnancy on their own health status.

Diagnosis and Suicide

In the early days of HIV — with fewer people infected, the extraordinary stigma, and the lack of information, medical treatment and hope — suicide attempts were common. Even now, some people who are diagnosed may become suicidal.

A 24-year-old gay man was recently diagnosed with HIV. He hadn't told his parents about his orientation or his diagnosis. He was involved in his first relationship, which wasn't working out well for him. He had a lot of expensive tastes, but only a minimum wage job at a fast food outlet.

When he saw the social worker, he was contemplating telling his mother. A few days later he was in emergency for attempted suicide. While in hospital, he did tell his mother, and he began to contemplate leaving his partner, but was concerned about how he would survive. He asked a nurse about some temporary options. He killed himself that weekend – before the social worker had a chance to meet with him and go over his choices.

Had the young man known his options, he would probably have been less likely to take his own life. Other information can also help people deal with overwhelming anxiety, such as the life expectancy of people with HIV and recent advances in medical treatment.

Being aware of their choices and the available resources can have a profound effect on people's perception of their circumstances. It's a practical way to help despairing people ("I don't know what to do. I'm desperate. I might as well be dead or kill myself.") see past the uncertainty to a time when they will have more support and more control.

Many people who feel suicidal also benefit from peer support — the reassurance from someone who has been through the same thing and survived. Buddies — other people with HIV — can be a strong source of support, because they can relate to the experience of having HIV and help people with HIV see others who are living and coping with the illness.

When a Client Commits Suicide

Despite the best possible efforts to help clients cope with their diagnosis, some who want to commit suicide will follow through on their desire. If this happens, social workers may experience feelings of anger or guilt, especially if they feel they

failed to prevent an avoidable suicide. They may also experience feelings of shame or doubt about their competence as a helper. They may be preoccupied with the existential search for meaning in an untimely death and with questions such as: why did this happen? could I have prevented this death? should I have done more?

If you are in this situation, how can you deal with these reactions?

After the loss of a client to suicide, it is advisable to:

- recognize that you can't save everybody
- speak to another professional or support person
- recognize that feelings such as guilt, anger, shame and doubt are normal grief reactions and it's important to have an opportunity to vent those feelings
- discuss your interventions and review the events leading up to the suicide — this will allow you to explore some of your unanswered questions and give you some direction around future interventions with suicidal clients
- allow yourself to grieve the loss.

Services such as a suicide postvention program, a psychological autopsy (which attempts to clarify the nature of the death), or critical incident debriefing ensure that professionals have a way to deal with the impact of a client's suicide.

A client's suicide will have a direct impact on the social worker, other members of the care

team, family members, friends and acquaintances. Over both the short-term and long-term, people close to the person may be a higher risk themselves for psychosocial problems. Loss of someone to suicide is more likely to cause intense feelings of anger and guilt in those left behind, and they may need help coping with these strong emotions.

Practice Issue

When a Client Threatens Suicide

You have a newly diagnosed client who begins to talk about suicide or a client who is so devastated by the news that you are concerned that she might try to take her own life. What do you do?

The social worker can:

- try to find out whether the client has ever attempted suicide before — if so, there's a 40 per cent chance he or she will try again
- try to find out how concrete the person's suicide plan is (e.g., how? when?) — people with specific, clear plans are more likely to carry them out
- check for an existing addictions problem — diagnosis may trigger heavy drug or alcohol use which can, in turn, make it more likely the person will follow through on a suicide threat (People with serious addictions problems may need to be referred to emergency and psychiatry services and/or addictions programs.)
- check for other unresolved psychosocial issues
- be aware of the person's age — depending on their situation, younger people may be less aware of their choices, have less support, and be less comfortable asking for help (An analysis of users of social work services in an HIV clinic by age indicated that people over 30 were heavy users of social work services, while those in their 20s were low users. Social workers may have to reach out to people in vulnerable age groups.)
- be aware of the potential for manipulation — some people will threaten suicide as a way to get other things they want, such as money, housing or attention
- make sure the client knows about all the available resources — people are most likely to consider suicide when they feel they have no other options
- identify a quick response team made up of a psychiatrist, HIV specialist, physician and social worker, who will be available to deal with a suicide attempt.

A LOOK AT COUNSELLING AND COMMUNITY SUPPORT

Clients diagnosed with HIV should be able to choose the type and amount of counselling they want or need, and identify the issues they want to discuss in those sessions. However, it may be easier for clients to ask for what they want when social workers make it clear that their door is open and they're available when the clients are ready.

In HIV, a significant amount of work has gone into developing peer support or peer counselling programs as well as support groups. This gives clients choices beyond the traditional one-to-one counselling with a professional. Some clients begin with one-to-one counselling and then go into a group. Some start with a group and, when they have some sense of support, are then ready to deal one-to-one with some of their other issues.

Practice Issue Managing Peer Support

When I make referrals to the people who provide peer support, I try to make sure the connection will be manageable. I screen out serious psychiatric risks, such as people who are likely to commit suicide or substance users with little motivation to change. We had one referral made to a peer by the emergency department. The person referred committed suicide, which was hard for the peer counsellor to deal with. In hindsight, the referral should never have been made.

However, social workers should be prepared to have recently diagnosed clients reject the idea of a support group or any ongoing counselling. For some people, it's not the right choice. The person may not want or need the support, or he/she may not be ready. However, it's important that social workers let people know that they are available if they need support any time in the future.

After five years of practice, I believe the stigma of HIV is the power behind why people usually shy away from joining groups right after they are diagnosed. The fear of meeting friends is too great a barrier. Ironically, if the person's circle of support is too weak or non-existent, it is more difficult to move out to an alien, unknown "support group."

For this reason, social workers should not over emphasize groups to people who are recently diagnosed. It is enough to tell them that the groups exist. The social worker cannot rely on groups as a stepping stone through the diagnosis crisis as, more often than not, it will be a misstep.

At the best of times, only 5 per cent of our patients (in a major outpatient HIV clinic) are attending group. Most of them take at least one year after diagnosis to join a group.

More effective than groups in the early stages of awareness is a one-to-one connection with someone in similar circumstances — either someone else who has HIV or someone with a similar medical/psychosocial profile. At the very least, this peer counselling allows people a chance to

try out their “new identity” and discover acceptance and the freedom to explore its meaning with someone who has already navigated that process successfully. The client can practice “coming out” with HIV to someone in a situation where the risk of rejection is minimal, and prepare for the time when he/she confronts people who are riskier to tell. The process of linking with one other person can be a powerful motivator in finding new ways to cope.

Peer counselling offers an effective resource for people who are afraid or suspicious of the medical/psychosocial community. In a number of settings, peer counselling has been used successfully with couples, people who have attempted suicide, in prisons and with “minorities” in the HIV community, such as women, aboriginal peoples and people from specific ethnic groups.

Practice Issue An Alternative Systems Approach

A community-based AIDS organization in a small community in a rural area tried for several years to organize a support group for the HIV positive men in the surrounding area. Most of the men were isolated. Many were not “out” and did not want to be associated with a gay organization or an AIDS group.

Convinced that the men and their families needed some support within the community, the organization persevered but this time organized a group for the mothers of the men, who were also feeling extremely alone and isolated. The mothers’ group was very successful. The mothers gained support and a sense of belonging, which they in turn were able to use to help their sons and other members of their families.

A program in a large urban centre also had trouble organizing a group for women. Because of family commitments, the women had trouble arranging meetings in the evening, so they agreed to meet for coffee or lunch, and that works well for them.

A hospital-based clinic holds “family” information nights in the hospital auditorium where people sit anonymously with partners and other family. The most popular topic is new developments in treatments. The information night helps people put a face to the names in the clinic, demonstrates that clinic staff are open to family and partners, and provides a forum where people can discuss timely issues. All clients who come to the clinic for the first time now see a social worker briefly so they are aware of what the services he/she can provide and will feel more comfortable calling them anytime in the future.

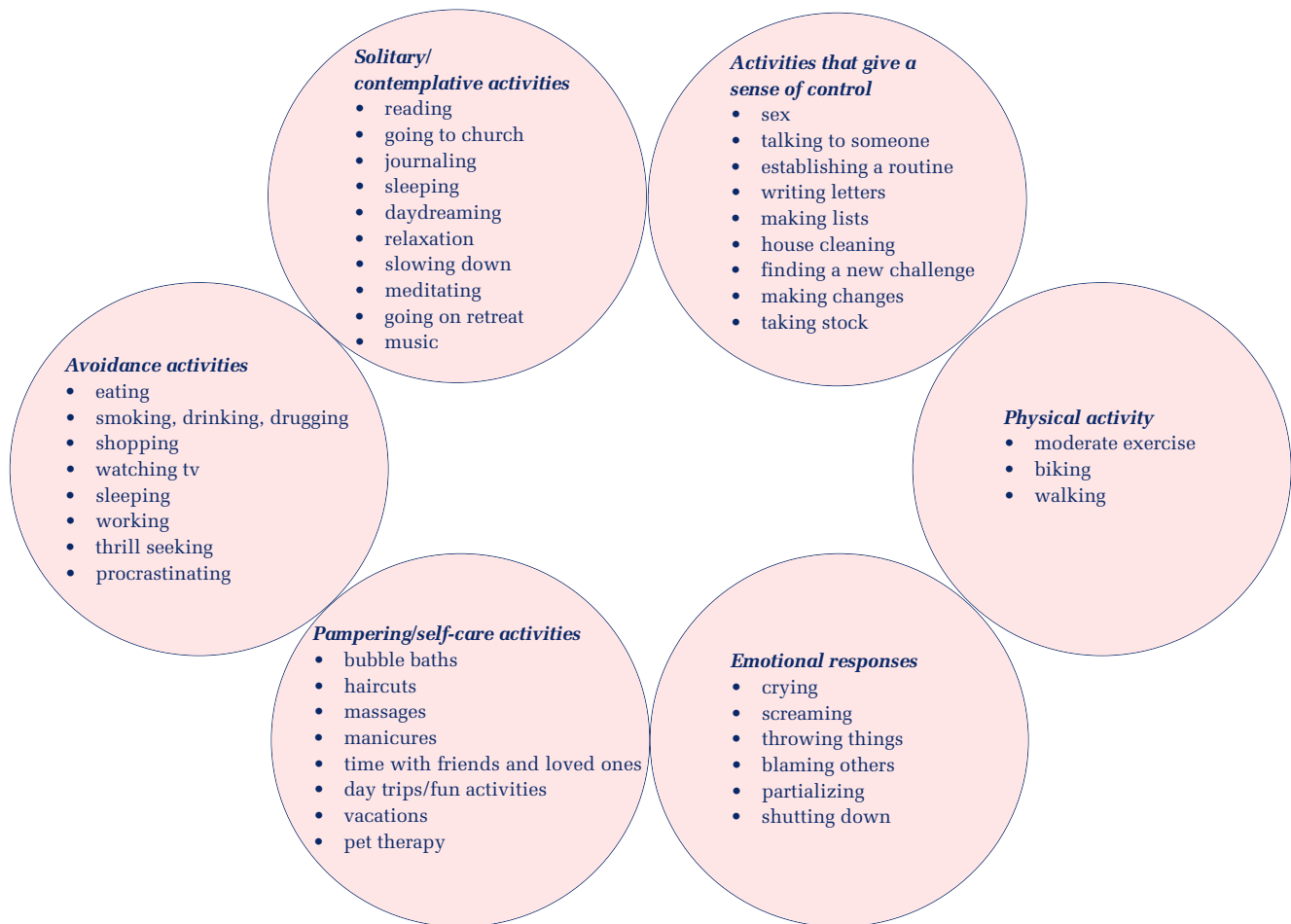
People with HIV often prefer to get their information from peers because:

- peers provide the information in clear language
- they are more likely to trust peers
- peers understand
- they can avoid the negative connotation of “needing professional help.”

To be effective, peers need training. The Community AIDS Treatment Information Exchange (CATIE) has developed *HIV-positive Peers as Treatment Information Counsellors — Training Manual and Organizational Resource*, a 12-week peer training program based on the principles of interactive and participatory learning. In the CATIE model, peer counselling is non-directive, non-judgemental and uses an interactive approach to support another person living with HIV/AIDS in making informed choices. Other organizations have developed similar resources. Starting a peer training program takes a significant amount of time (about 20 per cent of one person’s time for the first few months) but once established, it takes about eight hours a month of support time. One community group hired a psychologist to provide this monthly support, and used funds raised locally to cover the costs.

Common Coping Strategies

People may use a number of different ways to cope. Many are quite healthy and affirming, if **not** done to excess.



Other Coping Strategies

Clients may find other ways to cope with a positive diagnosis or to get the support they need, including:

Connecting by phone

Some people are so upset by the diagnosis and its stigma that they cannot immediately connect directly with a medical/counselling resource. Instead they explore the waters indirectly. Typically, the first contact begins with an anonymous call, low voice, nervous and lots of staccato questions. They are trying to test out or confirm what they heard at the test site. They will often be preoccupied with “who” at the centre or organization — including staff and patients — will know their status or have access to their files. They also want to know about the steps taken to protect confidentiality. They may end the first call unexpectedly, and they will often make three or four calls before they are willing to give their name or make an appointment.

In these situations, counsellors should not rush things for fear of scaring these clients away. Throughout the process, they should be patient and give information that is simple, clear and consistent. Counsellors should also recognize that, when these clients do finally make an appointment, they may not show up for the first appointment and, when the sessions do begin, progress may be slow and cautious. The client is still sizing up the counsellor and trying to decide how reliable, trustworthy and helpful he or she is.

The phone can also be a useful way to connect people in rural or isolated communities. In several places in Canada, support groups or peer counselling is done by phone or conference call. People often feel safer making their first contact with a peer or group over the phone, as it allows them to maintain their anonymity. The original links are usually made by a social worker or other counsellor, who checks in with the group.

Most provinces have a 1-800 AIDS information number that can also connect people with information and, in some cases, support and other services. (See resource list on page 164.)

Connecting on the Internet

Talk groups on the Internet also provide an anonymous way for people with HIV to get support. The process is completely in the person’s control, which has some advantages.

The disadvantages are the openness and expense of the Internet. Anyone who signs onto an HIV or AIDS group may become the target of hate mail and may feel his or her confidentiality has been breached. There is also some risk of receiving sales pitches for products that will “cure” HIV or prolong life. No one has any control over the quality or accuracy of the information on the Internet, so the client must be able to exercise some judgement. Social workers may be able to help the client assess the information and cope with any ill effects.

Buddy programs

Buddy programs link people with HIV with one other person who may or may not be infected but who is familiar with the issues. In any formal program, the “buddy,” who is a volunteer, goes through some orientation and training, and is willing to make a long-term commitment. The sponsoring agency or organization provides support for the buddy who, in turn, helps the person with HIV cope with diagnosis.

In addition to formal buddy programs, people with HIV may develop their own informal “buddy” relationships with people in their own community or circle of friends who can give them the sense of support they need.

Healthy denial/constructive avoidance

In Western culture, denial is usually seen as a negative coping mechanism. However, with HIV — an illness with a long, latent period that can last 10 years or more — denial can be a healthy coping strategy, especially at the beginning. Some clients make a conscious choice that they are not going to tell other people at this stage, and they are able to manage the tension of keeping a secret better than the process of disclosure. It’s important to respect the way that people cope and come to grips with their situation. It is also unrealistic to expect a sudden transformation to different types of coping mechanisms.

Unresolved Issues — The Argument for Teamwork

A diagnosis of HIV will bring to the surface any unresolved issues, as well as some the person may have thought were resolved in the past, such as sexual orientation, family of origin issues, addictions and responses to death.

These issues will usually arise after the person has successfully worked his or her way through the crisis of being diagnosed. The client should begin to reflect on unresolved issues between six weeks and three months after the crisis has been resolved — although it may take people with HIV longer to reach this stage.

In dealing with any unresolved issues, it is wise for social workers to acknowledge their role, boundaries and limits, and broaden their professional networks. They must be willing to call on other professionals with specific expertise in these fields

Practice Issue

When Positive Isn’t Positive

A young gay man comes to you, saying he has HIV and asking for support. He is openly positive and needs to talk a lot about his situation. He is anxious to get involved in groups and in other HIV-related activities. When you ask about his doctor or the diagnosis, he is vague. Rumour within the community is that he is not really positive, but just seeking to belong and to get some of the attention given to people with HIV. What do you do?

It may not be appropriate to question the man’s status or to ask for “proof” that he is positive. Some people may not have the clinic referral cards or HIV medications that would make it easy to confirm their status. Some agencies limit a client’s access to services such as financial assistance, until they have confirmed that he/she is HIV-positive. This may be particularly prudent if the social worker thinks the client is using substances.

A social worker who has doubts about a client’s HIV status would likely assume that this is more of a mental health issue, and that the person has gone to relatively extreme lengths to get attention, solace or some form of nurturing. Someone in this situation needs support and affirmation. The social worker would attempt to answer some key questions, including:

- is the person looking for services or is he just looking for something to belong to?
- is it possible to be compassionate and help him/her get the services or support he needs?
- is he/she using his HIV status to manipulate other people? is it destructive?
- is he/she using his HIV status to put himself at centre stage? are his/her actions harming others? If so, it may be appropriate to make a referral to a mental health professional.

and either refer the client to them or work with them to support the client in dealing with these issues. One person with HIV suggested that professionals working in HIV/AIDS find a “buddy” with experience in the other issues, such as addictions counselling. Those working in AIDS organizations must make it easier for clients to talk about their issues, just as those working in addictions or mental health must give clients permission to talk about HIV/AIDS. Efforts to co-ordinate services will be covered in more detail in the next section, *Living with HIV*.

Resources

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- Dansky S. “A Chronology of Exile” in *Now Dare Everything: Tales of HIV Related Psychotherapy*. New York: Harrington Park Press. 1994.
- Golan N. “Identifying and Defining the Crisis Situation” in *Treatment in Crisis Situations* 1978.
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- Macks J. “The Psychological Needs of People with AIDS” in *Face to Face: a Guide to AIDS Counselling*, ed. J. Dilley updated version. San Francisco: AIDS Health Project; Berkeley, CA: Celestial Arts. 1993.
- HIV and You* Edmonton: AIDS Network of Edmonton Society, 1992; #201-11456 Jasper Avenue, Edmonton, AB T5K 0M1
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3 LIVING WITH HIV

Many of us went into this epidemic thinking it would all be over soon. If we could just hang on until the cure was found, things would be OK. We imagined that a cure was just around the corner. In the meanwhile, we'd be good: condoms/dental dams, fewer sex partners, hit the gym, take our vitamins, cut out the drinking and drugging and smoking, early to bed, maybe a little meditation ... in the end, it would all work out. We'd awaken from this bad dream.

What reasons can we find in the second decade of this incurable, fatal and spreading disease to keep on going, to continue to practice safer sex, to stay healthy, to support the people we love, to do our jobs well, and to stay happy and optimistic? I think each of us needs to know the answer to this question for ourselves and for the people with whom we work if we're going to be effective in counselling situations.

Darien Taylor,
Opening Doors Counselling Conference, Ontario, 1995

When people are diagnosed early in the infection, they may well live 10 to 12 years and longer with no symptoms of illness. They appear physically well and are able to work. No one would necessarily know they are ill. Yet they are living each day with the possibility of dying. As one person said, "Everytime I cross the street, I see the bus coming."

Being infected but physically well can be a time of great uncertainty. It can also be a time of creativity. Some people make radical changes in their lives, live more for today and look for "new possibilities." Some develop a great sense of urgency about life, and are anxious to use the time they have left to develop supportive and satisfying relationships with others. Some manage well for a while, but as the years go by, they find it harder and harder to keep living with the threat of dying. Living with HIV can be extremely challenging emotionally. People who are physically well may still need psychosocial support.

When people who are positive make the transition from coping with diagnosis to living with HIV, the strategies required to support them also change. That is not to say that they will not continue to need crisis intervention or counselling services, but they will now be working through issues more in relationship to other people and to the community at large. They may need some support to develop and maintain a social support network, get services, and deal with unresolved issues. Social workers working with people living with HIV can use a combination of strategies including:

- encouraging the client to develop and maintain a personal social support network

- helping the client learn to live with disease
- mobilizing the community for the benefit of people with HIV
- providing case management and helping the client develop links with other services, if required
- advocating to help clients get access to the services and supports they want and need, to encourage broad community support and acceptance of people with HIV, and to counter any discrimination
- working with clients to influence policies that may affect their lives.

MOVING FROM ISOLATION TO INTEGRATION

Building Social Support Networks

The people who cope best with HIV and are best able to manage their lives, are those with strong personal/social support networks. They are people who are able to move past the devastating isolation of being diagnosed HIV positive, recognize that their lives will never be the same and become integrated with the world in a different way. They have family and/or friends who know their HIV status and who are accepting, caring and supportive. Eventually, they will be the people who help provide care when the person becomes ill and can no longer maintain his/her independence.

Some clients will already have strong and well-developed social support networks; others will not. When the person does not have an existing network, the social worker may first work to help him/her establish one.

The problem solving model can be very useful. The social worker uses it to clarify the issue and reassure the client that he/she understands the problems. The social worker then talks through the options with the client. Who do you know that you trust? Who could you ask for help? If you don't have anyone, how can you develop a support network? Do you feel comfortable going to the local AIDS organization? Are there other places you would like to go for support? The social worker listens to the client and doesn't make any judgements about who will be most helpful (e.g., a street kid may turn to another street kid, who may be more helpful than a professional).

The social worker then lays out the various options and leaves the person to "be in charge" and to decide which option makes the most sense for him or her.

The process of developing a support network can be very complex. Some people will choose to break from their previous supports. Some will cut ties with some people, and re-establish them with others. If the person's supports are dysfunctional, the social worker may have to first work with the client and his existing support network to resolve underlying problems, before dealing with the HIV.

Building a support system can be particularly difficult for people who are homeless or street involved, or for those who live in rural communities, where there may be more stigma and fewer other people with HIV who can provide peer support. Street communities can often be very supportive of their members, but may not have the resources to meet the person's needs over time.

When the Client Doesn't Call

Some social workers report that clients who came to them for help dealing with diagnosis or disclosure may “disappear” and have no contact with them or the agency for months or years. That's okay.

In many cases, people with HIV are just getting on with their lives. HIV disease now has such a long asymptomatic phase that, despite the presence of HIV, many people find healthy ways of managing their lives and their emotions, and do not feel the need for a strong connection to you as a professional or to other types of caregivers. This does not mean the social worker or the organization has failed. It simply means that the person's social support network is strong enough to sustain him or her through this phase. This allows social workers to focus on the approximately 20 per cent of cases that need attention and support.

With clients in small or rural communities, social workers may have to be more innovative. Places that may not be a source of support in large urban centres, such as churches, may play a pivotal role in smaller communities. Social workers may also find that, when people in smaller communities disclose their HIV status, they receive a tremendous amount of support.

Culture may also play a strong role in developing a support network. Some people may look for their support within their own culture, others may look outside. Some cultures may have norms around the “sick role” and caregiving that social workers will have to recognize and respect in order to understand the client's reactions.

Some people, particularly those in the gay community, may suddenly experience a strong sense of “belonging” when they become infected. People who may not have been able to build strong relationships in the past or feel part of a group, suddenly “qualify” for membership in a group that is based on mutual support. People who are not gay often have the opposite experience — a sense of belonging nowhere. It may take more time for them to develop a support network, and to decide what, if any, role AIDS organizations can play in that network.

To help people develop social supports, social workers should be:

- aware of the resources and supports available in their communities and what they offer
- be willing to work with people, families, groups and organizations to develop social supports in the community.

Identifying Needs and Strengths

Some clients may have other basic unmet needs that interfere with their ability to move on to building a social support network or living with HIV. In the biopsychosocial assessment at the time of diagnosis, social workers may have identified some of these needs and can begin to work with the client on them.

It is essential to let the client identify his or her needs and then work on them in the order that is most important to the client. Social workers should also help

clients develop a sense of control and self-esteem, by making them feel they are doing a good job of managing their needs.

In the assessment process, the social worker should also identify the person's strengths and capacities, and the skills and resources he/she can use to cope with and manage their HIV.

Looking for Financial Help

Many clients may be concerned about financial matters. Even if they are working and financially secure now, they will worry about their ability to manage in the future. Depending on the person's or family's resources, HIV — which affects people's ability to work and often requires expensive drug treatment — can move people quickly from a comfortable standard of living into poverty. As HIV begins to affect more people who are already socio-economically disadvantaged, such as street youth, injection drug users and people who are homeless, their financial needs will grow.

Offers of help to find financial resources can also be an effective way for social workers to develop a trusting relationship with people living with HIV. Clients who do not think they need counselling, crisis intervention or other social work services may well agree to see a social worker to deal with financial issues and other practical matters, such as housing. Social workers can help by talking early on — when people are still healthy — about insurance coverage (health, drug, life), the different types of financial assistance programs, and financial planning. Clients are then better able to plan for the future, which may reduce some of their anxiety and give them a greater sense of control over their lives.

DISCLOSURE

To get support from friends and family and to get appropriate care, people must first ask for it. When clients have told no one close to them about their diagnosis, they remain isolated and may become weighed down by their secret. To take advantage of a social support network, they must begin to trust their family, friends and caregivers, and risk telling them about their HIV status. They must deal with disclosure.

For most people with HIV, disclosure is a process that occurs over a long period of time. People usually choose carefully who to tell, depending on their relationship with that person. Disclosing their status to a social worker is a big step — although most people find it easier to tell a professional (who they trust not to judge them) than to tell the people in their lives. When they do begin to disclose to people they know, they often start with people they believe will accept them, and then gradually disclose to others, such as family members. They may also find it easier

when they have worked out a strategy for telling people (e.g., choosing a particular place and time, or having someone else with them for social support when they do disclose). While clients may need time to disclose, family members and friends may also need time to deal with disclosure. If clients wait too long — for example,

until they are ill — family and others may have to respond quickly without having a chance to come to terms with what is happening. Social workers can encourage clients to take all these factors into account when deciding about disclosure.

The client will decide who, when and how to tell. But the social worker can play a valuable role in helping the client work through his/her fears and anxieties, recognize the real risks of disclosing in some settings (e.g., the workplace), and recognize that certain people (such as sexual partners) may need to know, while others may not. For example, when the person is still well, there is no need for employers or co-workers to know, unless the client chooses to tell them.

The stress of disclosing to other people varies, depending on a number of factors, including:

- the past relationship with the person
- the person's sense of self-esteem
- the other person's attitude toward HIV, sex, sexuality and other issues
- the power the other person has over the person with HIV (i.e., does this person have the power to affect the client's life by, for example, kicking him out of his home or firing him from a job?)
- attitudes in the community toward HIV.

Practice Issue **Helping Clients with Disclosure**

Social workers can help clients work through the process of disclosure by encouraging clients to develop a strategy, including:

- be selective. Think carefully about how you want to share the information, who to tell first and who is most likely to be supportive.
- be someplace comfortable. Choose a place where you feel comfortable and have some privacy and wait until you have plenty of time (telling someone you are HIV positive can be an emotional experience, and you want to be in a place where you can safely express your emotions).
- prepare yourself. Think about what the person may ask and try to prepare your answers. Think about what questions you don't want to answer and plan how you will handle them. Feel free to tell the person that you just want them to listen, and you're not asking for any advice.
- have realistic expectations. Try to remember how you felt when you were first told you had HIV.
- remember that everyone may not be supportive. Some of the people you tell may react negatively and pull away from you. They may be reacting out of fear of the virus or fear of losing you. You may need to explain more about the disease. You may also just have to let the person go.
- don't feel responsible for other people's reactions. You have shown a great deal of strength in choosing to disclose. You are not required to make everyone feel better. Take care of yourself.

When clients are gay, the social worker can help by asking some key questions: Who have they told in their families about their sexual orientation? What about people at work? What about people you spend leisure time with? Is their family aware of their relationship with their partner? Are they supportive? Clients will likely have to deal with "coming out" to their families, before they can deal with disclosing their HIV status.

Clients may also need advice about how to tell people and still keep the information somewhat private. Social workers can suggest that clients tell family and friends that they want them to keep the information to themselves, until the client is ready to tell others. Clients can also tell them who else they have told. It

may help family and friends to know who else does know, so they can share their concerns and feelings with someone who understands.

When I told people I was HIV-positive, it was no longer my problem. If they had difficulty, that was their problem. I felt a great sense of freedom. However, I recognized that telling people meant a loss of control over who knew.

For many people, the process of disclosure is a way of accepting and acknowledging their HIV infection. They must reach this stage before they can agree to any interventions. It is difficult for caregivers to treat or care for people who continue to deny their HIV status. Social workers can play a key role in helping to facilitate disclosure.

Telling a Sexual Partner

If the client is in a sexual relationship, telling his/her partner is an important issue. When to disclose can be a dilemma:

- if the HIV positive person discloses too early and the other person cannot cope with the information, the relationship may end abruptly
- if the person waits too long, the other partner may react to the news as a kind of betrayal or broken trust, particularly if the couple did not always practice safer sex.

With either option, the person may face rejection, so social workers should encourage clients to disclose to a potential long-term partner early in the relationship.

Disclosure will also be affected by the nature of relationship itself. If it is an abusive relationship or if the relationship was in trouble before the diagnosis, disclosure will be more difficult.

Depending on their sexual practices, the other partner may be at risk of infection. The next logical step is for the partner to understand the risk and consider being tested.

If the partner is negative and the couple stays together after disclosure, the social worker should advise them to seek both medical and psychosocial counselling to help them integrate safer sex practices and learn how to negotiate the difficult dynamics in discordant (i.e., one person HIV positive, the other HIV negative) couples. If the partner is also positive, that raises other issues for the couple.

Telling Parents

For some people with HIV, parents may be the most difficult people to tell. Those who love and still want to please their parents may feel that they have let them down. Even people who have not been close to their parents may find it difficult to give them information that will cause them pain. Some people's parents will be older and may be in poor health themselves, which makes it more difficult to give them "bad" news.

Some advice on telling parents

1. What is the worst that can happen? You may be surprised to find that they are more understanding and supportive than you anticipated. But consider the range of possible reactions and determine how you want to respond.
2. How can you get ready? Collect the clearest and most straightforward brochures and articles about AIDS and HIV infection. Leave these with your parents no matter what their reaction. Discuss with friends or a counsellor how you want to approach this meeting.
3. How can you help them? Tell them ahead of time that you have something important to discuss. Set the stage for a serious topic. If possible, have your physician or counsellor write a letter to your parents outlining the actual status of your health and importance of support from loved ones. Assure your parents that you are being careful with your health. Tell them what you need most is their love and understanding.
4. Can you let your fears show? Now is the time to include your parents in the full range of your coping with this disease. Assure them that some people who are seropositive may never get ill, but also discuss with them that you are at greater risk of developing life-threatening illness. There is no reason to pretend that this is not scary stuff.
5. What if they? Once they know, allow your parents to respond with as much acceptance or denial as they need — just as you allowed the same for yourself when you first learned your status. Let them adjust at their own speed. If things go badly, bring an end to the discussion as calmly as you can.
6. What should you do next? Follow up your discussion with a letter or phone call, and tell your parents how important it is for you to talk with them. Assure them that you understand how difficult it may have been for them to hear your news. Give what you are asking for: love, understanding and a willingness to go through this experience together. Tell them where they can go if they need to talk to someone.
7. Finally, go out and do something nice for yourself. You deserve it.

Borrowed/adapted from: *The Canadian Hemophilia Program*, 1992 who adapted it from HIV+ Workbook, Seattle-King County Department of Public Health, 1991, and *Telling Your Parents*, Michael Helquist, *The Advocate*, July 1988.

Gay men who have not told their parents they are gay must face the added stress of that disclosure. When gay men consider disclosing to people outside the gay community, they face a different range of fears, including moral judgement, rejection and discrimination. To help them decide who, when and how to tell, social workers can explore some key questions. Clients will likely have to deal with “coming out” to their families, before they can deal with disclosing their HIV status. Family members may respond more positively to the threat of illness than to a disclosure about sexual orientation. However, parents often have great difficulty dealing with a child’s illness — even if that “child” is now an adult.

For parents, the news can be devastating. It is extremely hard to have a child develop a life-threatening illness. They do not want or expect to outlive a child, and they have difficulty accepting the illness. They may need someone to go for advice or someone to talk to. They may also need permission to grieve and feel sad. Disclosure may also raise unresolved issues within the family.

Telling Children

I tested positive when I was pregnant with my third child. So my husband was tested and he was positive, too. We had some anxious weeks while we waited for our two children to be tested, but they were negative. Thank God. And a year after the baby was born, we learned that she was negative too, and we were grateful for that. It took us a long time to tell

the children. We were afraid of how they would react. And I guess we were worried that they would blurt it out to other people. You know how kids are. They talk about things. We live in a small community, and we just didn't want everyone to know.

Parents who have HIV often find it very difficult to tell their children. They worry about the impact on the children and about other people finding out. They

worry about discrimination against the children, and they worry about their future. The situation is more stressful if the child is also infected and the parent must also deal with guilt.

Telling children is particularly difficult for parents who believe that their children should be allowed to enjoy their childhood and should, for that time in their lives, be protected from everything that is cruel or mean or hard. They want them to grow up normally, not worrying about HIV or how long their parents will live. However, many parents also fear that their children will find out from someone else.

Most families find that when they do finally tell their children, they experience a great sense of relief. They no longer have to watch everything they say or withhold information from the children. They are relieved of the burden that a big secret can become.

Parents must make their own decision about when and how to tell their children. Social workers can work with parents to help them reach the stage when they can tell their children, and to give them some advice on the kind of information that children can handle at different ages:

- young children may only need to know that there is a medical problem, which means their parents may feel sick or have to go to the doctor a lot and take medication
- children between 5 and 8 need information in language they can understand, and they may ask the same questions over and over, looking for reassurance
 - children between 9 and 12 may ask specific questions about how their parents became infected, and they need correct information but only as much as they can handle and as much as parents feel comfortable telling them
 - adolescents know and understand more about HIV, but they are at a very vulnerable age, and may need some special support. They may also need reassurance that the family is still stable and financially secure.

Using Non-judgemental Language

Women often experience intense guilt about having “infected” their children. These feelings can be reinforced by language such as “the mother passed the virus to her child.” Social workers can help reduce the guilt that parents feel by using nonjudgemental language. It is the virus that infects the babies, and the mother has no control over the virus.

Children of all ages will need love and reassurance, and will want to know who will help them or care for them if their parents can no longer do so. They will probably have sensed the emotions their parents are feeling and not know what is causing them, and they will look to their parents for reassurance. Children need to know that they did not cause the illness and that they cannot make it go away.

When a child is infected, disclosure can be more complex. But most children who are infected, particularly if they are ill and being treated by a physician, will develop a sense of the problem. They often need reassurance from their parents and permission to talk about their illness and their own fears. When parents do

not disclose, it can make it much harder for the child.

Many of the issues can be discussed without using the words “HIV” or “AIDS.” This is called partial truth telling. It’s an important concept for parents and

professionals to use as they build slowly on information they give children, based on their level of understanding.

Social workers are in an important position to help parents decide how best to handle disclosure to children, based on the children’s ages, coping styles, observations about medical care and the health status of all family members. Social workers can also help parents through the process of disclosing to children, and can be an important source of support to the family through this stressful time.

Families may decide together that this is one of those issues that is going to stay within the family to protect both the parents and the children.

Disclosure Issues for Families of Hemophiliacs

The hemophilia community has a history of non-disclosure. Concerned about the stigma of hemophilia and then the added stigma of HIV, many families chose to keep the conditions secret. Because of the way hemophiliac men and boys were infected — through transfusions administered by the health system — families often have a sense of betrayal and a deep sense of anger at the system and at the caregivers who were supposed to help them but made them more ill. The secrecy, shame and anger often keep hemophiliacs with HIV from using established HIV services or from accepting any

help from the health and social service system.

Within the family, the dynamics may also be complex. Adolescent boys sometimes centre their anger on their mothers who gave them the gene for hemophilia and, in many cases, administered the blood products that gave them HIV. At the same time, the mothers may live with an overwhelming sense of guilt.

Hemophiliac families may need to deal with their anger and sense of shame before they are able to consider disclosure.

Ethical Dilemma

When Parents Don’t Disclose

Gwen and Rus adopted Patrick, who is now 12, when he was a baby, knowing that he was HIV positive. They have never told him about his status and still insist that he not be informed. The social worker at the clinic where Patrick goes for regular check-ups is concerned that Patrick may soon become sexually active and that he has a right to know. What would you do?

The social worker would:

- validate the parents’ concerns about disclosing Patrick’s status to him. They want to keep their child’s life as normal as possible for as long as possible. They are protective of their child. The social worker needs to affirm that they are trying to do what is best for the child.
- help parents connect with other parents who have children with HIV
- talk to the parents about the consequences of not telling Patrick (e.g., Patrick may find out from someone else, he may be angry with his parents for not telling him)
- talk to the parents about the need for Patrick to have sex education
- stress that Patrick will have to develop the ability to care for himself and his ability to do that will be compromised if he does not know he is HIV positive. If he does know, he is more likely to be aware of important changes in his health and to take steps to protect his health.

Mario is a 17-year-old hemophiliac boy. He was diagnosed with HIV when he was 7. All his life, he has managed the drugs and transfusions he has to take for his hemophilia. In terms of his HIV, he is well, but his CD4 count has dropped recently and he is anxious that the disease may be starting to progress.

In his last year of high school, Mario is popular with the other kids at school. They are aware of his hemophilia, but do not know that he has HIV. The family has kept his HIV status secret from almost everyone.

Mario has recently fallen in with a group that likes to drink and party. He has had a steady girlfriend for a few months, and he feels some pressure from his peers to be sexually active. He has started to resent the rigid routine he must follow for his hemophilia. He is struggling with how to practice safer sex and whether to tell his girlfriend about his HIV. He is concerned that if he tells her, then everyone will soon know and he will be ostracized from the group. On the other hand, he doesn't want to deceive her or do anything that would threaten the relationship. What would you do?

The social worker can:

- give Mario an opportunity to voice his frustrations and anger about both his hemophilia and his HIV
- help him work through his behaviour and the choices he is making that could affect his health
- offer some family counselling
- talk about strategies for dealing with his relationship with his girlfriend, including delaying sex, disclosing his HIV status and practising safer sex
- refer Mario to programs developed and run by the Canadian Hemophilia Society designed specifically to help hemophiliacs with HIV deal with relationships.

Disclosure to Schools and Daycares

Parents of children with HIV often struggle with whether they need to disclose the child's HIV to the child's school or daycare. In these settings, parents and staff are often concerned about the virus being transmitted by biting, but there has never been a confirmed case of HIV transmission by biting and it is very unlikely the virus would be passed in this way.

Children with HIV have the same right to attend child care or school as other children. Parents have no obligation to tell the centre or school¹. If they do decide to tell a teacher or principal, that person has an ethical obligation to keep the information confidential — although he or she may be obligated to inform public health authorities. The parents of other children do not need to know, since a child with HIV poses no danger. All schools and day care centres should develop appropriate health policies and, for everyone's protection, use universal precautions and proper hygiene.

Practice Issue

When Families Disagree About Being Open

Ravi has made the decision to be open about having HIV. He has become involved with a local AIDS organizations and believes he could help other young gay men by being willing to talk about his illness.

He has told most of his family, who he doesn't see that often. Most live in a small community, and they aren't completely comfortable or accepting of his homosexuality, although they have been very supportive about his illness. He has told one of his sisters about his decision. Although she supports him, she is concerned about the effect his openness may have on his parents. They are well-known in their community, active in the church and she's afraid their friends will react poorly and ostracize the whole family. Her fears are complicated by concerns about racial discrimination, and their cultural approach to disease and disclosure.

Ravi's partner is also uncomfortable with the decision. He is not open about his sexual orientation at work and is concerned about the impact Ravi's activities could have on him. He is also concerned that the AIDS organization may take advantage of Ravi, call on him too often, and ask him to do too much. He worries that his activities there may threaten his health. Ravi is adamant. What can you do?

The social worker will:

- support Ravi, whatever his decision, and affirm his right to make this decision
- help Ravi explore his thoughts and feelings around the effects his decision will have on him and the others in his life. (The social worker will have to understand the impact of disclosure in his cultural community and may need to explore the nuances of such a disclosure in Ravi's culture.)
- work with Ravi to develop a plan to provide support for his family and his partner. The social worker may play a role (e.g., couple counselling) or may provide a referral to another professional.

Social workers should reassure parents that they are under no obligation to disclose to a school or daycare. If parents decide to inform the school or centre, social workers should either be available to provide any support or education the setting may need, and to advocate on the family's behalf against any discrimination that may occur, or involve public health in the process of educating teachers and others.

When Clients Decide to Be Open About their HIV Status

Some people make the decision to be very open about having HIV. Some become spokespeople for AIDS organizations and "champions" of efforts to get more support for research and for services for people with HIV. Some merely choose to be very open within their own circle of friends, family and co-workers.

Being open about having HIV can be an important socio-political act. When people are willing to discuss their HIV status and to give a face to the illness, they can help erode the stigma that surrounds HIV. For people who find the secrecy hard to deal with, it is also a healthy personal decision.

However, it is possible for people who are open about having HIV to be used or exploited. Organizations and groups with political agendas may pressure people into being open and getting involved. They may begin to see the person only as a symbol of the illness, not as a whole person with other needs. The decision to be open can also have repercussions for the person's family, friends and social support network. Some family members may feel strongly that the person should tell as few people as possible.

In helping a client decide how open he/she should be, social workers can:

- determine how comfortable the person is with being open
- discuss both the advantages and disadvantages
- remind the client that it is not up to any individual to "push the agenda"
- discuss the impact that individual decisions can have on family systems
- discuss some of the reasons that friends and family might object, and determine whether there are ways to overcome their objections
- decide who else needs to know before the person goes "public"
- support the person in his/her decision.

PROMOTING AND MAINTAINING HEALTH

People with HIV learn early in the course of their infection that there are things they can do to strengthen their immune system and keep themselves well, including:

Health Promotion Information for Social Workers

- The virus increases the body's need for energy by about 10 per cent (more during an acute infection). Maintaining a high energy intake will reduce the risk of severe weight loss and wasting.
- Clinical findings suggest that muscle loss may occur before noticeable weight loss. Any unintentional weight loss is significant. Clients who begin to lose weight should be referred to a nutritionist as soon as possible.
- Simple sugars, such as candy bars and cola drinks, may provide energy, but they provide no other nutrients. Consuming fewer simple sugars and maintaining good mouth care can help keep yeast infections from spreading.
- Excessive substance use that leaves people hungover or strung out weakens the body's ability to fight the virus.
- Using alcohol and/or drugs may impair judgement and lead to decisions — such as unsafe sex or drug use — that may put people with HIV at risk of reinfection or at risk of infecting others.
- Exercise helps reduce stress and strengthen the body, which may increase hope.

- getting plenty of rest
- eating well
- controlling stress
- avoiding a new exposure to HIV, which could increase the virus in their system and have a serious impact on their health
- doing what is right for them (e.g., massage, exercise, music).

However, their ability to act on this information depends on their situation. Do they have the resources they need to promote their health? Do they have psychosocial issues that may keep them from maintaining their health? Social workers can play a key role in helping people use their resources to stay healthy.

Just as so-called healthy people find it difficult to always make healthy choices, so do people with long-term illnesses. Denying yourself pleasure — whether it is food, drink or sex — takes self-discipline. Dealing with new drugs and rigid drug schedules is also demanding. People with HIV may find it difficult to “be good” all the time. They will live years with the virus, and may feel that being good is taking all the fun out of living. The first enthusiastic efforts to do “everything” may gradually diminish to a series of things that it is possible for people to do consistently and still enjoy life. For example, some people stop taking as many vitamins. Some begin to worry less about sleep or become more relaxed about what they eat. Some decide to have an occasional drink. Social workers can support people by helping them be flexible and decide what they can do and still take pleasure in life.

Many people with HIV have difficulty seeing themselves as sexual beings, particularly when they are first diagnosed. Social workers can help clients promote their sexual health by giving them the opportunity to talk about their fears and work through the issues.

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The Risk of Re-exposure

In the early days of HIV, many considered it not harmful for two people with HIV to have unprotected sex with each other. They were already infected, so why bother with precautions? However, scientists now believe that any new exposure to the virus from any source can be harmful for people with HIV. They could be exposed to slightly different strains of the virus, which would be harder for their bodies to fight. Re-exposure may also increase their viral load which could cause them to become sicker faster.

TAKING A FAMILY-CENTRED APPROACH

HIV doesn't just affect one person, it affects the person's family or community. It is a critical part of social work practice to see the individual within his/her family and community.

In taking a family-centred approach, social workers recognize the impact that HIV has on families as well as the potential role families will play in providing psychosocial support. A family-centred approach acknowledges and respects the pivotal role that

families play, and strives to support them in their natural caregiving role by building on their strengths.

By focusing on the family, the social worker can ensure greater co-ordination of care. To provide family-centred care, the social worker must begin with a family assessment:

- What type of family is it? Traditional? Two parents, both working? Family of choice or family of origin? A gay or lesbian family? (If it is a gay family, does the extended family or family of origin accept or support the relationship? What is the relationship between the two families? Is there conflict?) A blended family? An adoptive family? A combination? Some types of families have more legal or social status than others, and that may affect the family's needs and ability to cope with HIV. (For example, the hospital may not recognize a gay or lesbian family and not allow the patient's partner a spouse's privileges. In that case, the social worker may focus on establishing the family's legitimacy.) The client's family may also be a close-knit group of people who use drugs together or a group of street kids squatting together.

- What are the cultural, racial and ethnic variations in the family and what are the attitudes of its members to illness and death? Are they recent immigrants, which may mean they have less family support around them?
- What are society's attitudes towards HIV and how is this affecting family members? Are they reluctant to tell people about the family member's illness? Do they need help dealing with this issue?
- Do they live in an urban or rural setting? How will that affect their ability to cope?
- What about the characteristics of the members of the family? How do they affect their ability to cope? Are there any addictions in the family? (Addictions may affect the response they will have to HIV as well as the services they will need.) How burdened do family members feel financially, socially and personally?
- Do they share a religious faith that will help them deal with HIV or one that will work against them? Are they interpreting their experience in religious

A family is a group of individuals (which may include children) related by affection, kinship, interdependency and trust.

Canadian Association of Social Workers

My family is large, and they all know my HIV status. They talk a lot among themselves but I worry about my mother, who has not told any of her friends — who know everything about each other's children. My mother gets support from the family, but feels she has to keep this from her friends and appear as though nothing is wrong. I would like her to feel free to tell others, but I guess she is worried about their reaction.

- terms? Will members of their church, temple or synagogue provide support?
- Does the family seek out available social support? Does it already have good relationships with health and social service providers?

This information will help the social worker assess the family, identify its strengths and its needs, and find ways to help. Social workers should ensure that all service providers (e.g., clinics, nurses, physicians) welcome families into the care circle and give them access to information and support. They should also ensure that families have the support they need when disclosing to people outside the family.

HIV in Gay Families

A lesbian couple had been together for seven years, but had recently separated. Anne fell ill, and was diagnosed with HIV, likely resulting from a prior heterosexual encounter.

When her partner, Jane, heard about the diagnosis, the two resumed their relationship and were more committed than before. Jane, who tested negative, was comfortable looking after Anne. Both women are well-educated and have been able to communicate well with families and friends.

Although the lesbian community has been greatly affected by the impact of HIV in the gay male community, lesbian women are not at high risk of acquiring HIV, except through injection drug use and unsafe sex with men. These women's experience has helped make the community take notice and be aware of the risks of sexual transmission that do exist.

Gay couples may grow closer caring for one another, or one partner may feel that he can't leave the other because he is ill and begin to feel trapped in the relationship.

Every time Ron was hospitalized, all the problems fell on me, and I was angry. My guilt kept me going. Once I went away for a week to think about why I was looking after him. I knew I had a choice. I could leave. Why was I doing it? The last evening I still didn't know whether I was going back home, and I didn't want to go. But I had a reason to be there. So I decided to go back home ...

Gay couples may find more support within the gay community. Heterosexual couples may feel more isolated and, because of the stigma of HIV, feel they have to cope with the illness alone.

Regardless of who in the family is infected, families will go through three psychosocial stages:

- the crisis phase — the initial period of adjusting and coping after hearing of the diagnosis
- the chronic phase — a kind of day-to-day living with HIV and maintaining a semblance of normal life in abnormal circumstances
- the terminal phase — the time when the inevitability of death becomes apparent and dominates family thinking.

The family may not be at the same stage as the HIV positive family member — particularly during the terminal phase. Sometimes families will continue to try to save or rescue the family member, when he or she is ready to die. The long chronic phase may be particularly difficult for the family who may live in limbo for many years.

In the case of HIV, complicated loss is exacerbated by anticipatory grief, secrecy and, in the case of some families, multiple loss.

Maintaining or Developing Couple Relationships

Now that people with HIV are living longer, there will be more couples where one partner is HIV positive and the other negative. For many years, gay men and hemophiliacs have had to manage their relationships with one partner infected. The issues that couples have to deal with vary based on when the relationship began — before or after the one partner was infected.

If a couple met after one was positive, they must deal with when to tell and how to manage the relationship. If the couple was already together when one partner tested positive, the dynamics and the issues are different. The route of transmission can become an issue in the relationship. For example, the partner of someone infected

through blood products will likely react differently than the partner of someone infected through an affair outside the relationship. The couple will have to deal with the following issues:

- the route of transmission and how that is perceived by the non-infected partner (Social workers should be aware that, for some couples, sex with people outside the primary relationship is a betrayal; for others it is an acceptable part of the relationship.)
- the disruption in their sex lives, due to infected partner's guilt and the non-infected partner's fear
- the ability of the non-infected partner to insist on safer sex. Many non-infected partners feel guilty when they insist on safer sex in their relationship. Because of their commitment to their partner, they may sometimes think they want to share even HIV with the person they love, and put themselves at risk.

Social workers can help both partners work through the issues. As is sometimes the case in other relationships, separation may be the best

answer for both partners. If partners do separate, there may be consequences, particularly if one did not want the separation. For example, the person with HIV may feel abandoned and suicidal, or the uninfected person may feel guilty, particularly if the partner is in a vulnerable state (e.g., dementia). Social workers may need to provide ongoing support.

The Impact of Bisexuality on Relationships

In most cases, bisexual men are not open about their sexual orientation. In disclosing their HIV status to a female partner or to their families, they will have to disclose their sexual orientation. The female partner may feel betrayed by her partner's "infidelity," so the couple may be dealing with a another set of issues. If a wife only learns about her husband's bisexuality when she hears about his — and possibly her own — HIV diagnosis, she may react with feelings of rage, shame and confusion.

A man I met recently was fine with telling his wife about his diagnosis and that he got HIV from an involvement with a man. But she used her own

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Advice From Other Couples

Couples who have decided to try to make it work offer, in the midst of all the noise, hysteria and tragedy, some simple advice:

1. Don't blame anyone for being infected, focus on today.
2. Get medical care.
3. Have faith in each other and in a cure. Each day you live, you are a day closer to the cure.
4. Dream!
5. Stay together.
6. Remember how much you loved each other. Remember the intense feeling you have for each other.
7. Talk ...talk all the time ...about everything.
8. Deal with issues as they come up.
9. Be safe now, if you haven't been.
10. Care about each other and the relationship:morning, noon and night.

Share and talk to each other. Caring, touching, holding hands, nothing more, you need that. You need the contact and to know that someone cares. Check with each other from time to time about what is important.Spend time together.

Milner GR. *How Gay Male Couples Cope with HIV Disease*. Wilfred Laurier University Research Project. Waterloo. 1991.



frame of reference for relationships and assumed he had had a long-term, meaningful relationship with someone. He was reluctant to tell her that it was actually through multiple casual contacts with men at the bathhouse. He found sex with men easier and pleasurable, and it did not necessarily mean that it was leading to a relationship.

In this case, both partners want to keep their relationship alive and maturing, and both need to talk about their insecurities and find ways to reassure each other of their commitment.

Families with More than One Person Infected

In gay couples, heterosexual couples and families with children, more than one person may be infected. When a partner or child is also infected, there is a greater sense of guilt and shame, and more stress on the family unit.

If one person in the family is particularly ill, the needs of the others may be neglected and they may not have the opportunity to deal with their own reaction to diagnosis. For example, when one child is infected and the other siblings are not, the relationship among the children and between the parents and children can become strained. Parents may struggle to balance the needs of the infected child with the needs of uninfected siblings. Social workers can help parents examine their own issues (e.g., guilt over a child's HIV infection, anxiety for a child's health, fear for the future of uninfected children, practical issues of caring for an infected child) and find ways to parent each child to the best of their ability. Parents may need help to address the emotional needs of uninfected children.

With families, social workers must be sensitive to the relationships before HIV. How did the couple relationship work? Who was the main caregiver? Has HIV changed those relationships? Some families grow stronger and closer because of HIV, others come apart. How will the family cope? Who will be the caregiver? What other supports and resources do the families have? Who have they told about their HIV infection? What effect will the family's culture have on how the family copes?

Nurturing the Children

Children in the family — whether they are sons, daughters, nieces, nephews or grandchildren of people who are infected — will need special attention to help them:

- understand what is happening
- deal with their emotions
- maintain a sense of stability
- deal with the need for secrecy
- get answers to their questions
- ensure they have a dependable caregiver.

It is stressful for families to care for someone who is ill and, at the same time, provide the nurturing that children need. In general, however, parents are the most effective primary “therapist” for their children, and the people best able to create

a sense of stability for their children and to attend to their emotional needs in the midst of uncertainty. However, to do this consistently and effectively, parents and other key adults in the family may need support.

Applying the Family-Centred Approach

A baby girl who was failing to thrive, and whose parents were injection drug users, tested positive for HIV. Both parents then tested positive. The mother, Sarah, was asymptomatic, but the father, Jason, was quite sick.

The parents loved the child dearly and wanted to care for her but, because of their addiction, often had trouble. Social workers (from the HIV clinic, child protection and social services) spent a lot of time with Sarah who, when she was not using drugs, was loving and able to care for her child. For periods of time, she would get her addiction under control. However, the father continued to use, and was occasionally abusive to her.

Eventually, the mother moved out and got a place on her own, but she was not able to completely sever her ties with Jason — although she knew that when he was around she was more likely to use drugs. Whenever he arrived on her doorstep, she would provide what she could, including letting him stay overnight. Although social workers counselled her not to take him in, they had to respect her choices and the bond between the two parents. When he was not with her, he lived on the street. Eventually, he committed suicide by taking an overdose when he was staying with her.

Throughout this period, Sarah struggled with her addiction and with caring for her daughter. When she was in treatment, she managed well. But she could not sustain it. Eventually, concerned about her ability to care for the child, the social workers arranged for the baby to be placed with a foster mother, who bonded with the baby and provided excellent care. Sarah was still able to see the child, and the service providers continued to hope that she would reach the stage where she would once again be able to parent her child. In the meantime, the social worker provided support for the foster mother.

The baby died and Sarah later died from an overdose. The situation was extremely difficult for all the service providers who had worked hard to support the mother and help sustain the family. The HIV social worker spent time helping other service providers deal with their disappointment and frustration. She also continued to stay in touch with the foster mother (by phone and in the office) to help her work through her grief and deal with what the social worker described as a “unique experience in her life.”

Helping Families Live with HIV

In a recent study of families with HIV by Goldie et al, researchers identified five main concerns:

- the family’s future and the needs of the children — parenting becomes more

intense when time is precious, and parents have to strive in the midst of difficult circumstances to create legacies of love, emotional security, family memories and financial security for their children

- the stress of living with uncertainty
- the way health concerns complicate family relationships — it is difficult to balance the needs of all family members, infected and uninfected
- disclosure and living with the secret of HIV
- the stigma and its impact — many families feel isolated by society’s attitudes towards people with HIV, the lack of social support and the poverty that seems an inevitable part of living with HIV.

My attitude has changed. There was a lot of things I wanted to do: have a home, make the best of life for my child and me. After AIDS, it was not possible. I lost my hope for the future.

Families need access to flexible, simple and easy to use support programs and services that can assist them with future planning, coping with the stress of ill health, uncertainty and stigma. Social workers can play a key role,

advocating for family-centred care, and working to create a more supportive social environment.

HELPING WOMEN LIVE WITH HIV

Because of the stigma associated with the disease, women with HIV usually fear that they will be rejected or discriminated against. They fear being judged for their sexual behaviour or being considered “promiscuous,” and they fear being isolated with the illness. Many women also talk about the curiosity that often greets their disclosure. Most people can’t resist asking how they got infected.

Women often fear that they will become the topic for gossip, and that friends they tell may not keep the information in confidence. Many women, particularly those with children, avoid support groups or other women with HIV, because they fear the impact their HIV may have their families. For example, there are cases where children of women with HIV have not been allowed in the neighbourhood swimming pool, or have been teased at school. (In many cases, there are no support groups available for them to join.)

Women may neglect their own health to care for others, and that can have serious consequences. They may need help to recognize their own needs and put them first, and they may need support and encouragement to take care of themselves — particularly if they are caregivers of partners and children, and more so if their partners and children have HIV infection and are ill. Women may also need access to specific services, such as child care and transportation, so they can attend to their own needs (e.g., attend doctor’s appointments).

Infected women face different challenges, depending on their situation (i.e., single, trying to develop a relationship, a single parent, part of a family, hoping to have children). In addition, their ability to live with HIV will be complicated if they:

- have problems with substances, such as alcohol and drugs
- are in dependent or abusive relationships, and are limited in what they can do to protect or care for themselves
- lack self-esteem
- face practical issues, such as problems with housing, finances, treatments and drugs.

Women, Pregnancy and Their Reproductive Choices

With more women becoming infected and living for many years with the virus, they are faced with difficult reproductive decisions. Many will want to have

children, and will be continually grieving the fact they may not be able to. If they do, they may not live to see their children grow up. Because of the risk of mother-to-child transmission, the unknown prognosis for infected children and the possible risk to the mother's health, physicians have traditionally counselled HIV positive women to avoid or delay pregnancy until more is known about the disease. However, over the past five years, there has been significant pressure from women about their reproductive rights as well as significant improvements in therapies that reduce the risk of mother-to-child transmission. More infected women are giving birth to HIV-negative children, and children with HIV are living longer, more normal lives.

Treatment to Reduce the Risk of Mother-Child Transmission

Without any therapy, a woman with HIV has about a 25 per cent chance of having a child infected by the virus. The risk varies depending on the stage of the mother's HIV disease (the virus is more likely to be transmitted when women have advanced disease), the strain of the virus and other factors, such as the use of crack cocaine. Research has shown that treatment with AZT reduced the risk by about two-thirds, from 25 per cent to about 8 per cent in women who were infected but relatively healthy. Over the course of the study, the treatment had no major or permanent side effects. However, women trying to make a decision for themselves and their babies should also be aware of any limitations of the treatment:

- some children will still be born with HIV
- researchers do not yet know if there are any long-term risks for the child from exposure to AZT
- researchers do not know whether using AZT in pregnancy will make it less effective when the woman needs to take the drug for her own health
- Other treatments are now being tested, including combination therapies that are now standard treatment for people with HIV.

Taken from Matheson et al. "Efficacy of Antenatal Zidovudine in Reducing Perinatal Transmission of Human Immunodeficiency Virus Type 1." *The Journal of Infectious Diseases*. 1995.

The social worker who is counselling HIV-infected women must be well-informed about the issues. Women have the right to all information about HIV disease and to make their own informed reproductive decisions. As knowledge about HIV and its impact on pregnancy develops, women need easy access to new information and the opportunity to discuss emerging issues. Ideally, reproductive

counselling should begin before the woman becomes pregnant, but that is not always possible. Because the issues are intimate and complex, reproductive counselling should be an ongoing process. It is not enough to discuss the issues once.

The goal is to help the HIV-infected woman explore the impact pregnancy, childbirth and childrearing will have on her, the future child and her family, and analyze the risks and benefits. Social workers should encourage pregnant women to look beyond the medical information to assess their social support network and their ability to cope with a child. The social worker can discuss:

- the stage of her disease and the impact a pregnancy will have on her life

- the risk to her partner of becoming infected through unprotected sexual intercourse
- other options, such as conceiving through artificial insemination
- her desire to have a child and do the normal things she planned to do before she became HIV positive
- the hope she feels for the future, with or without a child
- the risks of the baby being infected
- the effect of recommended treatment with AZT on the woman and the child (see sidebar)
- the impact of a pregnancy on the woman's life and social support network, including
 - does she have a supportive partner and/or others who will help her care for the child?
 - is anyone else in her family/support network infected or at risk for HIV disease? if so, how is HIV affecting his/her health?
 - is there any risk of violence or discrimination and, if so, how would she seek help?
 - does she have any other health problems? addiction problems?
 - does she have adequate and secure housing, income and health insurance?
 - is she able to care for an HIV negative child? an HIV positive child?
 - what will her reaction be if, after taking the AZT, her child is still HIV-infected?
 - how will she feel if she becomes ill and dies early in life and is not there to mother her child?
 - how will she feel about other people raising her child?
 - are there any cultural issues? will the woman face any pressure or discrimination/disapproval if she doesn't have children?
 - what about possible discrimination against her baby and other children?

Women who are diagnosed in pregnancy may also have to consider:

- their ability to cope with terminating the pregnancy
- the impact of their religious beliefs on abortion.

The process of deciding whether to become pregnant is very complex and emotional, and is closely linked to women's aspirations for themselves and their lives and to cultural aspirations. When asked how they would cope with various scenarios, women often experience an intense sense of loss at never having been a parent, grief at losing a child and guilt over bearing an infected child or one that they won't be able to take care of if they become ill and die. To make an informed decision, the women should work through all the issues and options. Whether the woman decides to become pregnant, to continue a pregnancy or to terminate the pregnancy, the social worker should support the woman's choice and help ensure she has the resources and supports to help her cope with her decision.

Couples and Reproductive Choices

I have been working with a young man and his wife, who is HIV positive, who desperately want to have a child. Over the last two years, they

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explored the option of adoption, but have decided to try to conceive. They consulted doctors at a fertility clinic, and are considering freezing samples of his sperm, having the woman start on AZT prophylaxis, and then having her artificially inseminated with his sperm.

Although there is not a lot of research on this procedure, the couple hopes this will help them achieve their goal — conception — with the least risk to the man or the child.

HELPING ADOLESCENTS LIVE WITH HIV

Adolescents with HIV will have been infected in one of three distinct ways. They will either:

- be born with HIV (the virus passes from the mother to the child during childbirth)
- have acquired HIV through a transfusion of blood or blood products
- acquire HIV through risk behaviour as adolescents (e.g., unprotected sex or sharing needles to inject drugs, steroids or other substances).

When an adolescent grows up with HIV ...

In working with adolescents who were infected before birth, social workers should explore the following issues:

- the medical history of the mother and child, including the type of treatments the adolescent has already received and how they were explained, and the family's approach to disclosure — which may have to change as the child moves through adolescence.
- the family dynamic and any sense of guilt or blame that may affect the adolescent's ability to cope with HIV
- the adolescent's sexual development and need for appropriate information and counselling at the right age to help him or her make healthy decisions about safer sex.

I'm 20 years old. I don't even know what I am let alone where I stand spiritually or what my sexual orientation is."

When an adolescent was infected through transfusions of blood or blood products ...

A significant number of hemophiliac boys and a number of other children were infected with HIV through transfusions of blood and blood products before blood donations were screened for HIV. These children are now adolescents or young adults, and face some unique psychosocial issues. Social workers can:

- provide information and support to help them make responsible decisions about safer sex
- provide support around disclosure
- explore the financial resources that may be available, such as the government-sponsored extraordinary assistance program and other income and support programs

- make sure they are aware of the programs and resources available through the Canadian Hemophilia Society.

When an adolescent is infected with HIV during adolescence ...

A growing number of adolescents — including gay youth, street youth and drug-using teenagers and their sexual partners — are becoming infected in their late teens or early 20s. Many of these youth may already have experienced some disruption in their lives. They may have a history of sexual abuse, mental health problems or violence, and HIV may be just more horrible stuff that happens.

Working with adolescents

Adolescents and young adults may refuse traditional support services, and social workers working with this population must be creative. In many ways, the approach is the same as working with adolescents generally, and involves helping clients describe, clarify and prioritize the issues. In some cases, the social worker will find it useful to work with clients to:

- deal with basic needs first
- identify previous coping strategies and strengths
- help adolescents find areas in their lives where they can be in control
- help them develop a support network
- help them find hope and encourage them to continue to plan for the future, make career choices and achieve independence.

Services must be adolescent-friendly. To work effectively with adolescents, social workers should:

- create an environment of respect
- establish rapport
- build trust
- communicate clear, accurate and appropriate messages
- involve peers
- empower youth to make effective decisions and manage situations and behaviours that put them at risk
- help them with practical needs, such as housing, food, income and access to appropriate medical care.

As the median age for people infected with HIV has dropped from the 30s to the 20s, social workers need to be particularly mindful of the added stress associated with life stage. Younger clients may not yet have had the life experiences that teach them they can survive crises, solve problems and use community resources. Because of their age and stage of life, youth will be particularly concerned about their self-image and their ability to continue to be a sexual being with HIV. They may believe themselves to be immortal or “above it all,” and at the same time they often feel powerless.

People diagnosed in their 20s are faced with life stage tasks that usually occur to people in their 40s and 50s, such as re-evaluating life, career decisions, relationships and plans for the future. These added tasks may overwhelm some people, causing them to go into denial or withdraw from any help or support, although they may desperately need it. They may also turn to activities that block out the stresses, such as substance use.

Any effective work with teens must respond to their uniqueness, involve them in designing services and respect their beliefs and abilities. Success also depends on being able to establish and maintain appropriate boundaries. Some adolescents may have difficulty trusting others, particularly people in authority. This will challenge the social worker’s ability to build trust without getting enmeshed in the youth’s life.

The Canadian Hemophilia Society has done some effective work with adolescent boys around self-care and prevention.

Adolescents and young adults are likely to react to HIV with resentment. They may feel guilty, dirty or sexually abnormal, which can in turn lead to poor school performance (for those still in school), depression, isolation and acting out. Being HIV positive may threaten their self-image and their ability to “fit in” with their peers.

Gay youth may have unresolved issues around their sexuality. Although they may resist being linked with the gay community, they may benefit from contact with one or two people, such as peers who have dealt with their issues around sexual orientation, who can provide support and a positive role model.

Very few adolescents who are infected with HIV during adolescence will know they are infected. Most will not develop symptoms of illness until they are in their 20s. However, some will be aware of their status or will be concerned that they are infected. To support these youth and provide services that will meet their needs, social workers should ensure that:

- any adolescent referred for HIV testing receives effective pre- and post-test counselling
- the client has the right (according to law and practice in the province or territory) to consent to an HIV test. In some cases, it may be preferable to involve the adolescent’s parents.
- they spend time with any adolescent who tests negative to discuss the consequences of continuing unsafe sex or needle use
- adolescents who test positive receive crisis intervention services
- depending on the case and age of the adolescent, some consideration is given (in consultation with the adolescent) to involving and counselling parents, who can then be a source of support.

TAKING A SYSTEMS OR COMMUNITY-CENTRED APPROACH

A systems approach looks beyond the family to the broader culture or community. Within a system, culture, society or group, support can be a way of life. It starts with a person in need asking for help and being ready to act, and others in the culture or group assuming that they have a responsibility to meet that need. If the person is not ready to make a commitment to act, then any help or services provided will create dependency and all aspects of the person (emotional, spiritual, physical and mental) will not be nurtured together. For example, if a person’s emotional needs are being met but he does not acquire the mental or intellectual skills to manage himself, then he will always have to return for more help when he has a problem.

With a systems approach, the community (defined in a broad way) is responsible for learning the skills it needs to support and teach others. A community needs to be committed, open and willing to respond, and the responses are usually based on the values of sharing, caring, honesty and respect. However, the social worker starts with the community or cultural group and its values, and works from there.

Developing a Supportive System: Rediscovering the Aboriginal Experience

In traditional aboriginal culture, “community takes care of community and that is how it should be done,” said one social worker. “Instead of creating dependence, we want to help people take care of themselves. If we do our job right, we should be able to close our doors in five to 10 years, because the community will be able to look after all these issues.”

To create a supportive system for people in aboriginal communities living with HIV, social workers and counsellors go to the aboriginal communities and to the elders and ask for help. In turn, the communities have responded. They have used their traditional ways and resources, including teaching circles (“taking our children on our knees again and teaching them like we used to”), healing lodges and healing ceremonies. They also use band resources to organize workshops and prepare pamphlets. In some communities, the process of community development is so advanced that people who are concerned about HIV or who are HIV positive now bypass the social service agencies and go straight to the community for their information and support.

The traditional aboriginal view of health emphasizes the “whole” person. Aboriginal people believe that the mind, the body, the emotions and the spirit must all work together for a person to be healthy. Their spirituality is based on natural laws, and harmony and balance are basic to these beliefs. Health is often understood through the Medicine Wheel: the roundness represents the sacred circle of life. It is divided into four parts which can represent the physical, the mental, the emotional and the spiritual parts of life, as well as the four elements of nature: fire, earth, air and water. All are respected. All are necessary for life. In aboriginal life, the circle is sacred. It creates a safe place for people to talk honestly, share, support one another and heal. Not all aboriginal people share these views, but many are returning to traditional forms of spirituality.

The elders, women, medicine people and two-spirited people work together to provide teaching and support for the community. Social workers developing support programs for aboriginal communities may find the following guidelines useful:

- services for aboriginal people should be organized and run by aboriginal people, so it may be necessary to develop culturally appropriate service models, rather than trying to apply models that have been effective in other communities
- programs must respect and incorporate traditional ways
- elders must be involved in a respectful way (e.g., identifying issues, developing and implementing programs)
- programs must respect the use of traditional medicines alone or in combination with other treatments and therapies
- programs must take a holistic approach and work to address the physical, mental, spiritual and emotional needs of individuals, families (extended) and

- the community
- the extended family members must be involved in their self-identified roles
- programs, information and results should be owned by the aboriginal community.

ISSUES ...

... in gay communities

Since the early 80s, community-based AIDS organizations have been counselling gay men about safer sex and how to protect themselves from HIV. The gay community has invested heavily in education, and finds it discouraging and frustrating that infections continue to occur.

Depending on the community, there may be a sense among those who test positive, that it was “okay” to be infected before 1985 (before much was known about the disease), but not okay to be infected in the 1990s. In addition to coping with the stress of the illness, people infected recently may also be coping with a sense of guilt and failure. Gay men who have become infected recently may not get the same support from the community or the same sense of belonging. Those who tried to practice safer sex but who still became infected may feel resentful or betrayed. Said one gay man,

I'm bothered by the growing division in the community between positives and people who are testing positive since the big educational blitz. We're making second class citizens within our own community.

These attitudes, combined with the impact of cumulative losses to HIV, threaten what is a very supportive community. The community can not only influence the onset of a crisis, but can help resolve it. Part of the social worker's role is to ensure the community receives correct and adequate information and to help the person re-establish himself in harmony with the larger community. In a sense, the social worker helps the client rebuild his social network. To do this, the social worker can use several strategies, including:

- information/education. The social worker who provides information on HIV is not only helping the client, but ensuring the community has a better understanding of and response to the disease. In this case, the community may be well-informed about HIV transmission, but have less appreciation of how difficult it can be for people to practice prevention consistently or of the factors that may cause people to take risks (e.g., power imbalances in relationships, substance use, mental health problems). Given the recent findings on the risks of oral transmission, some people may have become infected from what they assumed was a “no risk” rather than a “low risk” activity.
- high expectations of the social network. An effective social worker has faith in

members of a person's social network and assumes they will be supportive. The response is often highly dependent on the expectations. An assertive approach usually leads to people volunteering to help and feeling they have something valuable to offer.

- community development techniques that can be used to mobilize a social network.

This is another example of a situation where the social worker has a role with the individual (to provide crisis intervention and other services), a role with the community (to advocate for more understanding and support) and a role in the larger society (to work with others to develop more effective prevention initiatives). For more information on the social worker's role in prevention, see Chapter 6.

... in ethnic communities

Confidentiality can be a critical issue in some ethnic communities, and it can shape the type of support and services people receive.

An Asian-Canadian woman fell ill and was diagnosed with HIV. The rest of her family was tested and everyone — her husband and two daughters, ages 1 and 3 — tested positive.

Confidentiality does not have the same meaning in the family's culture as it does in Canadian society. It is the norm in their community to talk about one another. The husband is trying to keep the family's HIV secret. He fears, with some justification, that "everyone" would soon know, and the family would be shunned. Although the family has a large circle of relatives and friends near by, they are calling on no one for help or support.

The father's fear about people knowing stretches beyond the family's community to social service and other helping agencies. Because he has no experience of confidential service, he does not trust anyone. He has refused any kind of assistance, including home care for his wife and daycare for the children.

The mother has been extremely ill and in and out of hospital. The father, because of the stress, has been unable to concentrate and had to leave a fairly demanding job in the construction industry. The father is insisting on looking after the children himself, although he was never much involved in their parenting before. The children do not appear to be receiving proper nutrition and one, who is now symptomatic and should be taking anti-retrovirals, gets the drugs she needs only about 50 per cent of the time.

The family is now facing severe financial pressure. They are behind on their mortgage payments and at risk of losing both the house and the car, which the husband needs to drive his wife from their suburban home to doctors' offices and clinics in a large urban centre.

The father resents the time the social worker tries to spend with him to work through some of the problems, and has said repeatedly that he would rather have the money the social worker is being paid. Because of concerns about the children, the social worker is monitoring the situation closely. She realizes that it may soon become a child protection issue and has discussed that possibility with the father, but knows that, if she does have to involve child protection workers, she risks alienating the father even more.

In working with different ethnic communities, social workers will have to be sensitive to the meaning of confidentiality within the culture, the problems that people may face disclosing HIV in the family and their need for support. It is vital to respect the client's wishes, and help him or her find culturally appropriate ways to cope with and manage HIV. At the same time, this case highlights the need for HIV education programs that will promote a more supportive social/cultural environment.

Reactions to HIV are usually affected by cultural values and beliefs. To become more sensitive to cultural issues, social workers should first acknowledge their own cultural assumptions and the values that are rooted in their culture. They should then be curious enough about other cultures to be aware of differences and seek out information. When working with someone from a different culture, social workers can talk to colleagues who are familiar with that culture or consult other people in the community who are knowledgeable about cultural issues.

... in aboriginal communities

Depending on where they live, where they were tested, other psychosocial factors, and the support services available to them, aboriginal people face different stresses. People living off reserve may not have the social and family support they need. Those on reserve may have to deal with negative attitudes from the community, and all the challenges of living in a small place where there is little privacy. Metis, who are not covered by federal health plans, may have difficulty financing treatments for HIV.

Social workers who want to help aboriginal people deal with any underlying issues and find their own way to live with HIV must be sensitive to the aboriginal view of illness, sexuality and spirituality, as well as the role of the family and larger community in caregiving. Within aboriginal communities, the task of caring for a family member who is ill usually falls to the women. People expect to be cared for by a mother, sister or aunt. If they are not — if all their care is provided by a home care agency or other formal service — this can have a very negative impact on their health. It can lead to resentment. The whole family must be involved and consulted.

(The Medical Services Branch of Health Canada has the capacity to finance counselling for aboriginal people through their non-insured health benefits programs. For more information, contact the federal government for the office nearest you.)

... in controlled settings

People with HIV who are in controlled settings, such as jails or detention centres, may struggle to balance the desire to keep their HIV status confidential with their desire to be able to confide in someone and seek regular support. They face a range of pressures that might not occur outside these controlled settings, such as fear of reprisal or victimization by other inmates, fear of discrimination by staff and concerns about access to appropriate medical and psychosocial care while in the justice system. They may feel extremely isolated with their illness.

Confidentiality is difficult to maintain in these settings. Rumours spread, and anyone who spends a lot of time in health services, is taking a lot of medication or is seeing a counsellor may be suspect. Trying to safeguard the secret for their own protection, inmates may be denied social support. Others may use their HIV status to manipulate staff or exercise power or control in their environment.

Social workers in these settings must be aware of the impact the environment and its policies and the attitudes of staff and inmates can have on someone with HIV. They must also be sensitive to the fears and anxieties of others in the setting. They can advocate for policies that would safeguard and keep confidential all medical records, and that would allow the person to get the medical and psychosocial support he/she needs without drawing attention to the person and his/her condition. They can also provide the education and support to help others in the setting cope with HIV, and work with their institutions to ensure that inmates have easy access to condoms/dental dams and bleach kits, so they can prevent the spread of HIV and other sexually transmitted diseases and bloodborne infections.

Practice Issue **When a Client Uses HIV to Manipulate Others**

In one correctional institution, many inmates asked for testing because they were concerned about risk taking behaviour. The institution provides a confidential testing service that inmates generally find acceptable. Most inmates keep the testing and results to themselves, and are very private about it.

One inmate, a 27 year-old male, announced his positive HIV status readily. The other inmates assumed he was infected through injection drug use, so he was relatively well accepted — although he probably became infected through sexual activity.

The inmate acted out against others, threatening them, and trying to use his HIV status and their fear and ignorance to scare other inmates and the prison staff. He seemed to “glorify” his status and continued to engage in risky behaviours as a way to be more powerful within the controlled setting. Rather than seek support, he was defiant and rebellious. What would you do?

Social workers in the institution dealt with the situation by trying to educate the other inmates and staff about the real risks of transmission. They reasoned that, if people did not react fearfully to the inmate, he would lose his sense of power and likely change his behaviour.

PREVENTING HIV TRANSMISSION TO OTHERS

People with HIV have an infectious disease. They know they are able to infect others, and they must live with the stress of that knowledge. Even though new drugs can reduce the virus to undetectable levels, the person can still transmit HIV. As part of their pre- and post-test counselling, HIV positive people are encouraged to take care of others by:

- telling sexual and injection drug use partners about their HIV infection
- adopting safer sex and drug use practices to reduce the risk of passing the virus to current and future sexual and drug use partners
- not donating blood, semen or organs.

Bruce is a 25-year old gay male. For the past year, he has known that he is HIV positive and has not yet told anyone. Out of concern for his mental well-being, his doctor has insisted he see a social worker.

Bruce's social life consists of meeting men in bars and engaging in one night stands. In each situation he tries to assert himself with his partner so they practice safer sex, but he acknowledges that this is not always possible. He feels that if he discloses his status to them, he would stand no chance of meeting anyone. He longs for a long-term relationship before he gets sick, but he is afraid he will die alone.

This case highlights the complex issues faced by many people living with HIV. Bruce is not trying to infect others, but he is afraid of being socially ostracized if he informs his partners. Within the gay male community, there is debate about the value of disclosing HIV status. From the early days of HIV, the education message to gay men has been: assume your partner is HIV positive and take precautions to protect yourself. The expectation of those who are infected is not that they will always disclose, but that they will always practice safer sex and protect their partners. The focus was on self-responsibility. However, this case illustrates the problems that gay men may face in trying to practice safer sex as well as the power imbalances within relationships that can affect decision-making. The risk is probably greatest for younger men, who do not identify themselves as gay and who may not have the information or power to protect themselves.

In this case, the social worker may relate to Bruce's fear of disclosure and his need for confidentiality. If there were less stigma and discrimination surrounding HIV, Bruce's fear would not be as great and the risk he faces in telling people would be much less. On the other hand, he may be putting a large number of sexual partners at risk who may then infect others. If he does meet someone with whom he wants to have a long-term relationship, what effect will a late disclosure have on the relationship?

The social worker would:

- acknowledge the moral dilemma that Bruce is facing
- help him deal with the moral dilemma by highlighting the issues
- encourage him to use his skills to resolve his dilemma
- ensure Bruce had accurate information on safer sex practices
- work with him to help him assert himself in sexual situations
- discuss strategies he could use to persuade partners to practise safer sex
- encourage Bruce to identify possible sources of support and to begin the process of disclosing to people who might provide support.

Ethical Dilemma

Being Client-Centred vs Protecting Others

You are working with an HIV-positive gay man who also uses drugs. When asked about notifying partners, he reports that he has had many anonymous contacts and cannot give their names. He has no interest in participating in any partner notification program. You are aware of at least two of the man's drug partners who could be at risk. In this situation:

You are aware of risk

You have an ethical responsibility to protect confidentiality

You have a responsibility to protect others from harm.

What do you do?

In this situation, the social worker would:

- Continue to work with the client, exploring his reluctance to notify partners and reinforcing the importance of practising safer sex and safer drug use.
- Explain that public health will notify partners for him, without disclosing his identity or anything about him. (Many people are relieved to learn that someone else will look after notifying partners.)
- Talk to all clients about the risk of HIV, how to practise safer sex and drug use, and the benefits of being tested. If you have a relationship with any of the man's partners, try to talk to them about practising safer sex without disclosing any information about your client or in any way breaching his confidentiality.
- If you have no relationship with the man's partners, try to connect with someone who does or contact the local public health department.
- Try to find out where the man meets his contacts (e.g., bar, bath house, local park) and work with the local AIDS organization to develop an outreach prevention and education program for people in that setting.
- Remember that people are responsible for themselves and the risks they take. You can't save everyone.

In an article in the winter 1996 edition of *The Social Worker*, Taylor et al. suggested the following guidelines for professionals in this situation.

- Explore with clients the protection of sexual and injection drug-using partners, educating them about the disease and risk of transmission.
- Create an atmosphere of trust and safety that will allow clients to examine their problems openly and experiment with new ways of handling their lives, including dealing with the issue of disclosure.
- Be open from the start of the relationship about the limits of confidentiality, and the purpose, possible risks and benefits of informed consent so clients realize that social workers have a professional obligation for the safety of others.
- Acknowledge the ethical challenges inherent in trying to balance competing professional obligations to protect client and safeguard others.
- Recognize that any effort to find out the identity of a third party who might be at risk is not the social worker's responsibility.
- Take a firm stand and confront clients with HIV who are unwilling to disclose the fact that they have HIV to sexual or injection drug use partners — or to develop a plan to keep from infecting others.
- Offer to be present when the person discloses to provide support, or to use techniques such as role-playing to help the client prepare.
- If the client still will not disclose or take action, ask for his or her consent to report the situation to the appropriate authority (This will maintain the trust in the relationship and, if the client agrees, can relieve the social worker of having to breach confidentiality.)
- If the client does not agree, consult with peers, supervisors and agency administrators to make a decision.
- Document the process accurately and completely.

The authors also note that “few absolute answers exist and certainty is usually impossible in ethical decision-making. Acting ethically does not always lead one to feel good. For social workers practising in the complicated field of HIV/AIDS, ‘professional practice sometimes requires painful choices among obligations that perhaps cannot be fulfilled simultaneously.’”

Ethical Dilemma

When Clients Knowingly Put Others at Risk

If a social worker suspects that a client is knowingly putting someone else at risk, what should he or she do? How does the social worker balance the client's right to confidentiality with the other person's right to safety? Is the social worker obligated to tell the person at risk? Should the social worker inform public health authorities? Is the social worker legally liable if he/she withheld information and a third person becomes infected?

Every province in Canada is now struggling with these issues. Social workers should contact their provincial AIDS office or local public health authority for advice on these issues.

According to the profession's Code of Ethics:

"A social worker shall disclose information acquired from a client to a person or a police officer where the information involves a threat of harm to that person."

According to the CASW Statement on the Impact of HIV:

"Social workers ... have a role to play in helping people living with HIV/AIDS to tell others about their illness in order to reduce the isolation often experienced by people with HIV/AIDS... Disclosure of a client's HIV positivity by a social worker to others without the informed written consent of the client can be justified only when the person with HIV becomes a danger to himself/herself or others."

As the earlier case studies showed, the issues are complex. Very few people wilfully put others at risk. But many have trouble dealing with their status, practising safer sex or safer drug use, and disclosing to others. To help someone who is putting others at risk, the social worker must first develop a trusting relationship with the client. Strategies that social workers have used in this situation include:

- confronting the client and asking if he/she is practising safer sex
- asking the client some "straight ahead" questions: have you told your partner you are positive? how did you tell him/her? what was his/her reaction? if you didn't tell, how did you explain that you want to use a condom?
- making sure the client has a supply of condoms/dental dams (Practical advice: some clinics and social service agencies co-operate with the local health promotion department to order condoms in bulk and share the cost.)
- working with the client to make sure that other factors, such as alcohol and drug use, are not interfering with his/her ability to practice safer sex
- specifically targeting the partner with prevention messages/information/education on safer sex
- calling public health for advice on how to handle the situation without disclosing the person's identity. At a certain stage, it may be necessary to report the person — particularly if he or she has a mental illness or an addiction that makes him/her incapable of protecting others. However, social workers should first seek advice from public health without breaking confidentiality.

In working with people who are putting others at risk, social workers should look at why they behave as they do. What is the cause or motivation? Does the person not feel good about him/herself? Is the person too stressed to make good decisions? Has his judgement been affected by the HIV or by substance use? Is there some way the person could avoid situations where unsafe activities may occur (e.g., go to the gym or a movie, instead of a park or a bathhouse). Social workers will also have to examine their own attitudes towards this behaviour.

...or when HIV is just more bad stuff that happens

For people with physical or developmental disabilities, people on the street, people who are homeless, people with mental health problems and people who use drugs and alcohol, HIV is just one more problem and source of stress.

People with Disabilities

People with physical or developmental disabilities have unique needs that may affect their ability to live with HIV. Some may not have the ability to understand what is happening to them or to take steps to protect themselves and others. Others may understand but, because of a physical disability, be unable to act on their knowledge. For example, someone who is physically disabled may need help to put on a condom and may not be able to practice safer sex independently. In some cases, being disabled may be disempowering enough that it makes people more vulnerable to HIV.

The most vivid case I remember was a young man and his wife, who were intellectually challenged. No one on the health care team was sure he'd understood his diagnosis. We worried how the couple would cope. The best tool we had was a committed volunteer from the local AIDS organization who took the young man to the library. They read together about the virus and its impact. The volunteer used the books (visual cues) and their conversation to reinforce what the man needed to know. His wife came into the clinic and we talked about safer sex and possible symptoms her husband might have, such as shortness of breath, and how to help him deal with them. The couple would frequently phone the clinic when they needed any clarification or reassurance. The volunteer began attending medical appointments with the couple, to interpret and reinforce important information given by the doctors. This helped avoid confusion and reduced the number of phone calls to the doctors and the clinic.

Over the years, the couple became solid volunteers at the local AIDS organization. The lessons for us were to: match volunteer skills with needs, develop a solid working relationship with both the man and his wife, and — most importantly — discard our bias that they weren't going to be able to manage.

Even fairly minor disabilities can affect people's ability to understand their diagnosis. For example, people who have dyslexia may not be able to read brochures, pamphlets or written instructions easily. Some social workers note the dyslexia on the client's file, and then try to give information verbally rather than in writing.

Clients who already have other chronic medical conditions, such as multiple sclerosis, may find it more difficult to manage with two diseases taxing their immune systems. They may also have more difficulty co-ordinating the care they need for each condition.

In the course of their illness with HIV, some clients may develop disabilities. For example, some people will lose their sight to cytomegalovirus (CMV) retinitis. In those cases, social workers have found it effective to refer the client to the local Canadian National Institute for the Blind (CNIB), which can provide a range of services, including a white cane, talking books and support for family members. Some clients may have less mobility and benefit from the assistance of the local physical disability association.

In some cases, the HIV diagnosis may precipitate events that lead to disability, and make it more difficult for people to cope.

Lise, a woman who had many other pre-existing problems (poverty, alcohol and drug use, lack of a support network, cultural issues) that had never been adequately addressed was diagnosed with HIV. Shortly afterwards, during a drinking episode, she had a “bridge accident,” falling or jumping from the bridge. The accident left her a quadraplegic.

Lise then began to receive some of the help she needed. She has been through rehabilitation, has a wheelchair and is now in a facility. However, Lise continues to be extremely depressed and, during an interview, stated that her life was not worth living and described images of letting her wheelchair go into traffic. The social worker immediately arranged that day for an assessment by a psychiatrist.

People on the Street

Life on the street is hard, and it affects life expectancy. Having a life-threatening illness may not be as devastating to people on the street as it is to someone with expectations for the future. However, in this population, as in any other, the ability to manage life with HIV will vary considerably. Some people find that a diagnosis of HIV provides a source of meaning or identity. They get strength from telling their story or helping others, or they develop a sense of belonging or being somebody in their community. Some see it as a message from the “creator” and try to change, live healthy and stay focused. Some continue as before with self-destructive behaviours. The challenge for the social worker is to listen to the clients and let them identify how they want to deal with their HIV status.

Professionals who work with this population stress that it’s vital to work on the client’s basic perceived needs first, which are usually housing, food, medical services and legal assistance. When these practical needs are met, the next step may be to work with the client to address any problems with substance use. HIV may be the last or least of the issues that clients perceive as problems.

People with Pre-existing Mental Health Problems

Social workers faced with clients with pre-existing mental health problems must deal with the person's long previous history, the weaknesses in the delivery system for mental health services and the lack of case management.

Gary is a 22-year-old male, who has been under psychiatric care since he was 12 years old. A few months ago, when he was diagnosed with HIV, the city's forensic psychiatry service referred Gary to the region's only long-term, rehabilitation centre, located about one hour's drive from the city.

Practice Issue Avoiding Mis-assessments

Social workers should be aware that HIV and mental health problems often "mimic" each other and have similar symptoms (e.g., fever). Mental health professionals may quickly assume the fever is due to the mental health problem, while an HIV social worker might be just as quick to attribute the symptom to HIV. Professionals may have to educate one another to avoid mis-assessments.

His acting out behaviours included urinating on the facility walls, which terrified the staff who were not familiar with HIV. (He was the first patient in the facility to have HIV.)

After several months of hospitalization, Gary was being discharged from the centre, but the discharge planner was not familiar with the specialized housing/mental health support options available in the city.

Because Gary was known to have sex with many partners, male and female, sometimes for money to support his cocaine use and sometimes for pleasure, the public health authorities had issued an order instructing him "not to have unprotected sex."

It was not clear whether Gary has the capacity to understand the order or to understand the seriousness of its intent and consequences. Gary's parents were struggling with a range of personal and family issues, and they could no longer cope with their son's behaviours and his HIV diagnosis. The social worker at the city's HIV clinic was told not to become involved because it was a case for the mental health system and its staff.

During the summer months, Gary lived on and off the street, often because he was evicted from his housing and had no other options. He did maintain contact with his mental health nurse (whose role is to ensure he complies with his medication, not to be Gary's case manager) and received his prescribed medications, but he received no other support or follow-up. With the closing of the downtown hospitals, the nurse's office is being overwhelmed with cases.

Recently Gary was hospitalized at another site and discharged again with little follow-up planning, which should have included a referral to a drug treatment support program.

In an attempt to provide some support, the social worker at the HIV clinic reconnected with Gary's parents. In long, angry phone calls, Gary's father criticized the system, its professionals and its lack of co-ordination. The social worker arranged a special assessment appointment for Gary with one of the clinic's psychiatrists who, in turn, booked him on the priority bed list.

Gary was then put on a waiting list for referral to the specialized addictions/ psychiatric program (it usually takes six to eight weeks to get in), where he would likely receive some occupational counselling around academic upgrading and job placement, as well as outpatient addiction and mental health services, specialized accommodation and supports for the family system.

Three months later, these plans fell through, and the only hospital-based long-term facility in the area refused to admit and monitor Gary. His mother has withdrawn from the situation, while Gary's father continues to rail against the system and the health and social service professionals. He "fired" the social worker in the HIV clinic and reported her for "not doing enough."

To work effectively with clients with complex needs, social workers will have to advocate strongly for a case manager, and be willing to work closely with other professionals. It's critical that all those involved with the client support one another. These clients need a strong circle of support. The challenge is to develop and nurture that circle.

Some system issues — such as public health protection, human rights and admission policies — are beyond the scope of the front-line social worker. In these situations, the role of the social worker is to assess client needs, identify gaps and problems in the system, and bring them to the attention of health planners and/or to advocate for action on these emerging issues. Until some of these complex system issues can be resolved, families and social workers will likely be extremely frustrated in their efforts to provide help and support.

People who Use Alcohol and Drugs

People overwhelmed with the stresses of HIV may turn to alcohol and/or drugs. This, in turn, can affect their judgement and their ability to manage the rest of their lives. Social workers may have to use a wide range of strategies with clients who are drinking or drugging excessively.

Phil was a 38-year-old gay man who was not out to his family or employer. When he tested positive for HIV, he retreated into alcohol. The drinking began to affect his performance at work. After 20 years with the company, his employer had to let him go, and he lost his benefits. A small group of friends contacted a social worker for help. What would you do?

In this instance, the social worker and friends met with an addictions counsellor/consultant to learn about the intervention of confrontation (facing a person together and describing the consequences of his drinking). In the process, they learned that one of the friends also has an alcohol problem and often drank with Phil. Before they could put the plan into effect, Phil who was distressed about losing his job, came to see the social worker.

Concerned that Phil might lose his disability and other insurance benefits

Ethical Dilemma Intervening With Employers

In deciding when and how to act, the social worker was guided by the Hippocratic Oath of “do no harm.” His goal was to ensure the client would have adequate drug coverage and, at the same time, safeguard the client’s right to confidentiality and to control his life. In this situation, the client had already “lost” his job and, with it, his income and benefits, and didn’t have the strength to deal with his employer. The social worker decided that he couldn’t do any more damage by approaching the employer, and decided to ask for Phil’s permission and take a calculated risk.

When it came to the point of disclosing the client’s HIV status, the social worker again considered all the possible consequences, and decided that, as the personnel manager was a professional, it was unlikely that she would disclose information about the client to others. If she did, the social worker reasoned, he would have the option of reporting her to her superiors for unprofessional conduct.

when he most needed them, the social worker talked over the situation and got Phil’s permission to contact the employer. The social worker explained that Phil’s problems were the result of a life-threatening diagnosis. When the personnel manager seemed unwilling to discuss the issue, the social worker revealed — again, with Phil’s permission — that Phil had HIV infection. The company reinstated Phil and put him on disability, and then developed a workplace policy on HIV and its employees.

When Phil continued to drink, the social worker then took another risk and wrote to Phil, confronting him in a letter with his drinking problem and telling him that when he was ready to deal with it, he should take the letter to the hospital where he would receive help. Phil showed up at the hospital with the letter, which meant that he received

significantly better treatment and more attention than the emergency department usually gives to people with alcohol problems.

While in hospital, Phil saw the social worker and started to work through other issues, such as telling his teenage daughter and his employer/co-workers he was gay. His health improved. He joined AA, and found a sponsor. His company recently recognized him with a long-term service award pin.

Phil eventually became involved in a pilot project to train peer counsellors. Two people have been referred to him who faced similar issues (both recent diagnoses, both coping with alcohol). He has been able to help them both — one has since become a peer counsellor in another city and the other got hooked into AA.

Where to Go For Help

Social workers who have no experience in addictions should build a network with colleagues who work in the field. Addictions counsellors can provide valuable advice and coaching. They may even be able to work directly with the client on their addictions issues.

Social workers should also examine their attitudes towards people with addictions. The health system has a tendency to devalue people with addictions, and this attitude can affect the services provided and how they are delivered. Social workers will have to learn how to work with people with an addiction problem in order to provide client-centred care.

People who are Addicted

In trying to help clients who are addicted to drugs or alcohol to care for themselves and improve their health, counsellors must deal with underlying issues. They must also have a plan to deal with behaviours, such as aggression, acting out and missing appointments.

The health of people who use substances may be compromised by the fact that they are not working and have no steady income, so they have poor housing and inadequate nutrition. If social workers do not deal with the underlying issues as early as possible, serious problems

may occur. For example, clients may be evicted in the late stages of their illness because they have used their rent money to buy drugs.

In most cases, the clients need a steady source of income and a way to manage their substance use, even if they have not identified that use as a problem. Their use of substances may also complicate or mask medical problems. For example, people

who use substances often report medical symptoms — such as leg pains and headaches — which can indicate late stage AIDS or be a symptom of drug withdrawal. Clients themselves may be frustrated trying to find one service that can help with all their complex problems.

Strategies that social workers can use with clients who are addicted include:

- establish strict boundaries and explain the organization's rules clearly (i.e., what the organization can provide, when you are available and what is considered acceptable behaviour)
- be reasonably flexible — don't set appointments for 9 am when it's clear the client won't be able to comply
- help them meet their basic needs — such as food and housing
- use a form of contract — for example, in exchange for income assistance or long-term disability, the client agrees to participate in an addictions program or to attend his or her medical appointments
- reinforce the need for prevention, focusing on harm reduction strategies and trying to make the changes manageable and sustainable
- encourage them to change their social group and remove themselves from situations where they are more likely to either use drugs or have unprotected sex
- be creative with the resources that are available to help the client deal with his or her complex needs
- use humour with clients
- stay objective — don't take it personally when clients don't keep appointments or have a relapse
- advocate for more addictions services — most communities do not have enough to meet demand
- forgive yourself for the mistakes you make as you learn and develop your practice wisdom.

When I was diagnosed with HIV, the services for HIV, addictions and mental health were very separate. I was very influenced by my recovery home — I am still sober — but they didn't have much information on HIV, and I couldn't really talk about it there. The AIDS services that I used were great, but they didn't want to talk about addictions. The mental health services I used helped me deal with the rape and violation I experienced, but the women's support groups couldn't deal with my HIV or my addiction. It has taken me seven years to get where I am now. If the three services could be brought together somehow, it wouldn't have taken as long — and really, how many of us have time for this long a process?

Social workers with clients with HIV may have to be prepared to deal with a complex range of issues, to listen to the “whole story” and to help clients connect with other services and professionals who can help them.

People infected through injection drug use may be reluctant to disclose their HIV status to needle sharing partners because of the risk of violence or ostracization. The addiction, their need for the drug and their fear that it might be withdrawn or withheld may also affect their ability to practice safer drug use. Social workers will have to take these pressures into account when helping someone with an addiction live with HIV.

REFLECTION ON SUBSTANCE USE

It is easy for people who work in medical settings or with clients who are ill to be seduced by the medical model of a quick fix or answer for any problem. People who work in HIV may also succumb to the sense of crisis and anxiety, and the feeling that they have to act quickly and “save” people with HIV because they may not have a lot of time. These perspectives may make it particularly difficult for them to work with people who use or abuse substances. They may be frustrated by people who don’t share the same sense of purpose or anxiety, and who miss appointments or show up late, and who seem more concerned about hitting up the social worker for money than dealing with their addiction or their HIV.

Mike, a 30-year-old man with HIV came to the local AIDS organization for food and money. An injection drug user, he had recently left a rehab program, lost his housing and was living on the street. One of the staff began to work with him to develop a plan to deal with all his issues. Concerned that he had no where to live, the staff person invited him to stay at his apartment. When he returned from work the next day, he found the man gone along with his stereo equipment, television, some other easily pawned goods and some cash. The staff person was extremely disillusioned by what he perceived to be a betrayal of his trust.

Addictions counsellors and other accustomed to working with people with addictions take a more measured view, one that recognizes that nothing will happen until the client is ready and that relapse is part of the process of change. It is critical for social workers to collaborate with addictions workers and be willing to refer clients to appropriate services.

Changing Addictive Behaviours

People with substance use issues who manage to change their addictive behaviour go through certain stages and processes in making the change:

- **precontemplation.** At this stage, people tend to be unaware of their problems and have no intention of changing in the foreseeable future. To move out of this stage they need information they can integrate into their lives so they can perceive a risk to their health and sense they have the ability to change.

Practice Issue

The Harm Reduction Approach in Addictions

Harm reduction is an approach and a policy designed to decrease the health, social and economic adverse consequences of drug use without necessarily requiring a cessation in consumption.

When someone with an addiction is faced with a life-threatening illness like HIV, he or she may not have the motivation to deal with the addiction. Why solve this problem if I am just going to die? For most people with a serious drug or alcohol addiction, the addiction may be more immediately life-threatening than the HIV, but they have lived with that risk for some time and still may not be ready to change.

Abstinence has been the traditional goal for people with addictions, and most treatment and support models are based on that. However, for some people, abstinence may be so far out of reach that it becomes an ineffective strategy.

People with complex problems and needs may benefit more from a harm reduction approach, which sets smaller, more achievable goals, such as reducing the use of substances. Contracting can be used effectively with a harm reduction approach, and the client's self-esteem may build as he or she is able to achieve more limited goals and maintain that level of behaviour change.

Abstinence continues to be part of the harm reduction continuum and for some people — depending on their addiction — it may continue to be the only workable option.

- **contemplation.** People at this stage are aware that a problem exists and are seriously thinking about over-coming it, but have not yet made a commitment to act. They are still struggling with the pros and cons of the problem and its solution. To move out of this stage, they need to continue to learn, to believe in their ability to change and to think about decision-making.
- **preparation.** At this stage, people are intending to take action in the near future, and may even report some small behaviour change, such as smoking fewer cigarettes each day or drinking less. They need positive reinforcement to act and some acknowledgement of any changes they've already made.
- **action.** People begin to modify their behaviour, experiences or environment to overcome their problem. This stage involves a lot of time and energy, and changes tend to be most visible. People are usually working toward an acceptable criteria. In many cases, that is abstinence, but that can vary. Over time, they begin to use the new behaviour consistently and become more skillful with it. They learn coping skills and become more assertive. To move to the next stage, they need support and acknowledgement.
- **maintenance.** At this stage, people have been practicing the new behaviour consistently for at least six months, and have reduced the unsupportive relationships in their lives. They are working to prevent a relapse and consolidate the gains they attained during action. Maintenance is a continuation of change, and can extend from six months to years to a lifetime. To remain at this stage, and not relapse, people need ongoing encouragement and support.

People trying to change an addictive behaviour may relapse and recycle through these stages. In fact, relapse is the rule rather than the exception with addictive behaviours. Relapse is part of recovery.

Social workers working with clients with addictions problems should be aware of these stages. Many treatment and self-help programs focus only on the "action" stage, and do not recognize that earlier stages of preparing to act are an integral part of making the change. Most people will not be in "action" stage. They must go through a supportive process to get there, and social workers should identify the

person's stage and work from there. When clients are not motivated, resist therapy or are defensive, they may not be ready to deal with their addictive behaviour and traditional interventions will likely fail.

The philosophy of social work practice with HIV, as with any other issue, is to outline options for clients and then give them time to reflect and make decisions. It is also important to be ready with a plan when the person is ready to act. Any delays at that stage can be damaging.

DEVELOPING A PARTNERSHIP TO MANAGE HIV

Perhaps because people with HIV had to fight hard for drug treatments and services or perhaps because HIV first affected young, assertive, middle class gay men, people with HIV are consistently telling care providers that they want to be actively involved in planning and directing their care. With HIV, the person and the caregivers come to see themselves as partners in managing HIV. For caregivers, this means outlining options and giving the person with HIV time to reflect and discuss the options before making a decision.

For a partnership to work, it must be nurtured. Social workers should encourage people with HIV to develop strong working relationships with their family doctor and specialists.

To be able to develop an effective partnership, clients must have a sense of control, a willingness to learn and access to the necessary information. Social workers can help people develop these skills by modeling the same type of partnership in their relationships with their clients, and by giving them practical advice, such as:

- stick to the same doctor so you can get to know one another
- see the doctor regularly
- be ready for the doctor's appointment; make lists of the issues you want to discuss
- be very directive so you can use the short time you have with the doctor well (e.g., I am fine ... and I have three questions to discuss today)
- be direct in dealing with any frustrations, conflicts or hurts. Too often people communicate their dissatisfaction with a doctor by simply switching to another doctor. But this does not help physicians improve their working style or help the person with HIV develop problem solving skills.

As more people choose to die at home, the relationship with the family physician becomes more important. It is the family doctor who will stay in touch and be available for home visits. It is easier for most people to discuss living wills with a family doctor who knows them.

Working as Part of a Multi-disciplinary Team

Most people with HIV will have a number of friends, volunteers and professionals involved in their care and support — a family doctor, specialists, a social worker, family members, friends, volunteers at the local AIDS organization. Depending on their needs, some clients will also have ongoing contact with income assistance staff, addictions counsellors, mental health professionals, home care professionals, hospital staff and others.

Practice Issue An Argument for Case Co-ordination

Building an effective partnership with caregivers may be easier with some clients than others. People with an addiction problem or those who do not speak the caregivers' language may be at a disadvantage. For these clients, social workers may have to do more advocacy with caregivers and take steps to help clients overcome barriers, such as language, culture and the attitudes of the health system. Social workers may not see themselves having a role in a person's medical management. But there may be exceptions to this rule for:

- people who are homeless
- people who are scape-goated easily (e.g., transgendered people)
- people who use substances
- people who are dealing with multiple diagnoses (e.g., mental health problems and HIV)
- people who have physical or developmental disabilities.

The social worker can help co-ordinate clients' care by reminding them about appointments, accompanying them on visits and helping with trustee arrangements. They can also help them request a few critical tests or certain drugs that may help prevent hospitalization. In addition, the social worker can provide a list of resources they can give to the people responsible for the client's medical treatment. In some cases, they can mediate between the client and the medical caregivers, and advocate on behalf of their clients.

It is vital that social workers help clients connect with these other caregivers. The multi-disciplinary team may be a formal arrangement co-ordinated out of an HIV clinic, or it may be a more informal collection of people all providing different services. In some cases, the services provided by different professionals and volunteers can overlap. For a multi-disciplinary team to work effectively, communication is essential. All those involved must recognize the shared and distinct roles among the professionals, recognize the different skill sets of each professional and adopt a complementary approach to the person's care — rather than competing with each other to provide services. (To help professionals develop the knowledge, skills and mutual respect essential to collaborate care, McGill University has developed interdisciplinary HIV education for physicians, social workers and other health care professionals. For more information, contact the Department of Social Work at McGill University.)

Ultimately the goal of all professionals should be to move to an inter-disciplinary approach, which is client-centred rather than profession-centred. In this model, social workers no longer “own” their clients but are there to help the client find the best professional to meet his or her needs. In some situations, professionals can ask clients for permission to communicate with each other and negotiate their tasks and roles. For example, the social worker attached to the HIV clinic may take the lead on disability forms and transportation applications that require a doctor's signature, while the community social worker is responsible for helping the client with other needs, such as income assistance and housing.

As part of the team, the social worker can:

- act as a facilitator, helping the client connect and work with other team members
- advocate for the client to be seen as part of the inter-disciplinary team.

TEST RESULTS: SORTING THROUGH THE NUMBERS ...

The Psychosocial Impact of CD4 Counts

Certain key indicators are used to monitor the health of people with HIV and measure disease progression. The most common is the CD4 count. While these numbers are useful for doctors, who use them along with other patient information to make treatment recommendations, they can pose problems for people living with HIV. Some begin to measure their own health and sense of well-being by these numbers. Then any sudden change or drop can trigger a psychosocial crisis.

When dealing with clients' understanding of medical information, social workers should clarify what clients know, how they are interpreting the information, any other information they need and where they can get it. They should encourage clients not to leave their physicians' offices until they understand their situation and what they need to do.

Social workers can also use clients' CD4 counts as a trigger for certain kinds of support. For example, when clients' CD4 counts fall below a certain level (in most cases, around 100), they will likely start taking expensive medications. (Before this point, they will likely be taking less expensive drugs over shorter periods of time or drugs that are provided by provincial drug plans. Some people may start taking expensive preventive medication early.) Long before this point, social workers should start asking questions about drug coverage, to make sure that everything possible is done to ensure clients can get the treatments they need when they need them. In time, clients with low CD4 counts may experience significant changes in their physical health (stamina, strength) or mental health (concentration, memory, mood, ability to process information). This may be the time for social workers to assess whether clients are still able to manage their jobs and to consider applying for long-term disability.

It's critical for social workers to use available medical information to help them discern when they need to act quickly.

Social workers should also encourage clients to keep the numbers in perspective. Healthy people have CD4 counts between 350 and 1300. The "normal" range for CD4 counts is much wider than people once thought. Clinicians often use CD4 counts as a trigger for disease progression and for initiating certain treatments. For example, as people's CD4 counts drop to about 350, they may develop the first symptoms of HIV disease, such as minor skin problems or yeast infections in the mouth or vagina. When their counts fall below 200, they begin to be more vulnerable to serious opportunistic infections, such as pneumonia,

and they are likely to see their doctors more frequently (maybe monthly), who will start to look for a range of infections, such as CMV (cytomegalovirus) retinitis, which can cause blindness.

These counts tell people the extent of the damage to their immune systems, but they were never intended to be a predictor for life expectancy. Social workers can help clients understand:

- A low count (between 0 and 50) doesn't mean the person is about to die, but it does indicate extreme immune system damage.
- CD4 counts are sensitive to many influences — drug use, a hang-over or recent cold can cause them to drop.
- People who are recently infected will have artificially low counts as their bodies begin to fight the virus. Over time, their counts will improve.
- One or two counts don't tell the whole story — they can change dramatically over time. Wait until you can see a trend — several tests in a row with steadily dropping counts — before making any decisions or choices.
- New tests, such as the viral load test, will eventually give a better sense of how well the body's immune system is fighting the HIV.

It is particularly important to stress this information with newly diagnosed clients who may over-react to the numbers and make rash decisions, such as giving up a job and applying for disability, before they really understand what is happening to them.

The Psychosocial Impact of Viral Load Testing

Physicians are also using viral load tests to help them decide how aggressive to be with a patient's treatment. The viral load test measures the amount of HIV in a person's blood. The higher the viral load, the more likely the person will develop serious HIV disease. Antiretroviral treatments focus on lowering people's viral load, and physicians can use measures of viral load to assess how effective a therapy is. Viral load testing is relatively new, and clinicians are still learning how best to use it in managing a patient's care.

Practice Issue

To help clients cope with viral load testing, social workers can:

- discuss the implications of the test
- explore how the person will react to a test result that shows he/she has a high viral load
- discuss the impact of protease inhibitors
- if the person is having trouble adjusting to their diagnosis, caution them not to have the viral load test too soon after the antibody test.

However, the psychosocial implications of the test are obvious. For many people — particularly those who have no or few symptoms, it can be like taking the HIV antibody test again. They may learn that their immune system is more damaged than they thought. Results of a viral load test may also precipitate a crisis that would have either occurred later or not at all.

Test results may also create pressure on people to start drug treatments before they are ready. For example, a physician treating someone who has a

CD4 count of 600 but a high viral load may want the person to start antiretroviral treatment right away, but the person may not yet be ready for the strict regiment involved with antiretroviral therapy.

Resources

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4 LIVING WITH SYMPTOMS AND ILLNESS

Ever after he greeted me with a hug. We used to joke that it was my assessment tool. From our hugs, I could tell how strong he was. I could tell if he had lost weight, if he had a fever, if he was dehydrated. We all need to be touched and when we are deprived of physical contact, we crave it. “Skin hunger” can weaken a person just like pneumonia.

Welcome Home
Stories from the Edmonton Home Care Program

HIV is an uncertain, insidious illness. For a considerable time before clients develop any signs of illness, their physicians will probably have started them on different preventive or prophylactic treatments designed to keep them from developing an AIDS-defining illness, such as *Pneumocystis carinii pneumonia* (PCP) or MAC.

Disclosure Again

At this point, the question of telling people re-emerges. Employers will wonder why the person needs so much time off work. People close to the client, who don't know his/her status, will notice the physical deterioration. Questions will be asked.

People the client chose not to tell earlier — including employers, friends, parents and children — may have to be told now. Clients may again need support in working through this process. However, they may find that the appearance of physical symptoms provides an opportunity to end the lying, secrecy and isolation, expand their support network, and increase their sense of self-esteem.

Despite these treatments, at a certain stage, people begin to become ill and develop symptoms. Doctors appointments will become more frequent. Even this, the first serious sign of an AIDS-defining illness, does not end the uncertainty. Clients will not necessarily begin a steady downward spiral. They may be sick for a while, well again, then sick and well. This kind of “roller coaster” cycle can continue for many months and years.

However, the first AIDS-defining illness can be a crisis point for many people and can mark the beginning of a permanent or perpetual vulner-

able stage where clients focus more on the loss of their health and their impending death.

With advances in treatment, clients will not necessarily be hospitalized for these conditions. But they will have to take more medications and treatments, such as home intravenous therapies. They will experience a loss of appetite and weight. They are less able to function at work or participate in other activities. They may need time to convalesce and recover.

Time away from work and the need for long-term convalescence signals to people that their lives are shifting in a profound way. The period of waiting is over, serious medical and social events are unfolding. This is a time of many losses and demands. Clients will feel the increasing pressure of practical needs.

What Social Workers Need to Know About ...

... clinical trials

A significant number of people with HIV will participate in clinical trials. They will be helping to assess the efficacy of new treatments or different combinations of drugs. Participating in trials can be stressful. Clients may suffer side effects from the medication. If they are involved in a randomized trial comparing one treatment regimen to another, they will not know which treatment they are receiving, and

some people may have problems with the uncertainty. They may also be required to attend more appointments. While some people benefit from a sense of hope from the trials, others find it emotionally trying and may need support in dealing with their issues and in communicating any concerns they have to the researchers.

... serious opportunistic infections

Some opportunistic infections develop very quickly and often lead to death, including:

- advanced dementia
- severe encephalopathy
- persistent multi-focal lymphadenopathy
- lymphoma of the brain.

Social workers should be aware of these infections so, when and if one occurs, they can act promptly to make sure that clients have signed their powers of attorney, named someone who can make their health care decisions for them (if necessary), arranged for adequate housing and drug coverage, and developed a support system for caregivers.

(Planning for legal and financial matters should have occurred much earlier, when the person was well.) Not all opportunistic infections are life-threatening. However, all will weaken the person's immune system. Continued use of substances — drugs or alcohol — can exacerbate any of these infections. Social workers should discuss with clients who use substances the potential impact on their health.

...treatment decisions and choices

At this stage, clients may become preoccupied with treatments and medical decisions. They are likely to seek out information on both traditional and complementary or alternative therapies. The HIV community has been particularly active in developing treatment information for consumers, and in pushing the medical field to be more open to complementary therapies.

AIDS-defining Illnesses

1. Candidiasis of the esophagus, trachea, bronchi, or lungs
2. Cryptococcosis, extrapulmonary
3. Cytosporidiosis with diarrhea persisting >1 month
4. Cytomegalovirus disease of an organ other than liver, spleen, or lymph nodes in a patient >1 month of age
5. Herpes simplex virus infection causing a mucocutaneous ulcer that persists longer than one month; or bronchitis, pneumonitis, or esophagitis for any duration affecting a patient >1 month of age
6. Kaposi's sarcoma affecting a patient <60 years of age
7. Lymphoma of the brain (primary) affecting a patient <60 years of age
8. Lymphoid interstitial pneumonia and/or pulmonary lymphoid hyperplasia (LIP/PLH complex) affecting a child <13 years of age
9. *Mycobacterium avium* complex or *M.kansasii* disease, disseminated (at a site other than or in addition to lungs, skin, or cervical or hilar lymph nodes)
10. *Pneumocystis carinii* pneumonia
11. Progressive multifocal leukoencephalopathy
12. Toxoplasmosis of the brain affecting a patient >1 month of age

Social workers do not have to become experts in medical care or be able to answer all clients' treatment questions. However, clients may expect social workers to help them work through their own decisions. For example, some clients may choose to keep taking gancyclovir for their vision care, but stop aggressive antiretroviral therapy, which may involve 16 pills a day. Others may decide to stop taking amphotericin because they find the nausea it causes worse than the original problem.

For More Treatment Information

To learn more about the medical issues:

- find an HIV medical specialist in your community who is willing to answer your questions
- develop a network with social workers who have a large caseload of HIV positive clients; they will be able to help
- get a copy of other modules in this series, Comprehensive Guide for the Care of Persons with HIV Disease: Module 1: Adults — Men, Women and Adolescents and Module 2: Pediatrics — Children and Youth
- check out the Internet
- contact CATIE or The Network

CATIE HIV/AIDS Treatment Information Network

The Community AIDS Treatment Information Exchange (CATIE) provides services to help people living with HIV and their caregivers make informed health care decisions. A wide array of services — including information for professionals — are accessible through The Network, a treatment information system that can be accessed by phone or computer. Anyone calling the 1-800 number will reach a trained Treatment Information Consultant, who can answer questions or provide print information on request. Anyone contacting the Network via the internet (www.catie.ca) will have access to the Network's extensive treatment database.

CATIE also produces a number of publications including:

- Managing Your Health
- Treatment Update, a journal that summarizes and comments on current developments in HIV research and treatment
- Factsheets on conditions, symptoms, treatments, side-effects, etc.
- info@catie.ca, a quarterly newsletter that deals with the social effects of treatment information.

For more information, contact CATIE at 1-800-263-1638.

What kind of life do they want to lead with HIV? How credible is the information they have on various treatments? What should they do if they disagree with what their physician recommends?

Perhaps most important, social workers may be able to help clients distinguish between good information and sales pitches that play on their fears and hopes for a cure. People who are ill — and the people around them — are often particularly vulnerable and willing to “try anything,” which can be costly and dangerous. Social workers can help them connect with credible sources of treatment information.

... *complementary therapies*

According to a survey sponsored by the Community Research Initiative of Toronto (CRIT), 78.5 per cent of people living with HIV used complementary therapies at every stage of HIV disease. These people were, on average, more satisfied with every category of complementary therapy than with drugs and the majority (67 per cent) expected these therapies to boost their immunity.

The therapies used by the greatest number of people were vitamins and supplements, exercise, spiritual/religious therapies, psychotherapy, naturopathy and Swedish massage. The people surveyed reported the greatest satisfaction with Swedish massage, sound therapy, spiritual healing, chiropractic, spiritual/religious therapies, relaxation, exercise, therapeutic touch, Shiatsu massage, guided imagery and diet/nutrition.

People are spending, on average, 10 to 20 per cent of their incomes on complementary therapies. As many people with HIV have low incomes or are on income assistance (and have incomes below \$15,000) this has serious psychosocial

implications. Social workers can help clients by ensuring they have access to credible information about complementary therapies and ethical therapists. They may also be able to help by arranging for services in kind. For example, some massage therapists may be willing to donate a certain number of hours per week to an agency or clinic.

Ethical Dilemma When a Client Declines Medical Treatment

A client has recently begun to develop symptoms of illness, but is refusing to seek out any care or take any of the available drugs. What do you do?

- explore and understand the reasoning behind the person's decision
 - is there any underlying depression? are there any organic causes (e.g., dementia)
 - does the person really understand what the treatments are? (Some people confuse the different drugs. They may mistakenly think that the drugs to prevent PCP have side effects like the antiretrovirals.)
 - are there any underlying fears? (People who are street involved may not want to take any drugs for fear they would have to be hospitalized. They may be receptive to treatments that will prevent hospitalization.)
 - are there practical problems? Do street people have any place to keep their drugs?
- start small (In one case, a social worker helped a street-involved woman to get free drugs to clear up a serious herpes outbreak on her face and got her into a hospice. Once she was settled, she changed her opinions about treatment and asked her physician to be more aggressive with her care.)
- accept the client's decision. He or she is the one in charge.

... new drug treatments

A group of drugs, known as protease inhibitors, are having a remarkable effect on some people with AIDS. The level of virus in their blood drops dramatically. They regain their health and vitality. Some are pulled back from the edge of death, and seem to have a new lease on life.

However, social workers should be aware that these drugs are new, their long-term effect is unknown, and they do not work for everyone. It appears that about 30 per cent of people with HIV do not respond to protease inhibitors. Some experience such severe side effects, they cannot take the drugs. Some cannot manage the rigid regimen required (see "impact on quality of life" below). Others show a marked improvement for several months, and then the virus begins to fight back.

While many believe these drugs are the answer to AIDS, there is still a great deal of uncertainty about how well and how long they will work. These drugs may also lead to an increase in risk behaviour. Some people may use them as a license to have unsafe sex again. It's important for social workers to realize that there will continue to be new developments in HIV care and treatment, some more hopeful than others. It's vital to develop services that are flexible and to be able to help people cope with radical changes in their health and the potential roller coaster of hope and doubt or despair.

... the risk of blindness

People with HIV are particularly vulnerable to cytomegalovirus (CMV) retinitis, which can cause detachment of the retina and loss of vision in the affected eye, and make the process of living with HIV that much more difficult. When people with HIV are seen regularly by a physician, the doctors will test for CMV early. Patients who have CMV are usually seen regularly by an ophthalmologist, who can treat the condition and help them avoid going blind.

Social workers can help by encouraging clients who have opted for minimal care to, at the very least, pay attention to their eye care. This may involve direct social work intervention.

I have actually gone with my client from the street to the ophthalmologist, to reassure him and the doctor. I remember the brave face my client put on when we went to the doctor's office, but I knew he was terrified. When the doctor told him he was fine, he wanted me to explain it to him so he could believe it. As we walked out, I asked him if he wanted to go for a cigarette and I never heard a more grateful 'yes.'

I was afraid that, if I didn't go with him, he would have acted out — as he often did with authority figures. I was nervous because I was afraid that one wrong move on his part would have the doctor asking him to leave. I know my presence reassured the staff. I think, in hindsight, they realized that street people are not such a big deal.

Now, I go out of my way to make sure that the hard-to-care-for folks get to the eye clinic. I phone them about their appointments, arrange rides for them or go down and squeeze them into the eye clinic if they happen to have wandered in to chat with me about their vision changing (i.e., cloudiness, loss in peripheral vision).

The pay-off for me is we have only had one man lose sight in both his eyes — out of 1,300 patients.

... the risk of tuberculosis

People with HIV and their caregivers, including social workers, are often concerned about possible exposure to tuberculosis (TB). People with HIV are vulnerable to TB, a highly infectious disease that is spread when people cough. Each province has an established program for TB management and control. Social work organizations that have regular contact with people with HIV should check with their local public health authorities about appropriate policies and procedures. The Canadian AIDS Society has also developed guidelines for AIDS service organizations working with clients with TB.

TB, once diagnosed, is usually treatable — although some people with HIV have developed drug resistant TB. People who develop tuberculosis and who do not comply with their treatment may have to be isolated until their condition is under control. This may raise psychosocial issues that social workers will have to address.

THE IMPACT OF TREATMENT ON QUALITY OF LIFE

With the new therapies, people with HIV must often follow strict treatment schedules and guidelines. Medications must be taken at certain times, some with food, some without, and clients may be taking 20 or more pills a day.

I didn't know that I was supposed to take that drug with food. I lost 40 pounds because of nausea. When we worked out a new diet/drug plan, I started to get better.

The schedule is extremely important. For example, people taking Crixivan, a protease inhibitor, must take it every eight hours — without fail — and they are not allowed to eat for two hours before or one hour after. If they

miss a dose, take it at irregular intervals or on a full stomach, they give the virus a chance to mutate and develop resistance to the drug.

These complex and rigid drug regimens can adversely affect people's quality of life, and may be a factor in a person's treatment decision. Clients may need an opportunity to discuss how treatment constrains or limits their lives, and peer support will be important. They may also need support in finding practical ways to manage treatment. For example, helping clients with HIV identify nutritionists and pharmacists who will work with them on diet counselling and drug scheduling can significantly improve their quality of lives.

Quality of life issues become more complex when the client is someone who is homeless or poorly organized, and who cannot manage their treatment schedules.

When People Begin to Get Better: “Uncertain Life After Certain Death”

For some people with HIV, new drug treatments are disrupting — at least for a time — the slow, steady slide toward death that they had come to accept. They now reside in a twilight zone between sickness and health, between uncertainty and hope. And, for some, the change is not altogether welcome.

Alex is gay man who, until he started taking protease inhibitors, had advanced HIV disease. He has gained 20 pounds and started to work out again. Most of his friends are dead. Alex has been on disability benefits for the past three years. His financial situation is worrisome. He had expected to die before his benefits ran out. Now he's not sure. He doesn't know how long the drugs' benefits will last. What if the government stops his disability payments? When asked about his situation, he explains, “I had accepted my mortality. I felt complete with my life. Now I don't want to get my hopes up and get them dashed again. I'm supposed to be overjoyed that I'm better and part of me is. But a turnaround like this brings up multiple issues.”

Taken from the San Francisco Chronicle.
Sunday, November 24, 1996.

Like other people with AIDS who thought their life was over, Alex is faced with serious life decisions. Am I strong enough to go back to work? Do I want to return to what I was doing before? Should I apply for graduate school? Do I start seeking out new attachments? Should I buy a house? The sudden change can be disorienting for many people, particularly if they have been HIV positive for a long time. Some react with anxiety, feelings of unreality, depression and anger, but they are often ashamed to talk about their feelings.

Social workers can help clients in this situation deal with their issues around work, feeling better, socializing and dating. Clients may also benefit from a referral to rehabilitation services that can help them make a gradual transition back to work, if appropriate.

MONEY, HOUSING AND OTHER BASIC NEEDS

HIV makes people poor. Most people with HIV are relatively young and may not have the resources to manage or afford a long illness. Drugs are expensive. People with HIV may have to leave work for a while because of their illness. Most don't have short-term sick leave or disability coverage. The money runs out. The bills pile up. Many people reach the stage of being unable to afford their housing, and face a drastic change in their lifestyle at a time when they are least able to deal with it. For people on the street who started without money, housing or other basic needs, the situation is even worse.

Access to Money = Access to Drug Treatments for HIV

Drug	Company	Phone Number
AZT, 3TC, Acyclovir, Gancyclovir	Glaxo-Welcome	1-800-661-3138
Sequinavir	Hoffman La Roche	1-800-890-6571
DiFlucan, Zithromax	Pfizer	1-800-267-2553
Indinavir	Merck Frosst	1-800-277-1433
ddl, d4T, Megace	Bristol Myers Squibb	1-800-267-1088
Mycobutin	Pharmacia	1-800-387-5646
Nizoral, Immodium	Janssen-Ortho	1-800-387-8781
Ritonavir, Advera	Abbot	1-604-222-9202

Call these numbers and ask for the name and phone number of the representative for your area.

As with other clients, social workers can help people with HIV get access to income assistance, subsidized housing and other services available to people who can no longer support themselves. They can also help them sort through the maze of benefits that may be available through the Canada Pension Plan, employment insurance and private company plans.

When people are asymptomatic, they don't usually need costly medications — except those that are provided through government programs. However, many

take vitamins and use complementary therapies (e.g., massage, acupuncture) which can be expensive and are not usually covered by government programs or company drug plans.

As they become ill — at a time when they are less able to work — they will likely start taking several new drugs, which they won't be able to afford without an adequate drug plan.

Average drug costs can range between \$500 and \$3,000 a month over the course of the illness. Even people who are able to keep working are hard pressed to afford these costs.

If money is an issue, social workers can draft a letter, which is signed by the client's physician, that can give some relief from other financial obligations. For example, government-sponsored student loans will cover interest payments for someone on short-term disability. If the person has no resources and is unlikely to be able to return to work, the programs will consider writing off the loan.

Social workers can also help clients get access to appropriate drug coverage through:

- employer plans
- private plans
- social services.

They may also be able to help clients get some drugs temporarily through pharmaceutical companies that offer compassionate release programs or programs for indigent people. These programs offer assistance (often one month) to people

who are in the midst of an eligibility period or application process for other income or drug assistance plans. Some companies will provide free samples of certain drugs to physicians or pharmacies for release to patients in financial difficulty.

Companies do not advertise these programs. Social workers will have to contact the drug companies' local representatives directly when the need arises. In some communities, the drug companies have worked together with community AIDS organizations to contribute to a transition funding program to help people over the waiting period for permanent drug coverage. However, some companies find it easier to release products than money.

Although most people recover from their first AIDS-defining illness and want to keep working, their need for costly medications makes many consider going on long-term

disability or income assistance. However, for many people with HIV it is a difficult trade-off to go on long-term disability or income assistance just to get help paying for their drugs. To qualify for income assistance, people must have no other source of income and few assets. This may mean that they have to leave jobs that have given their lives a sense of meaning. Instead of having their work to help them cope with the illness, they are left with less money and a lot of time to think about being ill. Some provinces have recently developed stand-alone drug plans for people with serious illnesses who need costly drugs, which pay for the drugs and allow people to continue working

Other Tips for Financing Drugs

- Drug costs not covered by any agency can be deducted as medical expenses on income tax forms (subject to the person's deductible). Clients should keep their receipts. If they lose them, the pharmacy should be able to print out a record of their drug purchases.
- If drug costs are too high for clients to wait to be reimbursed by company drug plans (e.g., more than \$300 a month or a significant portion of the person's income), they can ask their company's personnel office to give the pharmacy permission in writing to bill the insurance company directly. Pharmacies have standing permission from companies such as Blue Cross to comply with these requests.
- If government-sponsored plans are too restrictive for people who can't afford the up-front costs, social workers can collaborate with others in the community to develop strategies to overcome these barriers, such as raising money for a fund that people with HIV can borrow from to cover their up-front costs.

Given what we know about the link between work and self-esteem, social workers should be advocating for changes in income assistance and long-term disability policies that force people to give up work and go into poverty in order to receive the drugs they need. People should be able to continue working as long as possible without losing access to other services.

A better choice for most people would be:

- recent efforts on the part of government and industry to develop long-term disability programs that encourage part-time work and provide adequate drug coverage (Some private insurance disability plans exclude people with HIV or will provide coverage only if the person remains well for a certain length of time, for example, at least one year after joining the plan.)
- inexpensive individual drug programs that provide coverage and allow people to work can be purchased in some provinces through companies like Blue Cross. Some of these plans may not disallow pre-existing conditions and/or HIV and its expensive drugs.
- government-funded catastrophic drug plans that cover the cost of expensive

drugs — although the high deductibles, prohibitive up-front costs, long waiting periods to be approved for the plan or reimbursed for drug costs, and other restrictions make some plans inappropriate for some clients.

To support their clients, social workers should advocate for drug plans that will help people stay in the workforce. With the growing attacks and constraints on our health care system, social workers and clients may also have to advocate to have government continue to pay for drugs. In addition, social workers and other caregivers should be aware of efforts in their community to lobby for affordable access to critically needed drug therapies, especially new products. Access to these products is often delayed because of the administrative red tape involved in getting new products listed on provincial drug formularies.

Advocacy — what does it mean?

In the few years, at least six new AIDS drugs have been approved and released, including 3TC, Sequinavir, Ritonvir, Indinavir and Zithromax. The monthly cost for each of these drugs ranges from \$150 for Zithromax to \$600 for Sequinavir. While most provinces cover the cost of some of the early drugs, such as AZT, it is becoming harder and harder to get funding for new drugs.

In one community, social workers led an advocacy effort, targeting representatives in their provincial government: the people who decide how health dollars are spent. The campaign included attending a Town Hall meeting, writing to the member in that riding, organizing consumers across the city, finding people who live in each of the city ridings who would write to their provincial representative and, if possible, arrange meetings with them. Provincial politicians are learning about HIV for the first time from their constituents, who are giving HIV a face and helping to erode the stigma and gain more support for their practical needs.

If we were to do it again, we'd prepare a one-page fact sheet for people as well as some sample phrases they could use in their letters. We'd also spend more time finding "captains" for the ridings in the city so the work would be more co-ordinated. We also realized that this has to be a partnership among the local AIDS organization, the AIDS medical group, their boards and people in the community. If we don't work smart together in the future, we won't get anywhere.

Housing Issues

People with HIV often encounter housing problems. In some cases, landlords refuse to rent to someone with HIV. In others, people with HIV may be unable to maintain their housing because so much of their income is going toward drugs, or they become too ill to

manage on their own and need some form of supportive housing. Housing is often a serious issue for clients who also have mental health problems or an addiction.

Sometimes letters to creditors, landlords and housing authorities, drafted by social workers and signed by physicians, can help clients either avoid eviction or other drastic measures while they are adapting to the changes in their lives or waiting for access to appropriate housing. Letters to housing authorities asking for quick consideration of a client's application often have to include specific information about the person's medical conditions (e.g., mental and physical deterioration, risk) to justify the request.

Lack of housing can exacerbate other problems. For example, if a client's housing is uncertain and he has no where to store his medication, it is unlikely he will be able to keep to the strict regimens usually required for HIV treatments, and his health will suffer. Few communities have enough subsidized or supportive housing to meet all the needs. Social workers must be willing to advocate for a range of housing options. For example, one community developed a special emergency housing fund to cover temporary housing emergencies (e.g., people discharged from prison, people about to be evicted). The person co-ordinating the fund also organized semi-annual housing meetings to raise awareness of housing needs.

MAKING THE DECISION TO STOP WORKING AND GO ON LONG-TERM DISABILITY

Making the decision to stop working is often extremely difficult. For many people, it marks the passing of a major stage in their lives, and the change may trigger a crisis. When people decide to stop working, they are acknowledging that they:

- do not expect to recover
- will be losing work-related friends and contacts
- will lose an activity that was likely a significant part of their lives.

At this stage clients may start thinking about long-term disability (LTD). Social workers can help clients assess whether they should apply for LTD. Social workers should also be able to provide information on government disability plans and help clients sort through any requirements or restrictions on private company plans, if they have one.

In assessing whether people should apply for LTD, consider the following:

- will the person's health improve? Is there a chance that, with treatments, the client will overcome the "disability" and be able to work? This is particularly likely with the new class of drugs, protease inhibitors, now available. If so, it may be better to wait and see how the client responds to treatment. It usually takes about three months on the drugs to determine whether a person's health will improve.
- will the client need expensive drugs? People often apply for LTD as a way to pay for their drugs. However, if possible, these needs are best met through a drug plan rather than a disability plan. The social worker should ensure that the client explores all other options before applying for LTD.

- how demanding is the job? Some workers who need to be on their feet all day (e.g., clerks, waiters) and who have limited options may apply for LTD early, while people with “desk” jobs may be able to work longer.
- how long will it take to get disability coverage? Some clients want to start early in applying for LTD because they have seen friends who didn’t apply until they could no longer work wait months to start receiving their benefits. The Canada Pension Plan tries to process applications within four months, and assumes that people will use their sick benefits from employment insurance to fill the gap. Provincial disability plans have a similar waiting period. A covering letter from a social worker can sometimes speed the process. Some social workers cultivate a strong working relationship with income security offices (e.g., attending meetings, offering on-going training) and this can help their clients get faster service.

Practice Issue

Employment Insurance Sick Benefits vs Long Term Disability

A client diagnosed with HIV in the emergency department started drinking and using drugs to cope and decided on his own to apply for long-term disability. He was accepted by the Canada Pension Plan disability coverage immediately and began to receive cheques from them before his company’s six-month short-term disability plan ran out.

Four months later, when he had his substance use under control, he realized he didn’t like being without any work activity and tried to return to work. His employer, who was worried about how to deal with AIDS in the workplace, decided it was easier just to move him on to long-term disability.

Now his HIV physicians face a dilemma because his health has improved so markedly that it’s hard for them to sign forms saying he needs long-term disability.

This is an example of how the stigma of HIV combined with too quick a decision to go on long-term disability can have an extremely harmful effect.

It often takes some time for people recently diagnosed with HIV who are ill to become medically stable. During that period, they may need regular care and treatment. But once stable, they may regain their health and then go many months or years without symptoms or illness. Once treated for an AIDS-defining conditions like *pneumocystis carinii pneumonia* (PCP), people often recover fully. Drugs that suppress the virus often lead to a marked improvement in their health.

Given that, social workers should seriously consider using temporary measures, such as Employment Insurance Sick Benefits, that offer short-term income stability. By going directly to long-term disability, people may risk:

- closing off their options when they would prefer to continue working (and see work as a way to enhance their lives and self esteem, avoid boredom and have financial security) rather than “spending themselves into poverty”
- losing a position they value because their HIV status becomes known or the job is given to someone else
- complications with their insurance (if they have recovered when it is time to submit the forms, there may not be enough evidence to support their claim).

With the steady improvements in treatment, it’s important for social workers to talk about different options. It can be difficult to persuade clients who are ill and who see long-term disability as a quick and easy solution to their problem, but it’s best to present all the options.

Information to Include on the Application

Social workers may help clients complete application forms for disability insurance. To show that the person qualifies for disability coverage, it's a good idea to:

- answer questions about physical abilities (e.g., walking, standing, concentration, memory) with concrete examples that describe the problem in a measurable way over time. For example:

For the last six months, I can't walk more than two blocks without pausing to catch my breath.

For the past year, I have been forgetting the phone numbers of our best customers. I also forget requests for service and have to be reminded.

- make the link between the physical problem and work or social performance. For example:

I no longer look forward to greeting or serving new customers, and I mix up their orders.

- indicate how much work time has been lost in the previous year either to hospitalizations and visits to doctors/treatment centres/laboratories or any physical symptoms that interrupt work patterns:

During the last year, I have missed six weeks of work because of being hospitalized, and approximately half a day to a day each week to attend medical appointments. Because of recurring nausea or diarrhoea, I am often forced to disrupt my regular work several times each day.

- in marginal applications, solicit input from other professionals, such as psychiatrists, addictions therapists and occupational therapists, who may have finer tools to assess how the person's physical/mental condition inhibits his/her performance at work.

- is the need medical or economic? With the changes occurring in the job market, some clients may be laid off and find it difficult to find new employment. They may see LTD as a way to deal with both socio-economic and health pressures. Social workers should be knowledgeable about job retraining options through student loan and Canada Human Resources development programs. It is also helpful to know that private insurance companies are developing their capacity to offer vocational assessment and placement programs, and to help people make the transition to a job they can handle. People may leave their old company and start on LTD, then be retrained and re-enter the job market. The Canada Pension Plan also offers a three-month trial work period, where CPP benefits continue while the person starts a new job. By the fourth month, benefits cease but the file is kept open and, if necessary, the person can easily be transferred back onto CPP disability benefits without going through the application process again.

Avoid applying too early and having the application refused, which makes clients feel that LTD programs are inaccessible when they are needed. Careful timing of applications also ensures that the system is not bogged down with inappropriate requests and unable to deal with priority applications.

People with addictions problems, who may find it easier to cope with disability insurance than with the job market and their work performance issues, may want to apply early for LTD. In these cases, social workers should ensure clients know the LTD program limits or criteria as well as alternative income/job approaches, so that they have the facts and avoid frustration.

Exploring Opportunities for Job Redesign

Social workers should help clients explore opportunities for job redesign before they decide that LTD is their only option. Clients should be encouraged to talk to their employers about possible changes to their work hours or job responsibilities. Some people have been able to negotiate a job redesign without disclosing their

diagnosis. In general, companies are more willing to look at options, and this gives people with HIV the opportunity to continue working as long as possible.

Applying for Other Support Services

Some people with HIV who are well enough to work may choose to do something else with their time. For example, women with children may want to stay home and spend as much time as possible with their children. A woman who had been a sex trade worker since her teens and has no job market experience or social skills may not be able to find a good job. People in these situations may not qualify for LTD, but it may be possible to make a case for them to receive more generous income benefits or access to support programs.

Starting a Long-Term Disability Application

Social workers should ensure that clients understand the steps in and the consequences of making a LTD claim, including:

- how to obtain employee LTD information booklets and forms. Some people are reluctant to ask for information for fear it will jeopardize their job or their confidentiality. To avoid drawing attention to themselves or raising suspicions, some clients simply explain that they are doing some long-term financial planning and need to review the details of the company plan. Sometimes, clients can get forms through the union or directly from the insurance company.

Practical Advice in Completing Disability Applications

Criteria for Disability Coverage

To assess applications, most long-term disability plans use a variation on the Karnofsky Scale of Impairment, which introduces the concepts of mild, moderate and severe impairment, and includes physical and mental factors. Although the definitions used by each plan will vary, the basic concepts are as follows:

- mild impairment: some limitations to physical capacities but able to perform
- moderate impairment: can perform sedentary activities that do not require constant physical exertion
- severe impairment: cannot perform even at sedentary level.

- how to complete forms. Most forms are divided into three sections to be completed by the employer, employee and physician, respectively. If employers complete their part first, they will never see the part dealing with the diagnosis. Some employers want the forms to go through them to the insurance company. This is not necessary, and insurance companies usually understand the need for confidentiality and will accept forms sent directly to them. They will then inform the employer of their decision, but not reveal any confidential information about the employee.

- how the person will spend time after work. This is perhaps the most important question for the client (see section on Life After Work). Some people gradually get drawn back into work or into volunteering regularly. Clients must be aware that any paid work — if not prearranged as part of their LTD — could jeopardize their disability benefits. However, the Canada Pension Plan has recently changed its rules and no longer penalizes people for being involved in structured volunteer activities.
- how the person will react to not working. Clients will have emotional/spiritual issues about leaving work, and may experience sadness, regret, guilt and relief. Some may want to put some closure on that part of their lives, with some sort of

good-bye function with co-workers. Others just leave. Most people need an opportunity to work through these feelings.

In helping clients apply for LTD, social workers should explore their ability to function at work and at home.

Many disability plans will also look at the client's personal capacity, including:

- his/her ability to earn at least what LTD pays — particularly if the plan allows for part-time work. Applicants will often be accepted in the hope that they will continue to work part-time and the plan will “top up” their earnings. On the other hand, low income earners may actually receive more on government LTD programs than they did working. If this is the only reason they apply, they will be turned down — unless there are mitigating circumstances, such as the need for expensive HIV-related drugs.
- pre-existing mental health conditions — people with pre-existing conditions, such as chronic depression, anxiety disorders and schizophrenia, may not qualify for LTD if they apply solely based on those conditions. However, if they also have physical problems that the LTD would help resolve, their application is more likely to succeed (e.g., being on LTD will help ensure that a client has more stable income and housing, which will help the person comply with safer sex behaviours — someone with a personality disorder may be less likely to sell sex on the street if she or he has access to reasonable funds). Arranging for LTD may be the best way to stabilize accommodation, food and drug needs and to create a base from which to work on the person's other issues.

INSURANCE POLICIES AS A SOURCE OF FUNDS

Social workers may be able to help clients take advantage of “living benefits” offered by insurance companies. Many companies will pay out a certain percentage (often 50% up to a certain limit) of the value of the insurance policy to a policy holder who has only 12 to 24 months to live. This option usually appeals most to clients who have no dependents relying on the proceeds of life insurance after their death. The amount available depends on the payout amount of the policy, limits set by the company and often a budget the client submits with his/her application.

A man with HIV was in arrears on his child support payments. When he went on long-term disability, the Maintenance Enforcement program garnisheed his CPP benefits (which left him with less money to live on) and put a great deal of pressure on him to pay his arrears. The social worker was able to help him negotiate living benefits from his insurance company, which would cover all his arrears as well as his ongoing responsibilities. To satisfy the Maintenance Enforcement authorities, the client had to have a lawyer draft a letter guaranteeing that the Maintenance Enforcement program would be the permanent beneficiary of the policy.

Experience indicates that people who are strong advocates in their own right or who have someone to advocate on their behalf can often get a substantial portion of the value of their policy. To receive living benefits, the client will have to provide a medical report that describes his or her condition and the physician's belief that he/she has <12 to 24 months to live.

When insurance companies do not offer living benefits or are willing to pay out only a small amount (e.g., a maximum of \$25,000 regardless of the value of the policy), clients may choose to deal with viatical settlement companies. These are private companies that “purchase” people’s insurance policies at a discount (e.g., 60 per cent of their value) and then collect the full value of the policy when the person dies.

Viatical settlement companies cannot operate legally in many Canadian provinces, but clients may be willing to go to the United States or deal with an illegal company here in order to get some money. In these cases, social workers can help by ensuring the person gets some legal advice and negotiates the best possible arrangement. Clients should also be aware that, when they make an arrangement with an insurance company for living benefits, their files are kept confidential and they will never be bothered by the company. On the other hand, they cannot be sure that viatical settlement companies will keep their information confidential. They may have to “shop” their files around to find “investors”, and clients may receive regular phone calls from these companies checking on the person’s health and their “investment.”

In Canadian society, it is a generally held value that people should not “profit” from another’s death, so there has been less support for or development of viatical settlement companies. More jurisdictions in the United States are now regulating viatical settlement companies, which should provide some protection for consumers, but it is still a case of “buyer beware.”

LIFE AFTER WORK

It is not easy to be young, gifted and retired. Clients who stop working need to find other satisfying ways to use their talents and skills. Social workers can play a significant role helping people make the transition, find meaning in life after work and identify interests, skills and options for the future. They can also help prepare clients to step outside the normal life stage and find a way to explain to others why they are no longer working, particularly if they look well.

People with HIV will continue to need some structure, goals and contacts with others once they have left work. The change in their lives can be an opportunity to examine or rediscover a part of their life, their place within their support system and the contributions they can make to the lives of others.

A significant percentage of people living with HIV end up volunteering in something related to HIV, such as advocacy or volunteer work, peer counselling or community education. This can give people a sense of control and meaning, and improve their self-esteem.

Others choose to do something quite unrelated to HIV, and social workers should also affirm that decision. People may feel pressured to become part of the “cause,” and they may need support when they choose to spend their time and energy in other ways.

As people get sicker, they will be able to do less for themselves, and they will become more dependent on others. For most people, this will be very difficult. They will struggle with their loss of independence and look for ways to maintain some control in their lives. If they are living alone, they may begin to question whether they can continue to manage independently and start exploring their options.

Home Care

Clients may need some help getting access to home-based care, which can include a range of different services, such as health surveillance, home supports (i.e., help with heavy or difficult chores like vacuuming or washing) and in-home nursing care. Social workers can ensure that clients know who can authorize this kind of care (varies depending on the community or province), its cost (usually minimal), and its purpose and limitations.

Going Home

As clients' health deteriorates, they may consider going home to parents or other family members for care. The social worker can help the client work through this decision by asking about the client's expectations of how he/she will be received. Often the expectations can be extremely high (e.g., acceptance, welcoming back to the fold, no fear of HIV/AIDS) and may be very different from reality. The social worker can then explore possible reactions that would be "good enough." For example, some fathers have always responded to their children's problems by giving money and are reluctant to discuss the issues. Would that kind of response be okay? Other parents will talk about the situation briefly and then move on; they will be there, but they aren't going to talk about it. Can the client cope with that?

Social workers can suggest that parents and family members may need time to process the information and realize what they are being asked to do. Instead of making a sudden and final decision to move home, clients should begin to think and plan early. They could consider some options:

- writing ahead of time so people know what is happening and can respond more openly
- spending quality time with their families before they become ill
- making a visit home to get a feel for the situation and see whether the community has services the client may need and want, including:
 - physicians knowledgeable about HIV
 - a home care program
 - a way to finance drug costs
 - an AIDS service organization with supports such as buddies and caregivers.

If the community doesn't have these services, the client then has to consider the trade offs between good professional care and close family care

When a client discloses his/her illness to the family and makes a visit home, this often leads in turn to a visit from parents and/or siblings who want to:

- become knowledgeable about the disease process
- determine what supports the person has — particularly those that substitute for family
- resolve issues so that the family and the person are at peace with one another.

Living Somewhere Else

Based on this trial experience with their families, some people decide not to go home and burden their family with their care. In that case, clients are assuming that they will continue to have regular contact with critical caregivers, such as the social worker and home care nurse. A professional's willingness to assume this role contributes to the client's safety and comfort, and makes it easier for families to provide care from a distance. The social worker can also help the client develop a workable way to get the close family contact they may need. They can decide:

- how often will I be in touch with my family?
- when will/can I ask someone to visit from home?
- when I am dying, do I want family nearby?

Social workers can also help the person find appropriate care in other settings, such as a long-term care facility or some other form of supportive housing.

SUPPORTING FAMILY CAREGIVERS

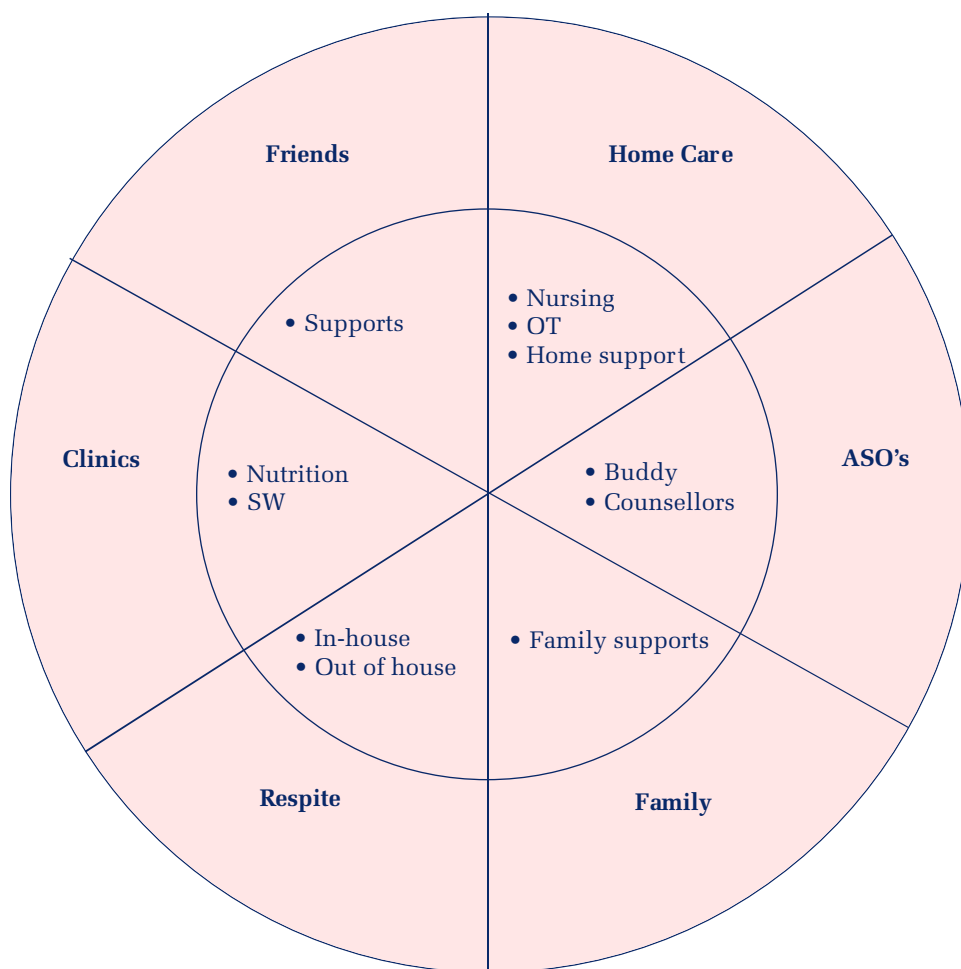
Often family caregivers come back into the person's life well into the disease process, when they have little time to adjust to the person's dying and they don't know enough to be able to help the person manage or cope.

In these situations, social workers can help by offering family caregivers the time to come to terms with the situation, much as they did with the person with HIV during the crisis period of diagnosis. They should also make sure family caregivers are aware of services, such as home care and its ancillary services, including housekeeping services, meals on wheels and respite programs, and other things they can do to care for themselves.

Care Circles

In promoting care for the caregivers, social workers should reinforce that one or two people cannot do it all, 24 hours a day, seven days a week, for months on end. Instead, the social worker can introduce the concept of a care circle, in which the person with HIV, professional caregivers and family caregivers negotiate what care is needed and how to provide it. At the very least, a care circle should ensure that the main family caregivers get a few hours of respite every week and that no one becomes exhausted caring for the person with HIV. Partners and families should be aware of the range of different people they can call on for support.

When family caregivers have to be absent for several hours at a time, they can make arrangements for some practical aids around the house, such as a portable phone, that will keep the person with HIV from feeling isolated or abandoned and ensure that he or she can get help if needed. They can also develop a network or care teams, so the person does not have to be left alone.



Providing a Care Circle in Hospital

The role of family caregivers doesn't stop at the hospital door. However, many people are intimidated by the hospital environment and may back off, thinking they are imposing or interfering with the person's care. Social workers may need to encourage family caregivers to develop a hospital care circle, with a schedule of family and friend visiting teams, so one person doesn't end up shouldering all the responsibility.

Remind caregivers that:

- short visits are better than long visits
- the person with HIV may not have the energy to tell you his or her state of health or the results of recent tests
- often, the person would prefer to hear a brief description of the visitor's day or thoughts, or hear about events outside in the world
- when people are particularly weak, it is often enough to sit quietly or read to them to keep them company.

Conflict Between Family of Origin and Family of Choice

Some gay men have been able to be open with their families about their sexual orientation and their HIV status and have maintained or developed a good relationship with them. Others have unresolved family issues. In these cases, families of origin may have problems accepting their gay son, his partner and his family of choice, and HIV may aggravates the situation. There may be conflict between the two families.

When decisions have to be made — particularly if the person with HIV is no longer competent — the family of origin and the family of choice may compete with each other to make the “best” decision, or the family of origin may use its legal and biological relationship with the person to keep the family of choice from being involved.

Social workers can mediate between the two families and work with the person with HIV, early in the illness, to develop the legal documents that will allow the people chosen to be involved in care or decision-making.

If the family can't visit very often or if the person is isolated or alone, many AIDS service organizations have volunteers who will visit people with HIV in the hospital. Some families bring pictures of family members who can't be there, such as young children or elderly parents.

Fighting Isolation

Family caregivers can feel isolated and alone. To avoid this, social workers should help ensure that they have regular contact (practically speaking, at least once a month) with professional caregivers. This might simply mean a short phone call. The social worker can also ensure that the family care circle has secured the services of a family physician. As the person's health deteriorates, this is critical because many hospitals will no longer admit people who are dying, and the family may need the help of a physician, who will make

home visits or be available by phone to provide advice and guidance. In choosing a physician, the person with HIV and the family caregivers should be clear on the services the physician will offer. Is he/she available on call? Is there a back-up service available? Who will answer back-up calls?

Normalizing the Crisis Experience

After times of crisis — such as sudden hospitalization, a seeming lack of response to treatment, or waiting for death to occur — family caregivers often describe themselves as having been “out of control,” “not kind,” “off the wall,” or “critical

and demanding of professional caregivers.” It may help to tell them ahead of time about these possible reactions and that they are understandable, expected and normal. If caregivers do react this way, they may need reassurance afterwards that the social worker or other professional still respects them and doesn’t think any less of them for their reaction to a crisis.

Conflict Among Caregivers

Wilhem is a gay man with HIV who has been in a long-term relationship. Wilhem had been alienated from his family for many years. When he was first diagnosed, he turned to his partner for all his support. As his health began to deteriorate, he began to re-establish contact with his family. After their initial shock, the family members adjusted to the situation and became an active part of his care circle. Perhaps a bit too active. As Wilhem became weaker, they became more forceful. Often several family members would visit at the same time, arguing over his care, and failing to listen to either Wilhem or his partner. What would you do? How should a social worker help to advocate for the person with HIV, and help the family provide the care and support he needs?

A pastoral counsellor faced with this situation established a ritual that everyone agreed to respect. When the family came to visit, he would attend and listen to the conversation. If it appeared that Wilhem was not being given a chance to direct his own care, the counsellor would light a candle. While the candle was burning, everyone had to listen to Wilhem. He was the only one allowed to initiate conversations. The others could only answer. The ritual gradually taught the family to listen and to be aware of the role Wilhem wanted to play and the one he wanted his partner to play in his life and care.

Using Employment Insurance Sick Leave to Help the Overburdened Caregiver

Even with a strong care circle, primary family caregivers may become overburdened, particularly when they are also trying to maintain a job. When social workers see a crisis developing, they can explore with the physician whether he/she is willing to sign forms that will give the family member three to four weeks of “sick leave” due to stress, which will give the person access to sick leave benefits available through the employment insurance system. If the family caregiver can cope with the waiting period to get the leave approved and the drop in earnings, this can be a supportive option. Some private company plans also provide for family leave or sick leave.

Dealing with Fear of Infection

As families begin to care for someone whose health is deteriorating and are dealing with blood, urine and feces, they may become

anxious about the risk of infection. Their fear can be a block to care. To overcome it, they need clear, practical information on universal precautions.

Dying at Home

A growing number of people with HIV are choosing to die at home. When a client wishes to die at home, the social worker can help the family find volunteers and other financial resources to support the care team. The social worker should also ensure that the family is aware about hospice and palliative care programs that will provide support for people dying at home, or will play a more active role if the family can no longer manage.

WHEN CLIENTS HAVE DEMENTIA

Many people with HIV will, at some time, become aware of a change in their cognitive abilities. Most will experience minor cognitive dysfunction, but some will progress to dementia. In some cases, the dementia is the result of the virus at work in the brain. In others, the loss in memory and/or cognitive abilities is associated with certain opportunistic infections.

For some people, cognitive disorders or dementia is their first AIDS-defining illness. From infection, the virus is active in the cerebral cortex. At first, its effect on the brain is imperceptible. By the time many people with HIV are ready to stop working and are completing their applications for disability, they will be aware of some loss of concentration and memory. Many describe it as taking longer to process and being less able to conceptualize. They become less able to “lay down new memory tracts” but they will often maintain their historical memory. The signs and effects are very similar to Alzheimer’s Disease.

Dementia and Antiretrovirals

Some clients reject treatment with antiretrovirals as being “too toxic.” However, they may be willing to reconsider their earlier decision when they learn that antiretrovirals can have a beneficial effect on the symptoms of dementia. Social workers should help clients get accurate information on the impact of different treatments on dementia.

People with dementia may also experience a sense of lethargy. They may begin to withdraw socially, which can be disconcerting to themselves and to their partners, family and friends. Contrary to many commonly held beliefs, people with dementia do not necessarily rave or become psychotic.

Dementia symptoms may be more marked in people who made excessive use of alcohol or drugs, had a pre-existing psychiatric illness, or had certain HIV-related infections, such as toxoplasmosis. They may develop cognitive and motor disorders, and deteriorate rapidly.

Finding practical ways to cope

Philippe is an 18-year-old with hemophilia and HIV. About six months ago, his behaviour started to become erratic. His grades began to fall, and he seemed to have trouble remembering things. He is frustrated, and has become uncommunicative. Concerned about his behaviour, his parents encouraged him to talk to his doctor, who diagnosed the early stages of HIV-associated cognitive/motor disorder.

Since the diagnosis, Philippe’s cognitive skills have continued to deteriorate. His speech is slower, he is forgetful and he often has trouble finding the right words. He is extremely angry, and has begun to act out. He has had two minor car accidents and has been verbally abusive to his mother. He is being treated by a psychiatrist, who referred the family to a social worker for practical support. What do you do?

With a client with dementia, the social worker can normalize the experience for the person and those close to him or her, and help them develop coping mechanisms.

Practical ways for people with HIV to cope with the early stages of dementia:

The Impact of Dementia and Other Neurological Problems on Caregivers

Caring for someone who develops dementia is not easy. Social workers should talk to family caregivers about the problems and symptoms that may develop with dementia, so they are prepared. The social worker should advise family caregivers to seek help immediately if the person with HIV develops severe behaviour problems, or begins to act out or be violent or abusive. Partners and family may be inclined to make allowances for the person and “put up with it” — perhaps because of fear or stigma or not knowing what else to do. A psychiatrist can assess the person’s needs and, if appropriate, prescribe anti-psychotic medications that will help the person manage these symptoms. Family members caring for someone with dementia at home will also need access to respite care, so they can have breaks and care for themselves.

An aboriginal man with AIDS developed dementia and became delusional. Convinced that he had won a \$2 million lottery, he went on a spending spree. His family — in this case, his sisters, were left to cope. They contacted a social worker at the local aboriginal AIDS organization who was familiar with the man and his family. What would you do?

In this case, the social worker acted as an advocate for the family. She found things the man had bought and returned them, and then talked to the merchants, and helped the family work things out. They developed a system to help him manage money, and to ensure the same thing could not happen again. It is important to know the soft and hard options around trusteeship. For banking matters, banks will provide power of attorney forms. Many income programs, including CPP, have forms that will allow third parties to deposit cheques. It may be more difficult to arrange formal trusteeship. The social worker also contacted the man’s physician to discuss his condition, and he eventually ended up on medication that helped relieve some behavioural symptoms.

- write down appointments on an easily accessible calendar — either wallet-size or a wall calendar (social workers can keep a supply of give-away calendars from book stores, banks or health organizations in their desk, so they can hand one to the client)
- find friendly ways to remind the person of things that might be forgotten
- teach clients and caregivers about pacing — clients may no longer be able to cope with too many events or responsibilities in a day, and may be better able to manage a calmer schedule; “one step at a time” may become “one event per day”
- establish a barrier-free residence — for some people, this may mean moving home or finding a place that has easy access (e.g., few stairs, public transit, grocery and drug stores nearby) — a place where the person feels at home, where things have a fixed place and the environment is easier to manage, even for someone who is becoming forgetful.

If the person lives alone:

- find someone to help with the cooking or other chores
- develop a buddy system where the buddy checks in regularly with the person with dementia.

Social workers can also help by talking to the person about giving up driving and/or his license, so he doesn’t endanger himself or others.

Support for People with Severe Cognitive/ Motor Problems

At the stage when people develop severe cognitive and motor problems, it is critical for social workers to ensure that there is a strong care plan and a satisfactory legal/medical plan in place. The care plan may include:

- having the person with HIV move to a 24-hour community care facility
- ensuring the home environment is supportive enough to protect the person.

For example, the person may need a medic-alert bracelet with an emergency phone number inscribed or a “neighbourhood watch” plan to help ensure he/she doesn’t wander off or get lost.

Part of the social workers’ job may be to lobby in their communities for supportive facilities for people with severe HIV dementia. In trying to find appropriate places for people with HIV dementia to live and receive care, social workers may come face to face with rigid attitudes and rules, as well as prejudice and discrimination. Many people still assume that young people don’t get dementia. Many long-term care facilities that have the knowledge and expertise to care for people with dementia are designed specifically to deal with older patients. They may have age restrictions, they may be apprehensive about dealing with someone with HIV, they may not have appropriately trained staff, they may be concerned about their ability to cope with younger and stronger patients, or they may be homophobic or AIDS-phobic.

For long-term care facilities, the cost of providing drugs may be a barrier to admitting people with HIV. Social workers may have to advocate with their provincial governments to increase drug funding for facilities that take people with HIV. They can also work with long-term care facilities to provide education and staff training that might make it easier for the facilities to manage clients with HIV.

Working with Other Mental Health Professionals

Some people with severe cognitive problems will need to be assessed by a psychiatric/mental health team, to determine how serious the condition is and to develop a mental/physical/social plan. Many will also benefit from other psychiatric interventions. Because of this, social workers should be prepared to work with other mental health professionals, such as psychiatrists and neurologists, and to refer clients when appropriate.

GETTING AFFAIRS IN ORDER

Gary and Jim were a gay couple who had a long-term relationship. When Gary was diagnosed with HIV, Jim cared for him. The couple was together until the end. During the last few months, Gary talked about what he wanted for himself at the end. He told Jim that he didn’t want any heroic measures. When he was no longer able to breathe on his own, he did not want to go on a respirator. He talked about the kind of memorial service he wanted, and who he wanted to come. And when he died, he wanted Jim to have what few assets he had, including the proceeds from a life insurance policy, some savings and his car. Although they planned for the end, Gary never wrote anything down.

When he did become seriously ill, his family suddenly re-entered his life. When Jim tried to explain Gary's wishes, they wouldn't listen. Gary's mother insisted on life saving measures which, in the end, were unsuccessful. When Gary died, the family took the body home and organized the funeral themselves. Jim was not invited. Because Gary died with no will, all his assets eventually went to his parents, even the proceeds from his life insurance. (When Gary had first taken out the policy, he had not wanted to disclose that he was gay, so he had listed his mother as his beneficiary.) In the end, Jim had to get a lawyer to stop the family from taking things from the couple's home that actually belonged to him.

Although everyone should have a will and an estate plan, many people avoid preparing them until some life event — such as marriage, the birth of a child or the death of someone close to them — makes them more aware of their mortality. A diagnosis with a life-threatening illness, such as HIV, may push some people to put their affairs in order. Others may avoid it, just as they avoid dealing with the diagnosis. Some may feel they have so few assets that there is no point in preparing a will.

That is not the case. Even those who don't have a lot of assets may want to have some say over how they will be cared for and how their affairs will be handled. When people die without a will, the events around their death or funeral may not unfold as they would have liked.

Social workers can help clients understand that wills, powers of attorneys, advanced medical directives and other parts of an estate plan can help give them control over their lives. For many, thinking through what they do want for themselves and others can be an affirming experience, and it is often best done early in the disease process, when the person is well. However, in fact, estate planning usually takes on more urgency as the person becomes sicker. As death becomes more imminent, he or she may then be ready to develop a plan or to revisit plans made earlier.

Having a plan is particularly important for those who develop dementia or become so sick they can no longer direct their own care. There are three main steps in estate planning:

- a “living will”
- a power of attorney or trusteeship to look after legal and financial matters
- a will.

It is critical to see each step as a process that people go through, rather than simply a document they sign. Each involves thought and communication, and a gradual understanding of what is possible and desirable.

The **Living Will** tells health care providers about the kind of health care that the person does and does not want, and it appoints someone to make care decisions when the person is no longer able to speak for him/herself — a substitute decision maker. In some provinces, these are now called “advanced medical directives” and

are legally binding. Even when they aren't, just having the person with HIV, the caregivers and a substitute decision maker talk about, plan and guide the person's care together is extremely helpful.

Deciding When to Stop Aggressive Treatment: The Role of the Social Worker in the Doctor/Patient Relationship

Many people have a long-standing, trusting and hopeful relationship with their physicians, which is built on problem solving and healing. Dealing with less hopeful issues — such as the end of life, living wills and dying with dignity — can cause tension for both the person and the physician. The social worker can support the patient/physician relationship by being the critical third party of trust who can introduce the subject of dying to the patient and begin to talk about palliative care. The patient can then “give permission” to the physician to consider when the efforts to heal and prolong life should stop. Social workers can also talk to people about quality of life issues, give them materials to read, help them prepare for the discussion with their physician, and give them a framework for thinking through their choices and wishes.

Usually the discussion with the physician goes well — particularly when the patient is prepared — and both parties feel relieved and believe they share a mutual understanding of what will lie ahead. However, if the discussion does not go well, the patient may look at other options, such as choosing another physician or finding other ways to broach the issues. When the patient doesn't have the energy to deal with a “hassle,” the social worker could help him or her consider other options.

People who are struggling with their fear of dying often find that working through the process of deciding the kind of care they want brings them great peace of mind. It can also bring greater peace of mind to other informal caregivers, who are relieved that some decisions have been made.

Social workers should encourage clients to begin this process by talking to:

- a family physician who has known the person over a period of time
- the decision maker who will consult with the family physician and other doctors and medical staff if/when required.

To do this, the person should book a “counselling” appointment with his/her family doctor — so they can have a thorough and unhurried discussion. Together they talk about critical questions and issues. How does the person define quality of life? What are the person's goals in the midst of having HIV disease? How do they want to live with the illness?

This process allows the person and the doctor to decide together on some principles they can use to guide medical decisions when certain events occur. Because of the unpredictability of HIV infection, it is unlikely that a detailed living will will be able to anticipate every possible event. It is usually better for everyone involved to have a general understanding of what the person values and wants, rather than a long, complex, detailed document that cannot possibly cover everything.

The living will may be a handwritten document, signed by the person and the

physician, or it may be a formal document. Some jurisdictions have specific legal requirements for advance directives and living wills, and social workers should be familiar with them. The person and physician should review the person's wishes and any signed documents once each year and again when the person's health deteriorates to the point that it is time to implement the plan. Social workers should reassure people with HIV that they can change their minds and advance directives whenever they want. The purpose is to respect the patient's wishes and do what he/she truly wants. To help the people around them know what they want, people with HIV should talk openly about their wishes. The more people who know, the more likely the person will receive the kind of care he or she wants.

An **Enduring Power of Attorney** is a signed, legal document that gives someone the right to look after a person's financial affairs when that person is no longer of sound mind and unable to make his/her own decisions. They are usually done as a matter of course, when people prepare their wills. Like the living will, an enduring power of attorney is particularly important when people have an illness, like HIV, that may lead to dementia or long periods of time when the person is unable to manage his/her own affairs. Social workers should encourage the person with HIV to talk to the person given power of attorney over their affairs. As with the living will, the person with power of attorney needs to understand what the person with HIV values so he/she can, as far as possible, manage the person's affairs appropriately.

A **Will** is a signed, legal document that states clearly what people want done with their assets when they die. It is also the means by which people appoint guardians for under age children or other dependents. (See the section on future planning for children.)

Technically people can do their own wills, so social workers should have a working knowledge of what the law requires in their province. For example, some require that a will not done by a lawyer be "written by hand" and there may be certain rules that must be followed to have the will properly witnessed. Depending on the situation, it is often a good idea to involve a lawyer and ensure the document is legally binding, particularly if the person does have any assets, or there's likely to be any dispute over the person's decision.

Paying for the Will

Some people with HIV may not be able to afford the legal fees for a will. Several AIDS service organizations have arranged for lawyers to donate the time to do wills for people with HIV, and some legal clinics will also provide this service. It may take a few phone calls, but the social worker should be able to find someone who can help.

Again, preparing a will is a process. It may be the means by which the person comes to terms with various people in his/her life. While a lawyer will look after the legal aspects, and can help guide the person through the choices and decisions, a social worker can often play a useful role in helping people resolve any anger

or resentment they may feel toward people in their lives. Sometimes people may use their will to "get even," which can be very destructive for the person and those left behind. Social workers may be able to help people work through their anger and focus on the will as a way of saying "good bye" and "thank you" to people who have been important in their lives. Even those who have few possessions can leave small things in their wills to people, or include a mention of partners and friends and what they have meant in their lives. This part of preparing the will will likely have more meaning for the person and for those left behind, and will bring a sense of peace.

Future Planning for Children

After we found out we were infected with HIV, one of our first thoughts was — what will happen to our children? What if we become ill? Who will take care of them”

When Children Are Older ...

Isabel is a single mother with HIV. She has an eight-year-old son and a 14-year-old daughter. Her health has started to deteriorate, and she is beginning to make plans for their future. She has talked to several people about being guardians for her children, and is trying to decide who will be best. Her daughter is aware of the process her mother is going through, and resents the fact that she has not been consulted. She tends to look after her brother and tries to fill her mother's role when she is ill. Although she appears to be in control, she feels very vulnerable and as though her life is out of her control. Her mother has noticed that her daughter seems more distant and tends to be angry whenever they go to visit the family the mother thinks may be the guardian. But she feels her daughter is too young to make the decision about her guardian.

What can you do?

The social worker can:

- work with the mother to encourage her to listen to her daughter — adolescents need to have their say — and talk about the choices for a guardian and ask her daughter's advice
- reassure her that she doesn't necessarily have to do exactly what her daughter wants, but she should be willing to listen
- encourage her to talk to her daughter about her hopes for her future
- suggest that she spend some time watching her daughter interact with the different people she is considering before making a decision
- be available to talk and listen to the daughter
- see if there is anyone else in a similar situation that the daughter can talk to.

People with HIV who have young children must face the painful process of planning for their future. It is one of the hardest things for parents to do, and many will avoid doing it as long as possible. However, those who work with parents and families with HIV report that many experience great peace of mind and a sense of release when they finally face the issue of choosing a guardian and thinking about what they want for their children.

Social workers can work with parents, assessing when they are ready to discuss this difficult issue and encouraging them to plan while they are healthy, to choose a guardian, and to help their children build a relationship with the person/people who will care for them when parents are ill or die. Parents with HIV will go through a process of examining their own values and deciding what they believe is important for their children. Based on that, they start to identify potential guardians or working with child welfare agencies to find suitable caregivers.

In many cases, planning for children can become very complex. Do the parents have family or friends close by or are they all in another country? Will the children be able to stay together? What happens when parents become ill — can they make temporary arrangements to have their children cared for? If they don't have family or friends to help out, can the children be taken into temporary foster care? What if one or more children are also infected? What resources are available to help parents? How can parents help their children develop a relationship with their guardian and make it easier for them to deal with their parents' death? How much do children need to know?

Each situation is different, but social workers can help families work through their hopes for their children, their sorrow over “losing” them and their plans. They can refer them to child welfare agencies. They can also encourage parents to talk to the guardians about what they wish for their children and prepare a journal or other “gift” — pictures, letters or stories — that they can leave for their children.

Planning the Funeral or Memorial Service

As people with HIV live longer in good health, they often look for ways to mark the passages in life, such as birthdays (their own and others), anniversaries, retirement parties and any other reason to celebrate.

Many people with HIV get a great deal of satisfaction out of planning their funeral or memorial services. For some it is a way of continuing to have some control over their lives. For others, it's part of the process of coming to terms with their fear of death. For some, it provides an easy way to talk to people about their dying.

People usually choose the type of memorial they want — whether it is in a church or elsewhere. Some decide to have a party, rather than a service. Funeral homes can be non-denominational and churches will do memorial services without religious overtones.

For some people, the process of planning a funeral can remind them of painful times in their lives when they felt rejected by their church or religion. They faced rejection in the past, loneliness in the present and fear of recrimination in the future. Depending on their past experiences, they may not be able to turn to their church for help in planning a funeral. Instead, they may turn to the social worker. Some social workers and AIDS service organizations are developing links with pastoral care workers, students or associations in their community to help with funeral planning and life reflections.

Social workers can help people:

- decide what kind of memorial service is appropriate for them
- choose a master of ceremonies
- choose one or more people to talk or give a eulogy
- select the music
- choose a place to have the service, which feels right to them and represents something of their lives, such as a community centre
- discuss the plans with other family members to avoid conflicts after death.

Planning for their death usually brings people face to face with how they have lived their lives. Some people may honour social workers by talking to them about their lives, their accomplishments and their regrets. They may also want to talk about their thoughts of an after life. It is crucial that social workers not be afraid of these discussions or close them off by suggesting that “someone else” might be better able to talk to them about spiritual beliefs. Social workers' own beliefs — or lack of them — should not hinder other people from exploring their own thoughts and ideas. At the same time, social workers should not expect that everyone will invite them into these kinds of discussions.

Resources

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- Living with HIV and Dementia: a Guide for the Extended Family*. Canadian Psychiatric Association, 200-237 Argyle, Ottawa, On K2P 1B8; phone: 613-234-2815; fax: 613-234-9857; available also from National AIDS Clearinghouse)
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5 DYING, GRIEF AND BEREAVEMENT

AIDS, like other fatal diseases, is about aloneness — aloneness now and the fear of an eternity of aloneness. We must confront this fact unblinkingly.

Accompanying a Client on the Journey

With the exception of those who work in hospital and palliative care settings, most social workers do not have a lot of experience in helping clients through the process of dying. HIV has changed that.

He had come to the conclusion that he was going to die. OK. So now he's preparing his family. So what is happening is that everybody is lagging behind in that belief. He's already talking about his funeral and you don't want to talk about any such thing. So you kind of accept these things and work away and grind away and it's a kind of sanding process. You work at it and finally you accept the fact that he's preparing for his funeral. And you say, OK, that is what he wants to do, that's what we will do. If he's going to face his future, then we better get with him and face the future so that he's not alone.

Every person who is dying will approach the last stages differently. As helpful as Kubler Ross's four stages of death and dying are, not everyone will follow that journey. Some choose to "rage" literally or chemically. Some fight to the last breath and seek out every possible treatment. Some set limits around what they will do, and try to protect their independence and their sense of quality of life. Some may consider ending their lives at a certain time, so they can have some control over both life and death.

During the last stages of the disease, control usually becomes very important to people with HIV. They seek to keep or regain control over their lives and to direct the roles that others will play. Face to face with fear (of the unknown, of the unpredictability of dying, of physical deterioration), the reality of their losses and a growing sense of aloneness and isolation, people with HIV may focus on the real essence of who and what they are and what it is that gives meaning to their lives. They may revisit some of the questions they asked when they were first diagnosed.

At this point, the client will be:

- recognizing the significant advance in the disease and responding emotionally to a sense of loss
- coming to grips with loss of mobility and independence
- experiencing conflicting emotions — planning for the end of life and, at the same time, holding onto dreams and fighting for life
- making decisions about treatment or end of treatment and entering into palliative care
- identifying a primary contact person (which can lead to conflicts between natural family and others in the support system) and seeking support
- working to maintain some sense of privacy

- making decisions about quality of life and end of life.

The social worker's role is to continue to respect the client's right to make his/her own decisions on care and treatment, and on how he/she would like life to end.

This may involve a process of working through choices, including:

- where the person chooses to die — at home, in a hospice, at a hospital
- the people who will be part of the palliative care team
- the type of care the client does and does not want.

In this process, the social worker may have to work to resolve tensions between the client and others, such as members of his/her natural family and family of choice — who may favour different types of treatment. In this case, the social worker's role is to advocate for the client, who may be unable to speak clearly for him/herself.

Using system theory, the social worker can approach these complex situations by focusing on the needs of the client and engaging members of the support network in a process of working through their own issues of grief and loss, and their need to care for the client. The social worker will try to help members of the client's support network address their emotional issues, balance their grieving and stress, and identify/set priorities for responding to the client in these last days. The social worker can also be a conduit between medical personnel and the support system, helping caregivers get clear information.

EXPLORING ASSISTED SUICIDE

A client may decide that he/she wants control over his/her death and ask you for help with assisted suicide. How far should you go in supporting a client's right to self-determination? What does support entail? Is it providing information? Is it advocating for the client's right to assisted suicide? What are the legal implications? What guidance do workplace policies and the professional code of ethics provide?

It's important to get informed and try to understand all parts of the debate. What are the local laws? What are the social issues?

Social workers may begin by working through what the client really wants. Is it really assisted suicide? Is it a painless death? Is it control over the treatment? In many cases, people are not aware of their options. For example, they can choose from the four levels of care offered in most Canadian hospitals:

- all interventions
- all but mechanical interventions
- aggressive treatment but no complex diagnostics
- pain control and comfort.

The client needs to sit down with his/her primary care physician, explore these options and decide when they should be applied. The client has the right to decide when the long term gain no longer seems to justify the interventions. Clients also have the power to dictate the care they wish to receive and to receive that care if it is reasonable and feasible.

CASW Principles on Euthanasia and Assisted Suicide

1. The fundamental right of all persons to determine their own best interests. While self-determination can be compromised by the interests of the collective, a delicate balance is required between these two entities.
2. The right of all persons to participate in decisions affecting those they love, where that person is clearly unable to make critical decisions.
3. The necessity to view the issue of euthanasia in the broader context of care for persons who are dying. In our current economic milieu, with cost-cutting in our health care system, we must not incorporate the issue of patient choice in such a way that funds for palliative or chronic care are deflated.
4. The right of all persons to be provided with appropriate social, psychological and medical resources is essential at the end phase of life. The provision of these resources in a fair and equitable way ensures that people are given the opportunity to die with dignity.
5. The various positions of professional and other interest groups need to be balanced with the needs of fundamental stakeholders in this issue. The stakeholders include the ill persons themselves, their family (as defined by the ill persons) and other caregivers.

The social work profession has a long-standing role in advocacy, assisting those with little influence themselves to be understood and accepted by society.

We need to explore this issue further through community dialogue, education and research that will enhance understanding and serve to develop new social policy, which will encourage humanity, justice and tolerance of divergent views.

We are all stakeholders in a society that values death with dignity. Understanding what this means to both individuals and members of our society is our task.

Some people with HIV make this decision by stopping some drugs or by not attending specialty clinics. People who do not want to prolong their lives through repeated hospitalizations may choose not to.

Often the worst part is the fear itself. Social workers can help by giving people permission to state their fears, explore them and resolve them. Social workers should also be aware that when clients bring up the issue of assisted suicide, it may be a signal that they want to talk about related events, such as their memorial service, burial service or commemoration. They may also be concerned about who will make medical decisions on their behalf when they are no longer able to, and the social worker can help them work through decisions about power of attorney, advance directives and living wills, if they have not already done so.

Advocating for Effective Pain Control

Although the “good” death may be a myth, the ability to control or minimize pain can go a long way to making dying bearable and to allowing people to die with dignity. Social workers can play a role in advocating with doctors and nurses for effective pain control for clients who are suffering. They can help clients who are concerned about suffering endless pain become aware of the narcotics (e.g., morphine, morphones) that can help them manage both threshold and breakthrough pain.

The use of these drugs can be a big issue for many clients, who cannot think of themselves

in relation to the drugs they need to manage their symptoms. Clients may need some time to work through and accept the nature and meaning of pain (i.e., progressive disease) and overcome any stigma before they can accept the medication. Care providers cannot provide good pain management for people who

deny their condition. The use of pain killers can also be an issue for health professionals, who resist their use for fear they may lead to addiction. Health providers may also be unaware of some people's special needs. For example, people who have used drugs have developed a high tolerance for pain killers and may need significantly higher doses to receive the benefits.

Social workers can also advocate for non-medical approaches to pain control, for example, encouraging the use of physical touch as an anaesthetic and stressing the importance of intimate contact in helping people deal with pain. In addition, they can help clients be informed about the kind of pain they are likely to experience and to understand it, so they are better able to cope. At a certain point, the social worker can help develop a bridge between active and palliative care, and encourage caregivers to use aspects of palliative care that will give people relief from pain.

HELPING EXPLORE SPIRITUAL ISSUES

As people with HIV focus on the real essence of who and what they are, and what it is that gives meaning to their lives, they embark on a search for spiritual understanding and peace. For some, this spiritual journey is affected by earlier negative experiences with religion or spiritual issues, or by a disenchantment with established churches. The client may turn to the social worker for help with this journey. To support the client in this spiritual exploration, the social worker must undertake several tasks, including:

- being open to exploring spiritual issues in a professional relationship. Many social workers were trained that it is inappropriate to discuss spiritual issues because of the risk of imposing their values on their clients. However, there is a growing amount of literature that now supports including spiritual issues in social work practice.
- clarifying his or her own sense of spirituality. Spirituality is often a very personal and emotional matter for both social workers and clients. Social workers must be comfortable with their own beliefs, and prepared for clients to express strong emotions that may challenge those beliefs.
- developing some basic understanding of the client's religious beliefs or background. This is the place where clients begin their journey.
- developing a resource list of clergy or pastoral counsellors who are comfortable with issues of sexuality, grief counselling and bereavement. Social workers who are uncomfortable discussing spiritual issues in a counselling relationship should refer clients to a pastoral counsellor.
- developing a sense of comfort with activities such as prayer, meditation and ritual. Clients or family members may ask social workers to pray with them, to help them plan a memorial service or to advise them on how to meditate, and social workers should be able to respond.

SUPPORTING PARTNERS, FRIENDS AND FAMILY

Hope has different meanings for everyone involved — the person with HIV, partner, family, friends and for non-family caregivers. The person, partner, friends, family and caregivers may disagree about what will work, what will be done and when enough is enough.

They will also be dealing with different grief issues. The table, taken from *Module 4: Palliative Care*, summarizes some of the issues. (See Appendix III.)

As the person is dying, everyone around him or her will struggle with detachment. Some will be more ready than others to let the person go, and a social worker or other objective “third party” caregiver can play a significant role as an observer,

giving voice to the experience, helping to clarify reality and acting as a go between when there are conflicts.

When there is a care team, the social worker can play a key role in facilitating the team. Social workers know how to work with a system of people, and they can help team members interact on different levels to the benefit of the person who is dying.

Dealing with Caregivers’ Emotions

I have to be careful about what I say where. People will think less of me if I reveal my frustration and despair. I just want it to be over. When will it end? I know I will miss him, but enough is enough.

When someone with HIV is dying, family caregivers may find this a conflicted time. They may feel they have to keep up a brave front for the person. At the same time, they are beginning to acknowledge and accept in themselves that the person is dying. If the person has been ill for a long time, family caregivers may have reached the stage where they “just want it to end.” Busy comforting and supporting the

dying person, they may have no one to comfort them.

Social workers can help alleviate the conflict by identifying it, normalizing it and perhaps proposing a means of coping with it, such as respite, journaling,

Death and Culture

In some cases, social workers may have to learn enough about death and dying in the person’s culture to be able to provide support and comfort. A social worker who was helping plan an Ismaili funeral for a patient, knew that the family had kept the son’s illness from the community and wanted it to remain secret. It is common practice for members of the congregation to come to the home after dark, wrap the body and take it directly to a mourning site. The family was concerned about contagion, but the social worker learned that the fluids would be drained, and that the ceremony would happen soon after death. This helped give the family peace of mind. They were reassured that no one needed to know the cause of their son’s death, and that he could be buried as they would wish.

A social worker in an aboriginal community had a different kind of experience. In this case, the aboriginal man who died of AIDS was cremated, on the insistence of the funeral director, who said the body had to be cremated because the person had AIDS. This was extremely difficult for the community because it is not how aboriginal people grieve. Usually the body is kept at home for a period of time, and the family home is open for people to visit and support one another. The community was left with unresolved issues around this death. After the fact, the social worker learned that cremation was not necessary, and is prepared to educate families and advocate with the funeral director if there is another death from AIDS in the community.

supportive counselling or support groups. They can explore with caregivers their support network. Who provides support for them? Who can they tell about their family member's illness and death?

It's important to be sensitive to the fact that some people will postpone dealing with their own conflicted emotions until after the person has died and, for them, this may be an effective way of coping. They have to maintain an internal equilibrium, so they can cope with the major stresses. In some cities, support groups for survivors have formed and some people continue in the groups for several years after their loved one has died. Only after the person died and they finished grieving were they able to identify, acknowledge and resolve other conflicted issues.

Helping Children Deal With Death

Both parents in a family had HIV, and their seven-year-old daughter, Jennifer, was negative. The father, Tony, fell ill. Jennifer knew her father was sick and was told that both her parents had "a problem with their blood," which was why they had to be so careful about blood around the house.

As Tony became more ill, Jennifer and her mother, Louisa, would visit him in hospital. Louisa allowed the girl to take the lead and waited for her questions. When Jennifer asked a question, Louisa would answer, giving the information she thought her daughter wanted. For example, when Jennifer asked if her father was going to die, Louisa replied, "yes, I think so."

When Tony died, Jennifer attended the funeral, and Louisa continued to be available to listen and answer her questions openly. Over time, they talked about the father's death, and Louisa was able to tell Jennifer that her father had HIV and died of AIDS.

Because HIV takes so many people when they are young, it may be the first experience that children in a family have with death. In this situation, children will have real issues around the reality of pain and their own fear of pain. They have a constant need for clarity and acceptance. While adults will struggle to understand death, children will struggle to feel and accept death and dying.

Children:

- need truth and facts
- are resilient but need to see and feel stability
- interpret the world literally so will need help to understand the difference between sleep and death
- fear the unknown but have a great interest in the "afterlife" — so the situation presents for them ambiguity with finality
- need an anchor and will look to adults for reassurance.

In this situation, children may be more upset about not knowing what is happening than knowing about death. Some may not be upset at all and some may be upset for only a little while. Some may think that the person will be dead for only a short time. Others may not want to go to the funeral because that would confirm the death.

Most adults try to protect children from any knowledge of death, which reflects our society's general discomfort with death. They see it as a loss of innocence. When someone close to a young child is dying, it provides a real opportunity to educate the child about dying and death. When the person is dying of HIV, it provides an opportunity to educate about difference and stigma. A statement such as, "I'm dying. I am so sad. I never wanted this to happen. Nothing you did caused my illness. When I die, these are the people you can go to for support. I'm going to make sure you are cared for by ..." can help reassure children.

Talking with children is necessary and therapeutic, but it can be heartbreaking.

A social worker can help support parents as they nurture, support and talk to their children over time, through the process of illness, palliative care, death and bereavement.

Validating the Professional Care Team

In this highly emotional situation, members of the professional care team are also vulnerable. They will have developed a bond with the person — one that may not be adequately recognized by the family or partner, who may minimize the professional caregiver and his/her feelings. At a certain point, family may seek to exclude all those who are not family. In this situation, caregivers may question their right to grieve.

For many of us HIV represents our loss of innocence. It is our "disaster" experience — a situation in which hundreds die unexpectedly and too young. In dealing with a disaster, we have to experience the arbitrariness of it, knowing that some of it was and should have been preventable, but accept the reality that the damage has been done.

In an historical sense, we are living the same experiences of countless human generations before us. What we have some control over is how to fashion the consequences of our life experience. It can exhaust us or defeat us. We can hold it through depression or we can choose to accept it, honour it and temper it with a lightness of spirit, loving and caring more deeply for those who remain. We need to cherish each moment, abandon what is not important, and help the members of the next generation understand that they can survive the challenges that will confront them, but not escape the fundamental human reality of life, death and tragedy.

Social workers can help by affirming the caregiver's relationship to the person and his/her right to grieve and, if necessary, working with the family to try to ensure the caregiver is not excluded.

Caregivers who devote a lot of their time to HIV/AIDS care or are involved with someone whose dying extends over weeks or months may experience chronic fatigue and exhaustion. Long-term caregiving can have an adverse effect on their work performance, and create stresses in other parts of their lives.

When a Client is Dying ...

As a client is dying, other caregivers – formal and informal — will gather around. Many social workers find that this is time for them to back off. Even if they have known the person for a long time — a decade or more — their time with the person is passing.

Closure with the person and with his or her partner, family and wider circle of support may not be possible. There may not be enough time or energy. In these situations, social workers have to reassure themselves that their work is done, to learn from the situation what they can which may be useful to help others in the future, and to know that what they did was good enough.

DEATH, GRIEF AND BEREAVEMENT IN UNIQUE CIRCUMSTANCES

The model for a “good” AIDS death is based on people who have a strong social support network — people who will come together to form a palliative care team — as well as access to in-hospital or hospice care if they need it. They have the people and resources to care for them through their death. But that is not always the case.

People with Complex Psychosocial Needs

People with HIV who do not have a strong support system or who have a drug addiction, are street-involved or do not have housing or money for food may not face such a “good” death. They may need help getting services that can help, such as money, treatment for drug addiction and a place to live. When they become terminal, they may need help finding a hospice or other setting where they can go to die.

Canada has very few hospices, and most are not equipped to deal with people with complex psychosocial needs or people with HIV, who usually have more complex medical needs than other terminally ill patients. People with HIV often continue to be treated for opportunistic infections, such as cytomegalovirus or brain infections, even in the late stages of AIDS. To maintain their quality of life, their care tends to be more aggressive than it is for others who are dying. The home nursing and hospice programs that do exist and can handle people with HIV may not be prepared to care for women, people of different cultures or people with addictions problems. Social workers may have to advocate for services to meet their clients’ needs and/or actively encourage hospice and nursing organizations to train staff to meet the needs of the diverse range of people with HIV.

Families with More than One Member Infected

The first death in a family where more than one person is infected can be extremely traumatic. That person's death is a harbinger of things to come. If the person dying is a parent, there may be intense anxiety over who will care for the children and how the rest of the family will manage when the one parent is dead. If the person dying is the mother, she may find it difficult to be the recipient of care, rather than the family caregiver.

Even if the family has been through the process of future planning, dealing with a parent's imminent death and the impact that may have on children is extremely difficult. Parents may choose to revisit the plans they have made for their children.

Children in Foster Care

When a child who was in foster care dies, both the birth family and the foster family will need comfort and support. If the child has bonded closely with the foster family, they will experience an intense sense of loss and grief that may not be recognized because the child "wasn't really theirs." They may need support over several months to deal with this experience in their lives.

WORKING THROUGH GRIEF

Grief takes as long as it takes.

One Day I Was Fine, A Book About Grief and AIDS



Grief work takes time, and people are often not allowed enough time to mourn. The great danger is the expectations people place on themselves as well as the expectations others place on us. There is a natural need to "get over it" and get on with living. Social workers and others in a person's support network need to encourage people to take time for self care. In supporting people who are grieving, social workers can help by encouraging and reinforcing the need to slow down and take life in manageable pieces. Healing hearts and emotions is a long-term process.

Those who are grieving need help to be aware of their emotions and the events, places and occasions that will trigger emotional reactions. A normalizing process must be supported. Grievers must become comfortable with memories. Social workers can help clients in the process of integrating memories as a way of healing and maintaining a healthy way of dealing with loss, trauma and grief.

One of the models for grief work is:

- acknowledging the loss is real and permanent
- feeling the intense feelings



- adjusting to that which is no more
- reconciliation and reconstruction.

Not everyone will go through these stages in order, and some people will go through some of the stages more than once.

Social workers can also encourage people who are dealing with grief to connect with what they have lost and what they can keep from the person, and then, in a series of small acts, to gradually let go of the past. To deal with grief, people need a support network: people they can trust and talk to. The social worker may form part of that network, or simply help the person identify his or her network.

Remember Us

*Remember us who are living with HIV/AIDS.
Remember us who have fought the greatest battle of our lives, but have lost our lives to AIDS.
Remember us who have had the courage to tell our stories to others so that they may learn not to contract this disease.
Remember us who wished to remain silent about our illness. We dealt with HIV/AIDS in our own special way.
Remember us for our friends, partners and families, that they have also been affected by this disease. They also need love and support.
Remember us in your hearts and minds that in some special way we have touched your lives.
Remember us for our smiles, our laughter, our tears and our fears.
Remember us for what we gave to our communities and to others, either through our work or our volunteering. Each of us was given talents that we loved to share with others.
Remember us for our triumphs and accomplishments and not for our faults or mistakes.
Remember us for the lives that we have shared with you. Each of us is special in some way or another. We have all been put on this earth with a task to do. We have each been given a message to give others. When our work here on earth has been completed we are free to go on to the next world. Remember those of us who have gone and the message that we leave behind for you.
Please remember us in your daily lives and do not forget us in your hearts.*

LeRoy

People who are grieving have lived with uncertainty and fear for extended periods. In supporting people who are grieving, social workers need to help people move beyond fear and uncertainty, and help them in their struggle to regain hope, trust and a faith in their own sense of who they are and their place in their community.

When There Are Too Many Deaths to Grieve

When people are faced with several losses in their family, circle of friends or community, several things happen. They struggle to communicate the depth of meaning of multiple loss. Support networks reel and weaken from the impact of grief overload. There are too many anniversaries, birthdays and other occasions to remind them of the losses. People's emotions may become exaggerated through the constant repetition. They may eventually become numb, or experience fear and hopelessness, and be left with a sense of unfinished business. In some cases, they may be more likely to engage in risk behaviour themselves, triggered by their sense of loss and survivor guilt. They may also develop intense anxiety about the safety of those who are still alive.

The goal for the social worker is to help people find order out of chaos and find a manageable way to grieve the multiple losses:

- identify the threads of emotion that connect loss to loss
- help the griever recognize patterns of response
- explore ways to resolve issues, bring closure and establish an anchor
- explore the process of self care and the health of the person's support system.

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6 PREVENTING THE SPREAD OF HIV: THE SOCIAL WORKER'S ROLE

One of the most important contributions I can make as a social worker is to help prevent the spread of HIV. In my ability to start where the client is, foster self esteem and help people get the resources they need to enjoy better quality of life and avoid other factors, such as poverty and drug use, that make them more vulnerable to social and health problems like HIV, I believe I can do something to stop this virus.

HIV infection is caused by a virus, but it is also “caused” by poverty, by discrimination, by fear, by power imbalances in relationships, by low self-esteem, by the inability to make healthy personal choices, by drugs and other substances that cloud people’s judgement, and by social attitudes that keep people from talking openly about sex and sexual orientation and from negotiating safer sex practices.

HIV thrives in the cracks and crevices of society’s inequities, and implications of HIV disease are societal. People have known for over 15 years how the virus is spread. The first brochures about how to use a condom and how to clean needles came out in the early-80s. But knowledge, condoms and clean needles have not been enough to prevent infection. They are only tools. Prevention programs based solely on information have failed to produce the desired results.

Self-esteem, skills and social support — including the policies and services that create a social safety net — are the foundation of true prevention. With its focus on both the psycho (personal skills and abilities) and the social (the broader environment where people must use those skills), social work practice has great potential to influence the root causes of this illness and a responsibility to help prevent the spread of HIV.

PREVENTING HIV INFECTION IN PEOPLE AT RISK

A large percentage of social workers work each day with people who, because of their socio-economic circumstances, low self-esteem, lack of education and information, practical needs, addiction, behaviour or family circumstances, are at risk of acquiring HIV. They are people who are:

- just exploring or discovering their sexuality and lack the information or skills to protect themselves
- either unaware of the risk or refuse to take it seriously
- forced into prostitution to survive
- in abusive relationships
- in relationships where they lack power and cannot negotiate safer sex use

- powerless in society - either marginalized or socially vulnerable
- emotionally vulnerable, such as recently divorced or separated people in their 30s and 40s who are re-entering the “dating scene”
- involved with groups who use injection drugs
- in settings, such as correctional facilities, where they may be coerced into risky sexual or drug use activities
- dealing with so many other issues and pressures that protecting themselves from HIV is not a priority.

Practice Issue
Prevention Strategies:
Community Development, Advocacy and Case Management

Strategies will vary depending on the client group, their attitude towards sex and their ability to have an influence over their lives. For example, for young people on the street, the most effective prevention strategy may be to help them get off the street, by providing housing, food and other practical supports, so they can begin looking at their choices and how they are managing their lives. For young gay men, the most effective strategy may be to help them develop a supportive link with the gay community. For people who abuse alcohol or drugs, the most effective strategy may be helping them control or manage their addiction. For women in abusive relationships, social workers may advocate for women's shelters.

Peer support has proven to be extremely important in prevention, particularly in the gay community. When gay men have the opportunity to talk to their peers about prevention, discuss the problems and get support from a group who are trying to make a similar change, they are more likely to change their behaviour and practice safer sex all the time.

Social workers must be prepared to use individual strategies, family strategies, group/community strategies and social strategies. The person needs the support of family/friends and society to be able to change and maintain the new behaviour.

Social workers involved with these clients can talk to them about safer sex and drug use, and refer them to services that will help them develop their self-esteem and skills. Self-esteem is increasingly seen as key. It helps define people's sense of their place in a society or sub-group. It affirms their social status, and it can empower them in their relationships. Although the role of self-esteem is little studied or understood, it appears to play an important role in prevention, particularly in vulnerable populations.

For almost all clients, prevention involves more than working one-to-one. It involves mobilizing communities through a combination of community development, advocacy, case management and counselling to create an environment that supports self-esteem, empowerment and prevention.

Prevention with Adolescents

One of the most vulnerable groups for HIV infection are adolescents. Reaching youth involves establishing rapport, building trust and communicating clearly. Youth are more likely to change their behaviour when they have developed an effective relationship with

someone. This helps them take control of their lives and make good decisions. The information is not as important as the process by which it is delivered.

Effective prevention with adolescents involves:

- developmentally appropriate messages that draw attention to immediate outcomes (especially rewards) and acknowledge the importance of peer support
- brief, explicit, direct, consistent and repetitive messages that avoid ambiguous or judgemental terms (e.g., promiscuous)

- information presented in the context of broader societal/family issues (e.g., such as family life education, sexuality, cultural values and norms, parenting, violence, substance use)
- a social worker who is perceived as trustworthy, nonjudgmental, knowledgeable and interested and who uses language and humour to good effect
- people living with HIV who can appeal to adolescents' emotions as well as their reason
- peers as counsellors
- social workers who have appropriate training in HIV issues, including communication strategies and values clarification
- education and counselling interventions that are flexible, creative and engaging enough to get adolescents' attention (e.g., games played with condoms/dental dams may be more interesting than a discussion).

Prevention with Young Gay Men

Young gay men (<25) are most at risk of acquiring HIV. That is because they are often isolated (cognitively, emotionally and socially) and have few contacts within the gay community. They have few positive models of what it is to be gay and have not yet developed a positive gay identity. They suffer from low self esteem as people and as gay men.

Their first sexual encounter often occurs in the midst of alcohol or drug use. Uncertain about their identity, they are often not able to insist on safer sex practices, and tend to take the lead from their partners.

Prevention with young gay men is more complex than providing information. It involves understanding the complex and challenging task of acquiring a positive sense of self as a gay man and gay self-identification. Effective HIV prevention programs must also respond to the dimensions of being young and gay that put these men at higher risk. Any initiative that provides social support, group identity, human rights advocacy for and to gay men will ultimately empower them as a group and as a community, which will include HIV prevention.

Very few groups have been as stigmatized in our culture as gay men and lesbians. Up until about 20 or 25 years ago, homosexuality was generally considered to be against nature, a mortal sin, a mental illness and a criminally deviant behaviour. These ideas still form the underpinnings of prejudices against homosexuality and influence the way that gay men and lesbians see themselves.

The rate of new infections in young gay men will depend on how society is able to normalize being gay and advocate for greater tolerance and acceptance in the general population. Social workers have an important role to play in this endeavour.



Prevention with Street Youth

Street youth are at particularly high risk of exposure to HIV and have fewer resources to protect themselves. They may be vulnerable to abuse or forced into activities that put them at risk, such as prostitution, for economic reasons. At the same time, they are a difficult group to reach.

Services targeted at street youth go where the youth are (e.g., store front agencies and drop-in services in areas where street youth congregate), and social workers in these organizations have an opportunity to do HIV prevention. To help prevent the spread of HIV among street youth, social workers must be comfortable discussing sex and sexuality. They should also work with the youth to develop a sense of the future and to encourage them to believe that self-efficacy is possible.

Strategies can include:

- focus group sessions to help identify the youths' needs, beliefs, interests and values. The sessions make youth feel their ideas matter, and the topics mentioned most often in the group should then be incorporated into prevention messages.
- programs and services that help with their material needs and work to get them off the street
- peer approaches that use street youth to educate other adolescents on the street. This usually leads to greater personalization of the risk. It may also be the only way to reach a population as disenfranchised as street youth, particularly those who are struggling with their sexual identity.
- outreach programs that affect skills as well as knowledge
- culturally and linguistically sensitive materials that make extensive use of graphics and pictures
- rap contests, games, puppets, videos and theatre
- information that uses humour rather than fear to motivate youth. Because of the risks they face in their lives, many street youth are immune to fear.
- a question box where youth can anonymously leave questions and get answers.

Prevention with Women

Women — sexually active women between the ages of 18 and 50 — are a key target for prevention, in part because they tend to underestimate their risk. Any health or social service organization working with women has the opportunity and the responsibility to deliver a strong HIV prevention message. Strategies that can be used to reach women include:

- providing information/education about the risks
- empowering them to use their knowledge to protect themselves — this can be particularly difficult for women in abusive relationships or women in relationships where the male is dominant
- helping them develop negotiating skills and become comfortable using them
- tackling underlying socio-economic issues that make women dependent on others and less able to have a say in their sexual relationships



- recognizing and working to mitigate any cultural norms that put women at risk (e.g., In some cultures, it is acceptable for the men to have extra-marital relationships. The men may become infected and then infect their wives. It may not be possible to change cultural attitudes towards extra-marital sex, but it may be possible to educate the men to wear condoms to protect their wives and children.)
- organizing outreach programs for women at particular risk, such as sex trade workers, injection drug users, victims of abuse
- helping women recognize the impact of drug and alcohol on their judgement and their ability to make decisions to protect themselves
- advocating for equality for women in society.

Prevention with Injection Drug Users

People who inject drugs are likely to have sporadic contact with a range of health and social services, through walk-in clinics, hospitals, treatment programs, shelters, food banks and the correctional system. Engaging drug users is difficult, but social workers in any of these environments have an opportunity to prevent the spread of HIV among drug users.

Because of the impact of an addiction on judgement, harm reduction is likely to be the most effective strategy. This includes providing access to:

- clean needles
- bleach for cleaning needles
- information about the risks of sharing needles
- counselling
- support for getting off drugs
- condoms and information about how to avoid acquiring HIV sexually (some drug users think their only risk is from sharing needles and practice safer drug use, but not safer sex).

Outreach programs are essential to reach drug users, who may distrust the health system and all forms of authority. To ensure that drug users get a consistent message about HIV prevention, social workers should ensure that professionals involved in addictions treatment programs are knowledgeable about HIV and that those who work in HIV prevention and support programs are aware of addiction issues and the impact they have on people's ability to protect themselves.

Prevention with Street-Involved People

Professionals working with street-involved people in Alberta report that it is a very conservative culture. People who come to this particular agency were reluctant to talk about sex or sexuality, and objected to the basket of condoms that appeared on a table in the main room. Social workers realized they had to shape their strategies to the culture. They worked gradually to get clients to talk about sex, encouraged humour and joked about sex to help people become more relaxed, and were then able to talk more openly about sexual activities that put people at risk and strategies to prevent infection.



Prevention in Correctional Facilities

People in jails and other correctional facilities are at high risk of infection and have few tools to protect themselves. The institutions themselves face some difficult ethical issues: how can they give inmates the information, tools and skills to protect themselves without condoning or encouraging drug use and coercive sex?

Effective strategies combine information, education, skills, support and policies. Social workers in those and other residential settings should work to implement the recent ECAP recommendations, including:

- providing all inmates with a health kit that includes small quantities of bleach and instructions on how to clean needles, condoms, dental dams, water-based lubricants, information about sexually transmitted diseases and band-aids
- providing appropriate education and prevention programs for inmates and staff

The Impact of Drug and Alcohol Use in Prevention

At one AIDS service organization, over 30 per cent of new clients have a history of alcohol and drug use or abuse. There is often a direct link between substance use and the risk taking behaviours that put people at risk of HIV. Alcohol and drugs affect judgement, and may influence people's ability to insist on condom use or avoid sharing needles. Helping clients identify strategies for managing their alcohol and drug use may help protect them and prevent the spread of HIV.

- providing addiction treatment programs and access to methadone
- making stronger efforts to prevent sexual assault or coercive sex by prosecuting or segregating sexual predators and ensuring that inmates who are vulnerable to abuse have single-cell accommodation and are closely supervised and protected
- changing institutional policies so that possessing bleach and engaging in consensual sex are no longer considered offences
- recognizing the unique needs of aboriginal inmates and ensuring they have access to traditional healers and appropriate prevention programs delivered by aboriginal leaders
- providing special instructions to inmates who offer tattooing or ear piercing services
- ensuring staff have the education, support, equipment and materials they need to reduce the risk of exposure to HIV on the job and also reduce the fear and potential discrimination against prisoners who may be infected.

HARM REDUCTION AS A PREVENTION STRATEGY

Within the HIV field, there is a growing trend away from abstinence models to harm reduction models, which focus on smaller, incremental changes that reduce the potential for harm. For example, needle and syringe exchange programs provide critically needed information and teach people how to reduce their risk. They do not eliminate drug use, but they work to minimize the associated health and social harm.

Harm reduction is not a theory in and of itself, but a set of practical principles that can be strung together and applied to unsafe sexual behaviour and unsafe drug use.

Aboriginal agencies in a certain part of the Maritimes are all drug and alcohol free because those who work there feel strongly that drugs and alcohol have been extremely harmful in their communities. They use an abstinence model and the staff are comfortable with that model. In fact, this model builds on their traditional culture, where people have to abstain from using drugs or alcohol for a certain length of time before they can participate in ceremonies and sweat lodges.

The staff are able to counsel harm reduction for sexual risks, but are personally less comfortable with that approach to addictions. In the community, there is some question whether people will come for help. They know the agencies are drug and alcohol free, and they may fear the staff will be judgemental.

Harm or risk reduction strategies have met with a great deal of resistance in established health and social services because they are relatively new and untried in Canada, and because they represent to many providers (whose ideal is absolute prevention and safety from HIV transmission) a defeatist approach to complex and perplexing problems. Some people may also be concerned that harm reduction strategies camouflage another political agenda, such as legalizing or decriminalizing activities such as injection drug use, other nonprescription drug use and the sex trade.

Most social workers, particularly those with a background in addictions, are used to working in an abstinence model and harm reduction may raise ethical issues for them.

For many people, stopping any behaviours that put people at risk of acquiring HIV (such as the use of substances that alter judgement) is the preferred goal. Harm reduction strategies recognize that this goal is often — at least over the immediate or short term — unattainable and must be placed on a hierarchy that recognizes the client's acceptable starting point and creates conditions that will improve decision-making and reduce risk.

Harm reduction is a common strategy used in other fields of health promotion. Smoking cessation programs that advocate cutting back or reducing the number of cigarettes smoked and mandatory seatbelt legislation are examples of harm reduction.

Example of harm reduction strategies in HIV are:

- safer sex education
- use of condoms/dental dams
- safe injection drug use information
- safe prostitution areas
- prescribing drugs, such as methadone.

Principles of Harm Reduction

1. Retain a value-neutral view of the activity. Whether the activity involves injection drug use, sharing needles, anal intercourse or the sex trade, the social worker must recognize that this is the experience and expression of the client and be cautious not to use a biased tone or make pejorative statements when discussing the activity. For the client, there is some inherent value in the activity, which the social worker must understand.
2. Retain a value-neutral view of the person. Although being nonjudgmental is a fundamental value for social workers, many social workers still have difficulty with some people (e.g., perpetrators, pimps and child abusers) and that attitude can bias their approach to clients. Resist the urge to demonize or stigmatize. Society has already equated drug use and the sex trade with criminals, and it serves no purpose to reflect those views in a harm reduction program.
3. Focus on the problem. This approach is consistent with social work practice. The problem is to reduce the rate of HIV transmission. Communicating views of the world will take the social worker off the goal.
4. Understand the place of abstinence in harm reduction. Abstinence is a laudable goal but may be out of the client's reach. In that case, it will lead to frustration and non-compliance.
5. Recognize that relapse is common, and is part of recovery.
6. Recognize the client's role. The programs must be pragmatic, user-centred with lots of emphasis on choice. The client must be an active part of the process.

Harm reduction is based on a hierarchy of change, a series of steps that lead to safety. For example, the first step towards greater safety for someone who shares needles might be helping the person get information and the resources to clean needles and find alternate ways to experience the bond addicts feel in sharing. Another step would be helping the person recognize the importance of not sharing. Later steps would be helping the person find alternatives to injecting.

Harm reduction practices require a shift in orientation for the social worker or health care providers. It demands significantly more openness and creativity. As a society we need a change in the social conditions that lead to poverty and marginalization as well as more respect for human rights, which will allow people to live lives free of oppression and stigma.

Social workers must recognize clients' starting points — which may be finding food and clothing for their children or finding a safe injection or sex trade area. As clients' fear and sense of isolation is diminished, their self-esteem improves and they will become more concerned about their health and their relationships.

In this way, they can move, one step at a time, along the road to safer practices.

Harm Reduction — An Organizational Issue

Do agencies need to learn more about harm reduction — even though it poses an ethical dilemma for some people? Agencies that move to a harm reduction model must:

- recognize the need for staff training and education
- provide opportunities for staff to question and discuss the policy and its implications
- be prepared to lose some staff

- discuss harm reduction with any new staff to ensure they will be comfortable working with that model.

Agencies can use the following practical questions (used by Chez Ma Cousine Evelyn, an HIV hospice for IDU homeless people) to assess an agency's or social worker's comfort or anxiety in working with injection drug users. They are not intended to shock or frighten, but to highlight issues that social workers must consider.

1. As a social worker, do you continue a counselling session if a client is high or stoned?
2. If the client is new to the area, do you help them find out where to make drug purchases?
3. Do you allow the residents or citizens to make drug purchases on the premises? If not, how far away — one block, two blocks?
4. Would you allow residents whose only source of income is the sex trade to use their rooms to turn tricks?
5. What is your relationship to the police?
6. What is your relationship to the neighbours?
7. Does your organization allow clients to drop in even if it disrupts schedules and routines?
8. Does your organization provide a drop-in room for clients?
9. Are solid boundaries important to build structure in lives that have known little or no structure?

The questions become more ethically and morally challenging when the clients are minors or children. For example:

1. To what degree do we teach homeless minors how to do drugs safely?
2. Do we show adolescents involved in the sex trade the safest place to do business?
3. Should we facilitate the development of “safe houses” so that street youth don't run the risks associated with parks and alleys?

These questions illustrate the complexity of the issues, and highlight the social work value of client self-determination and the social work maxim to “start where the client is.” In some cases, this will create a serious internal struggle for the social worker.

Social workers working with disadvantaged people are likely to see more clients with HIV, and be responsible for helping them cope with a range of psychosocial issues. Social workers involved with those who are at risk have a unique opportunity and a professional responsibility to help their clients — whether they are in a homeless shelter, an addiction program, the child welfare system, a group home or correctional facility — protect themselves from HIV. They also have a responsibility to help clients who become infected get the services and support they need.

Resources

- FIT. A Harm Reduction Video for Injection Drug Users.* Street Health/Parkdale Community Health Centre. Available from 1257 Queen Street West, Toronto, Ontario M6K 1L5; phone: 416-537-2455; fax: 416-537-5133. Price: \$35 plus \$5 postage and handling.
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7 SELF CARE

Working with people with HIV is always rewarding, but never easy. Social workers must deal with many issues at the same time. In general, clients with HIV tend to be more active and involved, and more certain about what they want. Although social workers try to encourage this kind of empowerment and client involvement, they may be challenged by the expectations and find the experience different than other areas of practice.

In addition, the boundaries or lines between social workers and clients may be different. Clients may also be friends or colleagues. Relationships with HIV positive clients may continue over many years. Many clients will die.

When life is short, everything becomes more urgent. Social workers in HIV practice see great resilience, joy and hope in the face of adversity. They also see a lot of loss, death and grief.

Personal Practices

According to CASW research, social workers in the HIV field rely on the following to provide support and self care:

- humour
- a stable home
- expressing emotion
- nutrition
- spiritual guidance
- alternative therapies
- friendship
- recreation
- partner support
- exercise
- counselling

There are too many people, too many needs, and not enough time or resources. The stress that social workers experience is usually due to their sense of helplessness in the face of HIV, their own discomfort with death and dying or overidentification with their clients. Social workers who overidentify will invest unrealistic amounts of time and energy in the client, and lose sight of their own personal needs.

Your social work training should have prepared you to establish boundaries and taught you how to empathize and identify with the client but still be objective. However, the stigma of HIV may push that training, and you may find yourself acting out of fear of contagion, homophobia or anger — emotions that you may not experience in other fields of practice.

The multiple issues associated with HIV disease can cause social workers to forget what is reasonable to offer as a social worker. It's easy to fall into the trap of "being there" all the time and doing everything. It is critical for social workers to remember that they are not omnipotent and that they alone cannot offer everything needed to ease the impact of this disease on clients and their loved ones. It may be that no one can.

The belief that "no one cares" or "no one else is going to do it, so I need to" can arise easily in a social context where, in fact, it appears to be true. But instead of changing boundaries and trying to do everything, the social worker could respond

in a different way, asking “who else can I invite into this work? other counsellors? other organizations?” and “is there a practical way that I can invite others, such as politicians and organizations, to show that they care?” Social workers could also work with their managers to build the case for more social workers.

Many of us living with HIV have more than one role in this disease. We are informal caregivers, family members, professional caregivers, volunteers and clients. With this juggling of roles and the resulting issues of stress and boundaries, it is critical that we have some support. Many of us have been involved in our various roles for a number of years, and our participation changes over time. I have worked both professionally and as a volunteer in AIDS-related activities. I have been an informal caregiver for many friends, and I have been a client.

Thoughts from a Social Worker

My philosophy has always been that “there is more to life than work.” While working in the field of HIV/AIDS, this thinking has served me well. Like everyone else, I am human and I do slip. At these times, it is helpful to have someone special remind you that you need a break or ask you why you are so wired. I have learned that if I want to help others, I have to do two things:

- *leave my work at work*
- *take time alone and time off.*

To survive in work and life, I think you have to take the good and the bad, and try to learn whatever you can along the way. I think it's both a challenge and a privilege to be involved in the HIV/AIDS field.

Doing what you can and what is reasonable helps create boundaries, and that is a form of practice wisdom. Boundaries may include:

- limiting the hours you work, and the hours you are available
- not visiting every client who is in hospital or dying at home; keeping visits short
- phoning instead of visiting
- having the nursing staff or other caregivers pass on your good wishes
- calling on others to get involved and share the responsibility.

For the most part, clients accept the limits of what you can do. As one client said to a social worker, “I know you’re with me, but helping others. If I don’t see you, it’ll be alright.”

Being reasonable also includes knowing what skills you have and how best to use them, and being willing to work in a team to balance your skills with other people’s. The social worker is not the nurse or the psychiatrist. It’s enough to be the facilitator and supporter. Chances are, everyone else working with the client feels the same way and is experiencing the same existential dilemma: “if I could only do more to make it better or make it go away.” Talking to other professionals about it may help everyone

develop some comfort with “what’s good enough.” It’s the collective input that makes the difference.

Transference Issues When a Social Worker Over-identifies with the Client ...

It is easy for social workers to work with people like themselves. They can identify with their problems, backgrounds and wishes for the future. When social workers do identify closely with their clients, it’s important to listen closely to the clients and recognize their uniqueness. For example, if both the social worker and client are pregnant, the social worker cannot assume that she understands everything the client is feeling about pregnancy or childbirth decisions. It’s important to ask about her experience, fears and wishes for her child. When both the client and the social worker are gay, it’s important for the social worker to remember that the client’s

experience of being gay may not be the same. For example, if the social worker is open about her/his sexual orientation, she/he may want to counsel gay clients to “come out,” rather than starting where the client is.

While there are advantages to being a client’s peer, there is also the danger that the social worker will lose some professional distance, overidentify and lose sight of the difference between the client’s issues and her own. She may feel that she has to do more to help, and may suffer more from a sense of cumulative loss when clients die.

Practice Issue When It Gets Too Tough

You have been working at a small community-based organization for three years. This last month, you have had three new clients referred to you who were recently diagnosed with HIV. Over the last four months, five clients with HIV who you have known for years have died. You’re having trouble sleeping, you don’t seem to have any interest in sex, and you don’t laugh very much anymore. Your partner is complaining that you spend too much time at work, and you don’t seem to be getting along well with your co-workers. What do you do?

- Talk to your supervisor. You should be able to get some support within your work setting. You probably aren’t the only one, and it may be that, as a group, you need some regular time to talk about all the deaths and process your grief so it doesn’t build up and overwhelm you. Reflect on what each client has meant to you. Supervisors can also help by ensuring that the organization has clear goals that value and stress the importance of employee health.
- Seek out peer supervision that can help you re-establish some balance in your expectations.
- Make more time for yourself. Do things that are good for you.
- Do what you need to do to be healthy (e.g., stop smoking, socialize, exercise, rest).
- Recheck your boundaries. Go back to your training and use what you know.
- Check your practice. Make sure you are referring people when you should — that your practice hasn’t been stigmatized by HIV and that you aren’t trying to “do it all.”
- Establish or re-establish friendships with people who are not involved in HIV work.

When the social worker is also HIV positive, again, there is a risk that the social worker will overidentify or that his or her issues and the client’s issues will become confused. Each time a client’s health deteriorates, it may remind the social worker of his/her own mortality. The social worker may feel pressure to set an example, to be the “perfect person with HIV” or to expect too much of clients. Co-workers may expect the social worker to be the resident “expert” and use him or her as a source of advice on everything. For some people, it can be too hard to live *and* work with HIV. There’s no escape. Others find it rewarding.

The situation can become more complicated when the social worker and client are part of the same social circle. In this case, the social worker should bring up the issue and the risk of blurring their professional and personal relationships in the office. The two should discuss what will happen in social situations, and agree that they will not discuss the counselling issues socially.

Acknowledge and Share the Feelings

Despite the pitfalls and barriers of naming feelings, social workers working in HIV owe it to themselves to name and explore them. Here are one social worker’s feelings. What are yours?

Anger

- at young people being infected because the system didn’t reach them
- at those who don’t care for themselves and advance the course of their disease

- at those who knowingly infect others
- at politicians who hold back necessary resources which could help.

Frustration

- at people with addictions who continue using and getting deeper into difficulties that no one can reasonably address
- at agencies who never seem to respond adequately to needs
- at colleagues who give you all the tough stuff.

Guilt

- over not being able to carry through on a promise because of circumstances beyond your control
- over wishing you could do more for someone who is so sick.

Sadness

- for all of the talent that is being lost prematurely
- for the children who will grow up orphans
- for the devastation to the third world, which is losing the people who could lead them forward.

Grieving Rituals

Some social workers have developed grieving rituals to help them deal with death and mark each person’s passing. For example, some request or collect the programs from people’s memorial services. Some keep a journal where they record their thoughts and feelings for those who have died. Others save the notes and letters from partners and family members, who write to thank them for their presence on the journey. Others simply recall the images or words of those they’ve helped:

with much love, appreciation and respect. Thanks for being my safety net, my sounding board, for kicking my ass when needed, for carrying me and for helping me to walk on my own. I couldn’t have made these last 8 months without you. You’ve helped me find hope in the midst of all this. Not an easy task! Know that your hugs, love and support have played a major role in keeping me alive.

A Spiritual Approach to Self-Care

Social workers in an aboriginal agency find a lot of their support in aboriginal culture, spirituality and ceremonies, such as talking circles, spiritual retreats, sweats, fasts and healing circles.

They also receive support from one another. The agency organizes a two-day retreat each month for staff and one day is devoted to self care. It provides days off and salary advances when people need them as well as opportunities to go to conferences and workshops. It encourages staff to diversify their lives and to take care of their body, feelings, spirit and mind, stressing that if they don’t care of all four, they will fail their bodies and they will break down. Humour is also very important.

The way the organization is run is also supportive. It is “flat:” everyone makes about the same amount, regardless of their title, and they are all involved in decisions that affect their work. The organization shares office space with three other agencies involved in HIV work, and the other groups are also a source of support and information.

In many aboriginal agencies, the staff also believe that being drug and alcohol free helps them cope with the stresses.

Instead of going to every funeral, some social workers choose to attend only one or two a year, and use them to honour all who have died. Some centres organize an annual memorial service

during Canada's AIDS awareness week (usually the first week of October) or on World AIDS day (December 1), where both professional and informal caregivers can remember and pay tribute to everyone who died during the year.

Knowing When Enough is Enough

Sometimes working in HIV becomes a cause or a calling instead of a job. While social workers would reasonably expect to change fields and "move on" to other types of social work practice, HIV can be different. It's hard to leave. People who go either have compassion fatigue or are "burned out." Those who choose to move on or make a change often feel they are "traitors" to the cause. But part of self care is knowing when it is time to go, and seeing how lessons learned working with people with HIV can be applied elsewhere.

CASW research indicates that social workers no longer working in the field of HIV/AIDS have gone on to pursue interests in advocacy, political action, bereavement, palliative care, long-term care, pastoral counselling, policy and program development, training and teaching.

THE IMPACT OF MULTIPLE LOSS ON SOCIAL WORKERS

The Conspiracy of Silence

by Guy Milner, Member of the CASW Ad Hoc Committee on AIV/AIDS

In 1988, the schools of social work began to include education on HIV/AIDS and identified then the isolation that social workers in the field faced. Other social work colleagues were unwilling to listen to the story about working with HIV. It is ironic that, more than 10 years later and with over 500 social workers now in the field, the silence continues.

The silence is most deafening in the workplace, particularly with other team members, who feel they always need to "do something" or are only peripherally involved and see clients as subjects for research. The silence is amplified by the downsizing of organizations, which have removed supervisors and created remote managers who rarely pause to ask "how is it going?"

It is not surprising that, in the Canadian Association of Social Workers survey, social workers working in HIV identified connecting at the grass roots with other social workers as one of their greatest needs and their preferred ways of learning. One of our challenges in the next decade is to weave the networks among ourselves for ourselves that will help us deal with multiple losses.

Silence is an unnecessary defense. To deal with the multiple losses, social workers and others simply need to be given time and the opportunity to speak. They do not

want answers or solutions, just someone to listen. People who are extroverts may benefit more from regular memorials, quilting bees and other rituals that bring people together to share, heal and honour life. For people who are introverts, it is particularly important to have chances to process thoughts and feelings, ideas and reactions, quietly and without interruption. And the opportunities need to be immediate and workplace-based, and come from other social workers who, according to the literature, are the best source of support.

To help break the silence, social workers involved in HIV need to write and talk more about their experiences. Workplaces need to honour the time taken to talk and listen, and not consider it “unproductive.” Social workers need to talk at the chapter and provincial levels of their associations, and they need to talk to their political representatives at constituency meetings or in person.

For the soul that is saddened by the loss of so many, so young, there is a need for soul work: silence, reflection, glorying in the everyday — such as gardening, food, dance, music. For the spirit, there is a need for hope — which must be kept bright by others tending it when it is low and by comprehensive strategies that address HIV on all fronts, from research to prevention. It must be hope nurtured by sages, not fettered by doctrine or hypocrisy.

When I search the well of my anger and frustration, I simply yearn for the silence to be broken. If I could give voice to the experiences and feelings, the dam would be open. If I could show the tears and speak the sadness, my soul would lift its eyes and see the hope that is around it. If you were there, you could share your hope in life, and we could walk together on life's journey.



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Appendix I Risk Assessment

Counselling about risk is complex because it is difficult to estimate or quantify risk. It has been common practice in HIV/AIDS education to help people assess their risk by classifying various activities in “high,” “low” and “no” risk categories. However, given the complex factors that can affect risk, this approach may be misleading for those who are trying to assess their own risk.

For example, most safer sex guidelines classify unprotected anal intercourse as “high risk” and anal intercourse with a condom as “low” risk. But the risk depends on a number of factors: anal intercourse with someone who *isn’t* infected is actually “no” risk; anal intercourse with a condom with someone who is infected will reduce the risk but — depending on the frequency of intercourse and the chance of condom breakage or failure — there is still a risk of infection that, compared statistically with other health risks, would not be considered low.

Everyone has a different perception of risk. Some people are more willing than others to take risks and, over time, a person’s actual risk — and his or her perception of it — can change. For example, when they understand the risk involved in anal intercourse with someone who is infected, some people may choose to accept some risk and reduce it by always using condoms. Others may find that they are not comfortable with that level of risk, and choose to reduce their risk more by avoiding anal intercourse. It is a personal decision.

Because the perception of risk is so personal and individual, it is important for counsellors not to categorize activities but to give clients the best possible information about risk, talk about the factors that affect risk and discuss steps clients can take to reduce it. Counsellors should also talk about the effect that emotions and substance use can have on a person’s perception of risk. It is very common for women to underestimate their current risk because of the feelings they have for the partner they are with at the time they are tested. It is also very common for people whose judgement is clouded by either alcohol or drugs to take risks they might not take when they are sober or straight.

Although explaining risk in this way may not be simple or easy, it will give clients the information they need to assess the risk in a given situation and make their own decisions about reducing it.

Factors that influence risk of sexual transmission

The factors that can increase or decrease the risk of sexual transmission of HIV infection are:

- the likelihood your partner is infected
- frequency of intercourse
- type of intercourse
- condom use.

The likelihood your partner is infected

HIV infection is spread during penetrative sex with an infected person. If one partner is infected, then insertive or penetrative sex will involve some degree of risk — regardless of the other precautions taken.

If — as is often the case — the client does not know his or her partner’s HIV status or past sexual or drug use activities, the client should be encouraged to consider the likelihood of that person being infected. For example, if the sexual partner is involved in activities that would put him or her at risk (e.g., men having sex with men, sex for prostitution, injection drug use, transfusions of blood or blood products before November 1985), then the client should assume that the person is infected and that there is a risk of infection during sexual intercourse.

To help clients assess their risk realistically, counsellors should make a distinction between the risks involved in sex between two men and sex between a man and a woman or sex between two women. The incidence of HIV infection in Canada is much higher in men who have sex with men than in heterosexuals or lesbians. It is more likely for one partner to be infected in a male homosexual encounter than in a heterosexual one. This means that insertive or penetrative sex between two men — unless both are known to be negative — will always be risky, while such sex in a heterosexual encounter will be risky only if one partner:

- is HIV-positive
- has a male partner who has sex with men
- has shared needles
- is from an endemic area
- received a transfusion of HIV-infected blood or blood products.

Knowing your partner's past sexual and drug use history can be a crucial defence against HIV infection. However, counsellors should stress that — even if the partner does not seem to be at high risk or has tested negative in the past — there may still be some risk of infection. The client should still take precautions and practise safer sex.

This is particularly important advice for women who often tend to assess their partners uncritically and so may underestimate their risk of infection. With heterosexual clients, counsellors should stress that unprotected penetrative sex is risky. The incidence and risk of HIV infection in heterosexuals will increase if precautions are not taken now.

Frequency of inter course

The risk involved in any activity increases with the frequency of that activity. Someone who is at risk because of sexual intercourse with multiple partners can reduce the risk by reducing both the number of partners and how often he or she has penetrative sex.

Anyone having penetrative sex with someone who may be infected or whose status or sexual/drug use history is unknown can also reduce the risk by having penetrative sex less often.

Type of inter course

The type of sexual intercourse is also a risk factor. Although there is a risk of HIV transmission with any type of insertive or penetrative sex, anal intercourse is much riskier than vaginal sex. The anus is more likely to have tears and abrasions than the vagina, allowing the virus to pass into the bloodstream. For the same reason, penetrative vaginal sex is riskier than oral sex.

Clients will often have many questions about the risk associated with oral sex. As of 1992, a few cases of HIV infection through oral sex had been documented in North America. However, it is difficult to assess this risk because few people have only oral sex as a risk factor. Like all other sexual activities, the risk varies depending on a number of factors. For example, if the partner is infected, the risk is greater. The risk also increases with the frequency of oral sex. Counsellors should make sure clients are aware that any abrasions in the mouth — such as mouth sores or bleeding gums — or on the penis also increase the risk of infection. (For more information, see the Canadian AIDS Society [CAS] guidelines on oral sex.)

The counsellor should explain that the insertor role in anal or vaginal intercourse is less risky than the receptive role but that **both are still risky activities**. This is important advice because some men may assume the insertor role is low risk and may avoid taking precautions.

Some clients may be concerned about the risk of HIV transmission during rimming (oral/anal sex). Many counsellors and safer sex guidelines classify rimming as high risk. However, counsellors should point out that the real risk of oral/anal sex is the possible transmission of hepatitis A, hepatitis B and parasites — not HIV.

Although there is usually no risk of transmission during mutual masturbation, the practice of using someone else's semen to masturbate *is* risky. Other sexual activities that do not involve penetration — hugging, kissing, touching, fondling — are not risky.

Based on this information, clients should be aware that they can reduce their risk by choosing the less risky types of penetrative sex and avoid risk by choosing non-penetrative activities.

Condom use

When used properly, condoms can substantially reduce — but not eliminate — the risk of HIV transmission during insertive or penetrative sex. They should also be used as a safeguard against other sexually transmitted diseases. However, clients should also be aware that condoms are not foolproof.

In spite of the risk of condom failure, clients should be reassured that — next to avoiding penetrative sex — condoms are the best available protection against the spread of sexually transmitted diseases, including HIV. If clients choose to have penetrative sex with someone who is or is likely to be infected, or someone whose past sexual or drug use history they do not know — and counsellors should stress again that it is always difficult to “know” about someone else's past — they should *always* use condoms.

Factors that influence the risk of transmission through needle use

The factors that can increase or decrease the risk of transmission of HIV infection through needle use are:

- the likelihood the needle-sharing partner is infected
- the frequency of sharing needles
- the influence of the injected substance on the person's judgment and decision to practise safer needle use and safer sex
- access to clean needles or bleach to clean needles.

The likelihood the needle-sharing partner is infected

The risk of HIV transmission from sharing needles to inject drugs or other substances is extremely high. If the needle-sharing partner has been involved in any activities that would put him or her at risk (e.g., men having sex with men, sex for prostitution, injection drug use, a blood or blood product transfusion before 1985, sex with someone who has HIV or been involved in a risk activity), the client should assume the person is infected and that there is a high risk of infection from sharing needles. “Flagging,” the practice of drawing blood out, mixing it with the drug and then reinjecting the blood, greatly increases the risk involved in sharing needles.

Frequency of sharing needles

The risk involved in any activity increases with its frequency. The more often people share a needle and the more people they share needles with, the greater the risk. In some cases, the sharing of needles is considered part of the experience. People who share needles can reduce the risk by sharing less often with fewer people — but the risk is still significant.

The influence of the injected substance on the person's judgment

The use of drugs and other substances, in itself, affects the person's risk. These substances affect judgment which, in turn, can affect people's decisions to practise safer needle use or safer sex, making them more likely to engage in high-risk activities. The need for the substance will often outweigh a person's desire to keep from being infected.

Access to clean needles and bleach

The only way to eliminate the risk associated with needles is to stop injecting drugs or other substances. The only effective way to reduce the risk is to always use clean needles. People who have easy access to new needles or bleach to clean needles are less likely to share dirty ones. However, their ability to practise safer needle use will continue to be influenced by the substance they are using.

The client's risk history

Once it is clear that clients understand how the virus is transmitted and the factors that increase or decrease the risk of infection, the counsellor should review the clients' sexual and other risk history (needle sharing, blood transfusions before November 1985) back to 1980. This date is often used as a convenient starting point for HIV infection, although some clients may have been infected in the late 1970s.

Sexual/drug use history

When reviewing the history of unsafe sexual activity, counsellors should ask clients to consider casual and regular sexual partners. Clients will often be selective and may rule out partners they assume were not infected. Likewise, clients may not automatically remember or discuss unsafe incidents in the late 1970s or early 1980s because they assume they would have symptoms by now if they had been infected that long ago. It is not necessary to review every partner, but rather to get a general idea of how often clients have engaged in risky activities.

Do not make assumptions about clients' sexual behavior, orientation or drug use. Some clients may not give accurate information or may be unwilling to fully discuss sexual or drug practices. To assume clients do not use drugs or that they are of a particular sexual orientation may lead a counsellor to omit important questions or information. Taking an adequate risk history may mean asking direct questions: "Have you ever shared needles?" "Are your partners women, men, or both?" "When you have sex with men, do you ever have anal sex?"

Blood transfusion history

When clients come for testing because of a blood transfusion, it's important for counsellors to try to assess two things: when the transfusion occurred and the type of procedure. Some clients will know they received a blood transfusion during the period from 1978 to November 1985. Some may have received a "look-back" notice from a hospital, telling them they received a transfusion and recommending that they be tested.

Some clients may know they were hospitalized at some time between 1978 and November 1985 but not know if they received a transfusion. Counsellors can suggest that these clients contact their physicians or the hospitals to find out whether they were transfused. However, not all hospitals can provide this information quickly or easily. In those cases, counsellors should ask the clients for more detailed information about the reason for hospitalization, then assess whether they are likely to have received a transfusion and counsel them accordingly. The majority of simple procedures do not require transfusions.

From this review of their activities and history, clients should have a clearer idea of their risk of infection, and their perception of personal risk may change considerably.

Excerpted from *HIV Antibody Testing: Pre- and Post-Test Counselling in Anonymous Testing*, Ontario Ministry of Health, revised 1995.

Appendix II

A Brief Guide to Pre-test and Post-test Counselling

Pre-test counselling can take up to an hour — if it takes longer, the counsellor has become side-tracked, rather than focusing on testing issues. The session includes clear information on:

- assessing risky behaviour and identifying why the person wants to be tested
- modes of transmission
- ways to reduce risky behaviour
- choices of testing locations and types
- the client's rights (e.g., confidentiality, informed consent)
- what the test process entails and what test results mean
- partner notification
- the community supports available.

In addition, the counsellor should:

- elicit information about the client's activities so the client can assess the risk realistically
- ask about any physical symptoms
- enquire about the person's present emotional status
- ask about the client's usual coping strategies and talk about how the client can use those skills to help cope with both waiting for and receiving the test results
- ask about their support system and talk about people the person might want to have close by when he or she receives the test results
- discuss the impact that test results may have on future behaviour and sexual partners
- discuss any possible concerns about confidentiality, partner notification, or disclosure — people who live in small communities or rural areas may feel more comfortable being referred to a testing centre in a larger community, where they believe their confidentiality will be protected
- help the client regain a sense of control in a situation where control is lost, by encouraging the client to choose when and where to be tested
- explore the person's relationship with his/her physician
- talk specifically about how the person will react if the test result is positive and the process of dealing with the crisis and regaining a sense of emotional balance
- assess whether there is any risk of suicide; if there is, counsel the client to wait until he/she has a stronger support network before being tested
- assess the need for advocacy, support and referrals.

Post-test Counselling

Post-test counselling sessions usually take about half an hour — unless the person has some serious immediate psychosocial needs. During the session, the counsellor will give the person the test results and explain what they mean.

Window Period

The "window period" is the number of weeks it takes after someone is infected with HIV to develop antibodies that can be detected by accepted blood tests. (As the tests improve, the "window period" will become shorter.) Anyone tested during that time may test negative although they are infected.

If the person tests negative — but is in the window period — the counsellor will give the test results, explain the window period, review the person's social supports and coping strategies in dealing with the uncertainty, reinforce how important it is to practise safer sex and drug use, and make an appointment for another test.

If the person tests negative — and is not in the window period — the counsellor will:

- give the client the test results
- review the person's risk assessment
- encourage the client to discuss changes that he or she can make to reduce risky behaviours. (i.e. "What can we do to keep you negative?")

If, based on the pre-test counselling, the counsellor believes a client is in an abusive or dependent situation that puts him or her at risk, and is unable to protect him/herself, the counsellor may talk about these issues and refer the client to other community resources or sources of support.

If, in the process of being tested, the client has identified some unresolved issues, such as "survivor" guilt (continued risk behaviour triggered by grief that someone close to him is infected and guilt that he remain uninfected), the relationship with his/her family of origin, gay/lesbian issues, an addiction or abuse, the counsellor will tell the client about other counselling/support services and, on request from the client, provide a referral.

Counselling and psychosocial issues for people who test positive are discussed in detail in chapter two. If the person tests positive, the counsellor will:

- give the client the test results
- provide support for the person in his/her initial reaction to the test result, validating the reaction and reassuring the person that it is normal
- ask if the person has someone supportive they can talk with immediately after the counselling session
- reassure the person that many people who are infected have lived more than 10 years with the disease and are still healthy; that HIV is a slow-acting virus, so there is time to organize important issues in their lives
- ensure that clients have retained and understood the information discussed in pre-test counselling
- talk about the importance of practising safer sex and drug use to avoid being reinfected or infecting others
- discuss ways to protect their health, such as getting adequate rest, exercise and nutrition, reducing stress, and avoiding excessive alcohol or drug use
- ensure the person has access to appropriate care and treatment
- discuss possible sources of emotional support
- introduce the issue of disclosure and discuss any anxiety the person may have about telling others about his or her infection
- encourage the person to notify his/her sexual and/or drug use partners so they can also be tested.

For more detailed information on pre- and post-test counselling, see *HIV Antibody Testing: Pre- and Post-Testing Counselling in Anonymous Testing*, Ontario Ministry of Health, revised 1995.

Appendix III

Grief Issues in AIDs Bereavement*

	Partner/spouse	Family of origin
Disenfranchised Grief	<ul style="list-style-type: none"> relationship not recognized: ex-spouse/common-law/affair loss not supported: partner was IDU so “is to blame” inadequate bereavement leave lack of meaningful funeral practical problems: will, belongings lack of spiritual support 	<ul style="list-style-type: none"> relationship to person with AIDS not acknowledged, thus delaying grief shame or anger about family member’s “lifestyle” grief needs of children complexity of sibling relationships not acknowledged
Homophobia and Heterosexism	<ul style="list-style-type: none"> lack of institutional sanctions for relationship problem with will, belongings, home, financial future lack of meaningful funeral and religious/spiritual support internalized homophobia: doubts about self-worth 	<ul style="list-style-type: none"> may blame partner for disease may be dealing with shock of having gay child may be in conflict with partner and friends shame about life-choices of gay family member
Stigma of AIDS, Secrecy and Isolation	<ul style="list-style-type: none"> may be isolated from own family/friends reluctance to disclose details of death, prolonging grief insufficient/no bereavement leave discrimination in workplace and home/neighbourhood 	<ul style="list-style-type: none"> issues of disclosure and confidentiality may be geographically distant traditional sources of support unavailable lack of meaningful funeral/memorial
Survivor Guilt	<ul style="list-style-type: none"> “why not me?” difficulty feeling joy in being alive guilt if suspected source of transmission 	<ul style="list-style-type: none"> “children don’t die before their parents” guilt if source of transmission (mother/child) other family may wonder “why not me?”
Illness Related Complications	<ul style="list-style-type: none"> fear of contagion anger about quality of care if poor exhaustion due to roller coaster of illness and caregiving spectrum of losses along the way: sight, physical appearance, ability, dementia 	<ul style="list-style-type: none"> fear of contagion low level of physical and emotional reserve if caregiving young deaths: forces confrontation with own mortality may be dealing with hemophilia there may be several in same family with HIV
Multiple Loss	<ul style="list-style-type: none"> many friends may also have died, depleting sources of support uncertainty about future: AIDS is not over; loss of community may be called on to care for others 	<ul style="list-style-type: none"> may be coping with additional illness of several family members mourning the death of a family in bits and pieces

* *Module 4: Palliative Care* © Mount Sinai Hospital/Casey House Hospice.

Friends	HIV +	Caregivers
<ul style="list-style-type: none"> • lack of recognition of relationship • lack of closure; funeral 	<ul style="list-style-type: none"> • own needs put aside 	<ul style="list-style-type: none"> • trained not to “attach” as professional resulting in denial of grief • lack of closure; rituals/funerals
<ul style="list-style-type: none"> • invalidated and unrecognized in role of “chosen family” 	<ul style="list-style-type: none"> • dealing with societal blame 	<ul style="list-style-type: none"> • may negatively affect caregiving role, resulting in guilt, anger • may be pulled into conflict between family/partner
<ul style="list-style-type: none"> • may be isolated from family/friends • reluctance to disclose details of death, prolonging grief • no bereavement leave • lack of meaningful funeral/memorial 	<ul style="list-style-type: none"> • issues of disclosure about own status 	<ul style="list-style-type: none"> • may face harassment about caring for people with HIV/AIDS
<ul style="list-style-type: none"> • “why not me?” • difficulty feeling joy in being alive 	<ul style="list-style-type: none"> • “why not me?” • difficulty feeling joy in being alive 	<ul style="list-style-type: none"> • may lead to overwork/burn-out to compensate for internal distress about own health
<ul style="list-style-type: none"> • fear of contagion • anger about quality of care if poor • exhaustion due to roller coaster of illness and caregiving role • spectrum of losses along the way: sight, physical ability 	<ul style="list-style-type: none"> • sexual repression • fear about progression of own infection 	<ul style="list-style-type: none"> • fear of contagion • low level of physical and emotional reserve from complex care • young deaths force confrontation with own mortality • may be working with hemophilia or other complicated illnesses as well
<ul style="list-style-type: none"> • many friends may have died, depleting sources of support • “grief on the run” • uncertainty about future • may be called on to care for others 	<ul style="list-style-type: none"> • stress of multiple loss can impact immune system • may worry about who will be there for him/her 	<ul style="list-style-type: none"> • lack of structured support for integrating ongoing losses, delaying grief • may be affected by inadequately addressed losses prior to AIDS death • helplessness/lack of joy in work

The following organizations can provide information about HIV/AIDS, direct you to services in your communities, or help you connect with other social workers.

National Organizations

Canadian AIDS Society (CAS) 613-230-3580	613-563-4998 (fax)
Canadian Association for HIV Research (CAHR) 514-340-8261	514-340-7502 (fax)
Canadian Association of Social Workers (CASW) 613-729-6668	613-729-9608 (fax)
Canadian Foundation of AIDS Research (CANFAR) 416-361-6281	416-361-5736 (fax)
Canadian Hemophilia Society (CHS) 514-848-0503	514-848-9661 (fax)
Canadian Public Health Association (CPHA) National AIDS Clearinghouse 613-725-3769	613-725-9826 (fax)
HIV/AIDS Treatment Information Network 1-800-263-1638	

AIDS Hotlines

Alberta	1-800-772-AIDS (2437)
British Columbia	1-800-972-2437
Manitoba	1-800-782-2437
New Brunswick	1-800-561-2437
Newfoundland	1-800-563-1575
Northwest Territories	1-800-661-0795
Nova Scotia	1-800-425-2437
Ontario	1-800-267-2437
Ontario (bilingual)	1-800-267-7423
Prince Edward Island	1-800-314-2437
Québec — general	1-800-463-5656
Québec — for health professionals working in HIV/AIDS	1-800-363-4814
Saskatchewan	1-800-667-6876
Yukon Territories	1-800-661-0507