

**The information needs of informal caregivers
involved in providing support
to a critically ill loved one**

**A synthesis report prepared for
Health Canada by
Janet Dunbrack**

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The views presented in this document are not endorsed by and do not necessarily reflect the views held by Health Canada.

Table of Contents

Executive summary	1
Introduction	3
Methodology	4
Terminology	4
Situations faced by informal caregivers	5
Information needs of informal caregivers	6
The right to ask questions or ask for help	6
Recognizing that needs evolve	7
Recognizing the diversity of learning styles and needs	7
Common information needs	8
Types of information services available	12
Pan-Canadian information services	12
Provincial/territorial information services	13
Other information sources	13
Gaps in information	14
Lack of service coordination	14
Lack of 24/7 information and service	14
Appropriate and timely information	15
Care provider communication skills and time constraints	15
Emotional and spiritual support	15
Diverse cultural needs	16
Conclusion	16
Information resources for informal caregivers: getting started	17

The information needs of informal caregivers involved in providing support to a critically ill loved one

Executive summary

Each year more than 220,000 Canadians die. Many die in hospital or other facilities but an increasing number are dying at home as the public health care system emphasizes home-based care in an effort to contain costs. As a result, the role of the informal caregiver – the families and friends of the ill person who provide care and support to their loved one – is becoming more prominent in end-of-life care. Research indicates that between 75 and 90 percent of home care is provided by informal caregivers. Whether their loved one is in a facility or at home, informal caregivers need information of all kinds in order to provide care for the ill person, practise self-care and resolve their bereavement after the death occurs.

Informal caregiving at the end of life can involve the transition to a new health care team and a new set of services as the care focus changes to comfort rather than cure. Informal caregivers need information in order to deal with new realities and make informed decisions. In addition to adjusting emotionally to an approaching death, the informal caregiver faces new demands in caregiving involving new situations and symptoms that may require their intensive involvement, particularly if the ill person is at home. Many informal caregivers may wish to provide care at home while others are uncertain of their physical, financial and emotional ability to do so. Some informal caregivers report that they felt they had no choice in the matter because of pressure from the health care system or a lack of facility-based beds. A further influence may be the desire to do the right thing, which is perceived as providing care at home. The idealization of home care by inexperienced informal caregivers or by professional care providers may further add to the pressure to say Yes to home care or to continue with home care in the face of exhaustion or financial distress. Informal caregivers need adequate, realistic information in order to make these choices.

Appropriate and timely information is an essential element in a positive caregiving experience. Those who receive the services of a hospice palliative care program report higher degrees of satisfaction with respect to adequate information than those who do not receive these services. Some fundamental attitudes influence the informal caregiver's ability to access information:

- feeling entitled to ask questions or ask for help
- recognizing that information needs change with time
- recognizing the diversity of personal learning styles and needs.

The most common information needs of family caregivers involve:

- pain management
- navigating a complex health care system with a variety of uncoordinated services
- bereavement support
- respite (time off for the informal caregiver)
- hands-on, practical caregiving information
- what to expect as the illness progresses

- dealing with the various members of the professional and volunteer care team: who does what?
- legal and financial questions
- emotional and spiritual support
- complementary and alternative therapies
- culturally appropriate services.

A number of information resources exist to meet the needs of informal caregivers. They include personal communication with health care professionals and volunteers, websites, toll-free telephone services, printed material, videos and DVDs. An increasing number of Canadians of all ages use the internet as a source of material although they have concerns about the validity of information from some websites. A list of reliable information resources for informal caregivers is given at the end of this report.

There are a number of gaps or challenges that create barriers for informal caregivers in their search for information. These include:

- lack of coordination between service providers
- lack of 24/7 information or services
- information that is not given in an appropriate or timely manner
- professional care provider communication skills and time constraints
- lack of adequate emotional and spiritual support
- meeting the diversity of cultural needs.

As informal caregivers take on a growing share of end-of-life care, they require appropriate and timely information so that they can fulfill the role they have chosen or assumed. A realistic assessment of their needs and the development of effective ways of communicating information will help them to both provide and receive high-quality end-of-life care.

Introduction

This brief report summarizes much of what we know about the information needs of informal caregivers -- sometimes described as families, friends and partners of the ill person -- who are involved in providing support to a critically ill loved one. The report is based on recent work by a number of Canadian researchers.

Each year more than 220,000 Canadians die. If we estimate that each person has five family members and friends, we realize that more than one million Canadians a year are affected by the death of a loved one. Many of those most closely affected are informal caregivers. Though informal caregivers are mostly women, there are indications that men are becoming more involved as caregivers. Researchers estimate that between 75 and 90 percent of care provided in the home is done by informal caregivers.

Throughout their caregiving experience and after the death of the loved one, informal caregivers need information of all kinds. Research indicates that informal caregivers are unaware of services that could help them and, because they have no information about these services, they do not ask for them. Some information needs are shared by most informal caregivers, such as the need to know how the person living with the illness will have their pain controlled, while other information needs are as varied as the particular situation being experienced and personal differences in learning style.

This report focuses strongly on the information needs of informal caregivers who are providing end-of-life care in their home because they often deal with many challenges and questions on their own. The report defines some terms commonly used in end-of-life care such as *informal caregiver* and *hospice palliative care*. It describes some of the common situations faced by informal caregivers and the information needs that informal caregivers have in those situations. The report touches on gaps in information for informal caregivers and includes suggestions that researchers have made for filling these gaps. The report ends with a list of resources that informal caregivers can use as starting points in their search for information.

Methodology

This report is based on the work of Stajduhar,¹ research papers written for Health Canada by Dunbrack and Ashpole,² the work of Heyland with a cross-Canada team of researchers (2004)³ and on a review of websites and publications listed in the resources section below.

Terminology

Many terms are used when we talk about care at the end of life. Here are definitions for some of the most common terms.

An *informal caregiver* is a family member, partner, friend, or neighbour who provides care for a critically ill loved one without pay. Informal caregivers are sometimes described as “loved ones”. *Family* is considered to include the biological family of “blood relatives” as well as the “family of choice” based on close relationships with the person who is ill. An informal caregiver may provide care and support at home or in another care setting where the critically ill person is receiving care. Informal caregivers are sometimes called *family caregivers* with the understanding that “family” can include anyone that the ill person or relatives consider to be close.

A *formal caregiver or care provider* is a paid professional who provides care, such as a doctor, nurse, social worker, or home care worker (sometimes called a homemaker).

Volunteers are trained members of the community who donate their time without pay. They are often part of a hospice palliative care team.

Hospice palliative care is defined by the Canadian Hospice Palliative Care Association as care aimed at relief of suffering and improving the quality of life for persons who are living with or dying from advanced illness or are bereaved. Hospice palliative care is sometimes referred to as palliative care. Hospice palliative care can be provided in many settings: hospital, residential hospice, nursing home, long-term care facility or at home.

End-of-life care includes all forms of care received at the end of life, including hospice palliative care, acute care (intensive care), and so on.

Home care is care provided in the home, usually with support from public or private health care providers. *Community-based care* is care provided in the community rather than in hospital; it can include home care or care in a long-term care facility or group home.

A *residential hospice* is a community-based facility offering hospice palliative care for live-in patients and support for their loved ones.

Respite is defined by the Canadian Association for Community Care as a break, time out or relief for the informal caregiver.

¹ Kelli I. Stajduhar. *The Idealization of Dying at Home: The Social Context of Home-Based Palliative Caregiving*. 2002.

² Janet Dunbrack. *Information Needs of Family Caregivers involved in Palliative and End-of-Life Care in Canada*. 2003.

Barry Ashpole and Associates. *The Informational Needs of Informal Caregivers from the Informal Caregiver's Perspective*. 2004.

³ Daren K. Heyland et al. *End of Life Care in Canada: A Quality Finish?* 2004.

Situations faced by informal caregivers

Informal caregivers provide care and support in a variety of settings, including the home, the long-term care facility, hospital or residential hospice. Those providing care at home will be involved in most aspects of care for the ill person, while those providing support to an ill person in a facility may be involved in feeding, clothing, exercising, care decisions and simply being with their loved one.

Informal caregivers may be involved in providing care for a period of months or years dating from the diagnosis of a critical illness and they may stay involved in caregiving until the loved one dies. This report concentrates on the information needs of informal caregivers providing care during the end stage of the loved one's life.

Once it has been determined that the ill person cannot be cured and that death is likely to happen within a few weeks or months, the informal caregiver is faced with a new situation and a new set of questions. The disease-specific organization that may have provided support and encouragement up to that point may not be able to provide support in the end-of-life stage. Many disease-specific organizations focus on finding a cure and supporting people to be survivors. Some persons living with a critical illness and their informal caregivers report feeling abandoned by the organization they had come to rely on even though the organization may have provided a referral to hospice palliative care services. In some cases, informal caregivers find themselves faced with the task of creating a whole new support network in addition to concerning themselves with the new details of caregiving at the end of life.

As the ill person and the informal caregiver enter the end-of-life stage, they are each adjusting to the reality that death will occur in the foreseeable future and that the loved one's physical and mental state may undergo significant changes as death approaches. This can be a major emotional challenge that requires time and support to come to terms with. Often in the preoccupation with the practical details of caregiving, the informal caregiver's emotional work is put aside only to surface in anxiety, fatigue, and depression or in physical symptoms such as headaches or muscle cramps. In addition to emotional working-through, spiritual concerns may come to the fore and be troubling to those who do not have adequate support. Although most of the information needs of informal caregivers concern practical matters, emotional and spiritual needs are also real. Some organizations that provide information services for informal caregivers report that informal caregivers may use a practical question as a way of finding a sympathetic ear for their emotional concerns in order to deal with the isolation and uncertainty of their situation.

Before we look in more detail at the information needs of informal caregivers, it is important to say a few words about choice, particularly concerning the choice to provide care in the home or to continue providing care at home as the illness progresses. Informal caregivers may make decisions about providing care in the absence of adequate information about what is involved. Realistic information about informal caregiving in the home could help them to make choices and assess whether they are able to put in place the resources they will need. In many cases, the informal caregiver may not feel they have the choice to say No to providing home care. Saying Yes to home care can lead to great responsibility because a high proportion of care in the home is provided by the informal caregiver rather than professional workers. The financial burden of home care can also be great because in many Canadian provinces and territories, drugs, supplies and nursing or care hours in excess of those provided by the health care system must be paid for by the family.

Research shows that women in particular feel that providing home care is expected of them, and they assume that they must take on the task regardless of whether they feel they can actually cope with it. This is true even for women who have to work to provide family income, who may have childcare responsibilities, or who may be frail and in poor health themselves.

As an illness progresses, informal caregivers may feel that they cannot cope any longer with care at home. They may experience guilt about these feelings, particularly if they see this as a failure or the breaking of a promise to the loved one. Informal caregivers report that the professional health care team may minimize the stress or burnout reported by informal caregivers and encourage them to “just keep going”. This links to the issue of the health care system’s focus on home care as a cost-saving alternative to publicly funded facility-based care and the loss of alternatives to home care as the number of facility-based beds is reduced.

In some cases, families may receive adequate support from publicly-funded home care services. In many cases, families who provided care at home reported that they did not receive adequate support and had to hospitalize their loved one when they could no longer cope. Some research indicates that the public health care system and many Canadians have an “ideology” of believing that home is the best place to receive care when the reality of informal caregiver experience indicates that more choices are needed because not all families can cope financially, emotionally or physically with the challenges of being at-home informal caregivers. The idealization of home care by the public health system and by inexperienced informal caregivers may also be related to an idealization of the concept of home, a concept that does not match current reality. Today most women work, families can be widely dispersed across Canada or around the world and many older people live alone, without the support of an extended family.

Information needs of informal caregivers

Appropriate and timely information can make the difference between a positive caregiving experience and a distressing one. Recent research reveals that informal caregivers attach high importance to the need to receive adequate information but that they are often not completely satisfied on this score.

As family members become involved in caregiving, particularly in the home, they are faced with new and sometimes bewildering situations every day. Knowing which questions to ask may be daunting in itself, as these informal caregivers said:

I didn't know what information I needed or what questions I should have asked. I was facing something I hadn't experienced before.

You don't know what you don't know.

Before we discuss the specific information needs of informal caregivers, it is important to note that there are some fundamental attitudes that influence the informal caregiver’s ability to access information.

The right to ask questions or ask for help

One of the hurdles faced by some informal caregivers is their reluctance to ask questions. Some informal caregivers will be assertive in asking questions while others will be more hesitant, especially if they feel that “the doctor is too busy” or if they have tried to ask questions and not received answers that satisfied them. Professional care providers have different degrees of openness to questioning and different levels of skill in responding to questions. Health care professionals are busy and some may not consider communication with informal caregivers to be of high importance, while others may feel uncomfortable about delivering bad news or dealing with issues with emotional content. These attitudes communicate themselves to informal caregivers who may feel reluctant to persist with questions. Some informal caregivers report learning to become insistent in asking questions and not stopping until they find satisfactory answers.

Feeling entitled to ask questions has an impact on caregiving. Research shows that families who are well informed are better able to be caregivers and experience less anxiety. Recent research also shows that informal caregivers feel that being involved in decisions about treatment and care is extremely important and that they often feel dissatisfied in this respect. Preserving dignity and autonomy is important for the informal caregiver, as well as the ill person, and feeling that their input or wishes are disregarded by the professional care team can lead to stress, fatigue and discouragement.

Recognizing that needs evolve

It is important to recognize the changing nature of needs for information so that both the informal caregiver and the care team can anticipate and plan for changing needs. As the loved one’s illness evolves, the information needs of the informal caregiver will also evolve. The priority one day may be learning about the newest symptoms and how to cope with them while the next day’s priority may be dealing with financial arrangements or wills and the day after that may be full of questions about finding respite care for the loved one so that the informal caregiver can have a break. After the death occurs, immediate concerns may be funeral arrangements while longer-term concerns may be finding bereavement support or arranging to go back to paid employment after a leave of absence.

Recognizing the diversity of learning styles and needs

Informal caregivers may need similar kinds of information, but their way of processing information can vary a great deal. Some people are hungry for all the information they can get – from health care professionals, the internet, books, volunteers, and friends. They want to know as much as possible as quickly as possible so that they can feel informed about the situation facing them in order to plan ahead.

Other informal caregivers prefer to receive information in smaller doses, as they feel ready for it, one step at a time. They may consult the same information sources as the information-hungry people, but they may need to have the information packaged and delivered differently so that they can absorb it at their own pace.

Informal caregivers who experience emotional stress or information overload because of the ever-changing nature of their situation may want to receive information, but many have said that they were only capable of remembering a small amount of what they heard or read. Few reported using paper and pen to write down information they were hearing because they had too much on their mind at the time. They preferred to have oral communication supplemented by information in a form that they could go back to again

and again so that they could assimilate it when they were able. Many caregivers reported that they were glad to have a pamphlet, book, website or video to refer to over time to refresh their memory or fill in the blanks.

Another factor in absorbing information is the difference between individuals in their learning style: some people absorb information best if they see it in words (books, printed information, and websites) while others absorb best from visual images such as videos or films. Still others absorb information best by hearing it (conversation, cassette tapes, videos, films) while others absorb best by doing (demonstrations or “show me what you mean”) and many get the best results from a combination of these approaches. Some hospice palliative care services have stressed the need to make resources available to informal caregivers as early as possible so that they can approach information at their own pace and know that the information is at hand when they need it.

In addition to having personal learning style differences, informal caregivers of diverse ethnocultural backgrounds may require culturally-sensitive approaches and information sources as they try to work with a host of services and care providers who may be of backgrounds different from their own.

Differences in vocabulary between health care providers and informal caregivers can cause similar communication problems. Physicians may use medical jargon that is normal in their culture (the medical world) but incomprehensible to a non-medically trained informal caregiver, no matter how well educated.

Common information needs

The information needs of informal caregivers will vary with individuals and their situations. Recent research, however, reveals that the following needs are most common.

Pain management

The need to know how to get pain relief for the loved one emerges as the most frequent information need of informal caregivers. In some cases, this need is a plea for help when pain management appears to be inadequate. Informal caregivers are often the most aware of the loved one’s condition because of the amount of time they spend with them, particularly in home-based care, and because they know the loved one and are sensitive to their states. Informal caregivers can feel frustrated if their observations are not taken seriously by the professional care team. Informal caregivers report feeling fearful when pain breaks through, especially during the night or on weekends when the home care team may not be available. Those registered in hospice palliative care programs usually have access to a 24/7 help line and the possibility of home visits but those who do not have access to these programs often resort to provincial telephone advisory services and are referred to hospital emergency departments or their family physician who may not be available.

Navigating the system

Informal caregivers need information about navigating the health care system: learning who does what and how to access services. Many informal caregivers report time-consuming telephone searches in the transition from hospital to home care when there is a need for a variety of services but little coordination among service providers. National help line and information services report frequent requests from informal caregivers for information on services in their region, or in other regions when families are dispersed and trying to arrange care from a distance.

Informal caregivers report having to become their own case managers and having to assemble a variety of services from various providers, some publicly funded and others at financial cost to the family. Many informal caregivers have expressed the wish that there could be a single entry point for all health care services and referrals, or that there could be a coordinator or navigator who could inform them about what is available and how to access it. Informal caregivers have also expressed frustration with having to repeat their story to a variety of service providers or to a constantly changing set of providers within the same service.

Bereavement support

Requests from informal caregivers for information on bereavement support are common, according to information services that respond to informal caregivers involved in end-of-life care. This may reflect the reality that many Canadians are not linked to hospice palliative care services that would have referred them to bereavement programs, or they may have lost a loved one to sudden death. Research has shown that men work through bereavement differently than women; the bereavement needs of men need more research and probably the development of new models that do not rely mainly on the sharing of feelings in a group.

Respite

Informal caregivers need a break in order to recharge their batteries and be able to continue caregiving. They also need breaks to attend to other things in their life such as child care, relationships with people other than the ill person and care providers, shopping, their own health care and so on. Informal caregivers often express the need for information on respite services. The challenge for most informal caregivers is similar to that encountered when trying to navigate the health care system: there are many public, voluntary sector and private providers of respite services and tracking them down can be time-consuming. The further challenge is that often these programs have long waiting lists.

Caregiving information

Most informal caregivers are not trained nurses or health care professionals and yet they find themselves taking on a large part of care in the home. This can involve operating equipment such as a hospital bed that may have been brought into the home, turning the ill person in bed, giving fluids, food or medication, changing soiled bedding and clothing, and so on. Informal caregivers have expressed their desire to do these tasks in an effective and safe way and many have said that they need information on how to do so. Information services report fairly frequent requests for caregiving information from informal caregivers. Informal caregivers are often referred to their health care professional for help or to caregiving books and videos or DVDs. Informal caregivers often report that the professional team does not have time to instruct them; they then try to cope as best they can, sometimes at the risk of injury to themselves.

Some informal caregiver associations and health care associations have expressed the concern that the health care system is off-loading home care to informal caregivers and that providing technical training to informal caregivers will only increase the pressure on them to do more. This is an issue that requires more public discussion.

As the disease evolves: what to expect so we can plan

Most informal caregivers have said that they need to know what to expect as their loved one's illness progresses so that they can both plan at the practical level and be emotionally prepared for changes. Questions often focus on the illness: *How long will my loved one live? How do I deal cognitive impairment or dementia? How do I deal with alarming new symptoms? What happens when death occurs?* Other questions focus on the financial and physical context: *How long a leave of absence should I ask for from my job? How long will we need this equipment in the home?* Still other questions focus on the informal caregiver's ability to continue to provide home care: *How hard will it get and will I be able to cope? At what point might the ill person have to be hospitalized if I can't cope? Will there be a bed in a facility for the ill person if they do have to leave home?*

Information services usually refer these types of questions back to the family's physician or care team. Here again, the professional care team may or may not have the time or communications skills to deal with these questions. Questions about the length of time until death are difficult for even the most skilled professional to answer because time of death is almost impossible to predict.

Dealing with the professional and volunteer care team

Some informal caregivers involved in home-based care report feeling that their home was "invaded" by a procession of strangers and that they felt displaced and no longer "at home" in their own house. The questions asked by informal caregivers about the care team often focus on what job each member of the care team does so that they know who they are dealing with and which questions are appropriate to ask of each member of the team. Informal caregivers will often ask if there can be continuity in the members of the care team so that they are not always getting used to new faces and having to explain their situation over again. Some informal caregivers have suggested that they be briefed about the members of the team who will be coming into their home or, if the ill person is in a facility, about the roles of the various health care providers.

Volunteers were mentioned by many informal caregivers in the research as occupying a special place. Informal caregivers will often turn to volunteers for information that they cannot get from the professional care team. They may also ask volunteers to verify information given to them by others or obtained through the informal caregiver's personal research. The volunteer is evidently seen as someone who is available and "there for them", probably because one of the volunteer's chief roles is to provide emotional support.

Legal and financial questions

Becoming an informal caregiver with a critically ill loved one involves many legal and financial issues. Informal caregivers who are in the work force may need to take time off work in the form of a vacation or a leave of absence. Many of their questions revolve around how much time off work to plan for, which may be difficult for a physician to estimate. The Employment Insurance Compassionate Leave plan allows for up to six weeks of partial coverage of earnings. Because the plan is fairly new, it is too early to know how much informal caregivers are using the plan and what questions they have about it.

Those who are taking care of their loved one at home have many financial questions about the potential cost of drugs, supplies and equipment that may not be paid for by the public health plan. They also have questions about the cost of obtaining more support

beyond the number of hours allotted by the public system. Some information services report questions from informal caregivers about where they might access financial aid to help them cover home care costs.

The need for legal information usually focuses on wills, advance directives (the “living will” in which the ill person may have stated that they do not wish extraordinary measures to keep them alive in the event of heart or respiratory failure), or the power of attorney and when it should be activated if the ill person can no longer make their own decisions. Some information services can answer these questions through referral to appropriate programs while others will refer informal caregivers to their provincial bar association. Some informal caregivers also need information about who to call when a death occurs and about the proper procedures to follow.

Emotional and spiritual support

Evidence indicates that the need of informal caregivers for emotional support may be great but this need has not yet been thoroughly measured by research. Being an informal caregiver when a loved one is critically ill is stressful and emotionally demanding, whether the ill person is being cared for in a facility or at home. Informal caregivers who are interviewed after the death has occurred, in looking back on their experience, often report that they needed someone to talk to who was not part of the family or care team, someone to whom they could speak frankly about their feelings. Being able to do so is seen as an important way to relieve stress and find the strength to keep going. It is not easy for some informal caregivers to ask the question, *Who can I talk to?*, because they report feelings of guilt about being concerned about their own needs rather than those of the ill person. They also express a reluctance to burden the busy professional care team or feelings of awkwardness about admitting that they have emotional needs.

Some information services report that the apparent reason for many phone calls from an informal caregiver is a need for practical information, but that the caller quickly begins to share their emotions if the listener is sympathetic. One information service estimated that 50 to 70 percent of calls from informal caregivers were actually calls for emotional support. As one informal caregiver said: *You can go through anything if you know you're not alone*. Informal caregivers and volunteers report that the volunteer plays the vital role of empathetic listener who has no personal agenda with respect to the family.

Death raises spiritual issues for many people as they seek to find meaning and to integrate the experience into their system of values. Canadians have a decreased attachment to faith communities compared to the past and our society is increasingly pluralistic. Some informal caregivers report that they wanted to talk to someone about spiritual concerns, or about the spiritual concerns of the ill person, but felt reluctant to approach chaplains if the informal caregiver had no official affiliation with a faith. At the best of times, it can be difficult to confront the big spiritual questions but unresolved spiritual questions can cause anguish at the end of life if no support is found.

Complementary and alternative therapies

Some information services and hospice palliative care services report that informal caregivers request information on complementary and alternative therapies such as massage, healing touch, herbal treatments, and so on. Some of these therapies are associated with a holistic approach to the person and to healing that may have special appeal for those dealing with approaching death.

Culturally appropriate services

Some informal caregivers who participated in studies expressed the need for culturally-appropriate information or services, although most Canadian studies to date have focused on informal caregivers who can speak English or French. Aboriginal families have often expressed the need to find culturally appropriate services.

Informal caregivers report intergenerational differences when their ill loved one is an older person who may have retained a strong tie to cultural traditions or their language of origin after they immigrated to Canada, while the generation providing family care was born in Canada and is more at home with the Canadian system. These informal caregivers need information about services that are culturally appropriate for their loved one. Other families who have arrived more recently in Canada often have questions about how to find information and services in their language of origin. Those in large urban areas have more success in finding a diversity of culturally appropriate services and may find support from ethnocultural associations.

Rural areas

Informal caregivers living in rural areas may have different means of obtaining information compared to those living in urban areas. Some professional service providers and information services observe that people in rural areas know each other and know their service providers. Information is shared through an informal network that can be highly effective. On the other hand, rural areas have fewer services to choose from than urban areas and concerns about privacy and confidentiality may cause informal caregivers to seek information from the internet and other neutral sources.

Types of information services available.....

A variety of information sources exists for informal caregivers. These sources are able to meet some, but by no means all, of the informal caregiver's information needs. Research indicates that a growing number of informal caregivers of all ages use the internet as a primary source of information, although some have concerns about the reliability of web-based information. All information services and resources listed here are considered reliable; some websites may have disclaimers with respect to linked websites.

The following section describes the most common types of information sources. Contact information for major information services is given near the end of this report.

Pan-Canadian information services

Canadian Hospice Palliative Care Association

The Canadian Hospice Palliative Care Association (CHPCA) maintains a website that provides information about hospice palliative care. The site has a directory of Canadian hospice palliative care services. It also provides links to a variety of other useful websites and to the provincial hospice palliative care associations. CHPCA distributes publications that may be useful to informal caregivers.

Living Lessons

The Living Lessons program is a joint venture of the GlaxoSmithKline Foundation and the Canadian Hospice Palliative Care Association (CHPCA). The program provides print and web-based resources for informal caregivers and professional care providers involved in end-of-life care. The national Living Lessons toll-free telephone information service and e-mail information service are housed at the CHPCA Ottawa office.

Canadian Virtual Hospice

The Canadian Virtual Hospice is web-based service for people dealing with life-threatening illness and loss. The service provides a means for informal caregivers to ask general questions of health care professionals, learn about end-of-life care, share their experiences with others through chat rooms and posted information, and obtain information about useful resources. It also provides resources for patients, volunteers and health care professionals.

Canadian Caregiver Coalition

The Canadian Caregiver Coalition represents the interests of informal caregivers, including those involved in end-of-life care. The Coalition aims to be a national clearing house for caregiver information, resources and research. It is an active advocate for caregiver issues at the national level but does not provide direct services to caregivers.

Disease-specific services

The Canadian Cancer Society maintains a national cancer information service consisting of a toll-free telephone line and web-based information as well as print resources. It does not directly provide information about end-of-life care but is well linked to hospice palliative care services and provides referrals to these services.

Other disease-specific organizations such as the Heart and Stroke Foundation, the ALS Society of Canada, the Canadian AIDS Society, and the Huntington Society of Canada do not offer national information services for informal caregivers, although they have some publications that touch on end-of-life care. Some organizations have provincial and local information and service offices.

Provincial/territorial information services

Provincial hospice palliative care associations

The Hospice Association of Ontario provides an End-of-Life Information Service for informal caregivers, patients and others interested in end-of-life care. The information service website contains material of interest to informal caregivers, among others. A confidential telephone information line is available.

Most provincial hospice palliative care associations do not provide a primary information service for informal caregivers because of lack of human and

financial resources. The associations do what they can to provide information and referrals to appropriate services or resources.

Provincial/territorial health care telephone advisory services

Most provinces and territories have toll-free telephone advisory services available 24 hours a day, seven days a week. These services provide referrals, information and, in some jurisdictions, can send a nurse to the home. Referrals are usually made to the family physician, emergency services, palliative care programs or voluntary sector services.

Other information sources

Health care professionals

Health care professionals, and especially doctors and nurses on the care team, are usually the informal caregiver's first resort when seeking information. In most cases these professionals can be good sources of direct information or referrals to information. In other cases, as has been noted in a great deal of research, health care professionals may not have the time or skills to provide the information that informal caregivers need. Another factor in receiving adequate information is the ability of the informal caregiver to absorb the information offered because of stress or personal learning style, as was discussed above. Many informal caregivers told researchers that they had much higher satisfaction once their care was turned over to a hospice palliative care program.

Interestingly, an Ipsos-Reid poll conducted in 2004 found that pharmacists were an important source of information about care, particularly for older Canadians.

Books, video and film

There are many books for informal caregivers, ranging from practical advice to personal accounts of the experience. Libraries, bookstores and the internet are sources of information on books, video and film (DVD). Health care professionals and volunteers are usually willing to recommend books that are well regarded as helpful for informal caregivers.

Gaps in information

Research shows that many health care providers and information services do a good job of providing information, with hospice palliative care services in particular receiving high satisfaction ratings from informal caregivers. Other research shows that informal caregivers are not entirely satisfied in their need to receive adequate information. In many interviews with researchers, informal caregivers spoke of the following gaps.

Lack of service coordination

Recent research has shown that having an adequate plan of care and health services available to look after the patient at home upon hospital discharge is considered extremely important by informal caregivers and that they are often not satisfied in this respect.

Lack of coordination between health care services is a major source of frustration for informal caregivers, particularly when the ill person is transferred from hospital to home. Many informal caregivers report that they spend precious time calling many services to find out who does what and how to receive their services. They report that professionals working for one service appear to be unaware of the details of other services and are therefore unable to provide information or advice. Informal caregivers suggest that a single entry point for all services would be an enormous help to them, or a person who would act as guide and navigator through the complex system. Further, informal caregivers suggest that a “map” of the system and the many services available would help them to know what is available and how to access it.

Lack of 24/7 information and service

Pain or other symptoms can break through at any time outside normal professional working hours. Informal caregivers express concern about who to call for information and help at night and on weekends when unexpected things happen. Some informal caregivers report being told by health care providers to take the ill person to a hospital emergency department, which has caused anguish given the frail state of the ill person and the prospect of dying in a busy hospital corridor. Those registered with hospice palliative care programs report higher satisfaction because these programs are often reachable on a 24/7 basis. The problem of lack of information or service outside normal working hours can only be solved by investing in additional staff and services, which involves the larger question of cost containment by health care systems.

Appropriate and timely information

Effective communication of information often depends on knowing what is timely and appropriate. Good information can be lost or not absorbed if it is given in too large doses when the informal caregiver is not able to receive it because of feeling overwhelmed from dealing with too many things at once. Information can also be lost if a caregiver who has, for example, a learning style that works best in personal conversation is given instead a stack of reading material. Many informal caregivers report that they value personal communication with a professional care provider or volunteer but that they need to supplement this communication with a variety of other types of information. Many say that they also need web-based reading or printed pamphlets supplemented by film or video in order to help them absorb the same information better and because they can refer back to this material again and again and absorb it at their own pace. They also point out that they are more open to information at some stages of caring for the ill person than at other times. These findings suggest that those dispensing information need to be aware of and sensitive to the reality of different personal learning styles, the variable openness to information of informal caregivers at different times and the need to back up one form of communication with another. It could also be useful for care programs to provide orientation to informal caregivers on how to access the many forms of information available.

Care provider communication skills and time constraints

Most research involving professional care providers or informal caregivers indicates that professional care providers often have limited time to spend in communication because of their heavy work loads. Some professionals admit that they find it hard to communicate bad news. They may also fall back on specialized professional vocabulary without being aware that the informal caregiver may not understand what is being said. Informal caregivers report that communication often receives short shrift from the professional care team. This transmits the message that professionals do not consider it important to brief the informal caregiver or involve them in informed decision making. Many informal caregivers and volunteers report that the volunteer is often the person they will turn to for information or support when they cannot obtain it from the professional team.

Those providing care can improve the informal caregiver's access to information by both improving the communication skills of the care team and recognizing that informal caregivers may sometimes need encouragement to overcome their reluctance to ask questions and "bother the busy professional". Professional training in recent years places a higher value on effective communication than in the past. This should have the gradual effect of improving communication between professional care providers and informal caregivers as new graduates enter their professions. The role of volunteers in bridging the communication gap should also be recognized and possibly enhanced.

Emotional and spiritual support

Emotional and spiritual support are real needs of informal caregivers that are often neglected because: the caregiver is so preoccupied with practical details that they push aside their other needs; they feel guilty about asking for personal emotional support when their loved one may be living with distress that seems more important than their own needs; or they feel embarrassed about needing emotional support. Information about sources of emotional and spiritual support may be available, but informal caregivers may be reluctant to use it. Volunteers often fill the gap because they have time and are trained listeners, as are the staff of telephone information services. Informal caregivers may also feel reluctant to turn to chaplains for spiritual support if they do not belong to a faith community. In contrast to hospitals, most home care service teams do not include spiritual support workers.

In order to fill this gap, both informal caregivers and those who provide service can recognize that the need for emotional or spiritual support is real even if it is not directly expressed. Respectful, non-intrusive ways of offering support can be learned. Volunteers can play an important role.

Diverse cultural needs

Every needs assessment shows the importance of being aware of diverse cultural needs, particularly in urban areas with many ethnocultural communities, and of providing culturally-appropriate information. This is an ongoing challenge for all service providers which involves working with ethnocultural communities to develop resources. Training for professionals and volunteers in working with diverse communities is essential.

Conclusion

The information needs of informal caregivers are many and diverse. The need to receive adequate information is an area of concern for informal caregivers and a challenge to service providers in the health care system. The growing emphasis on home-based care will result in a growing need for informal caregiver information as family members take on a greater share of end-of-life care. If informal caregivers are key members of the caregiving team, they require appropriate, timely information and support so that they can fulfill the role they have chosen or assumed. A realistic rather than idealized look at the situation of informal caregivers is required and the development of effective means of communicating information is needed. Otherwise a too-heavy burden will be placed on informal caregivers and all those involved in quality end-of-life care will suffer.

Information resources for informal caregivers: getting started

The following reliable information resources are intended to be a starting point for informal caregivers. Many of these resources link to other sources of information.

Employment Insurance Compassionate Care Benefits

The federal Employment Insurance program provides up to six weeks of benefits for those in the work force who must leave their jobs to care for a family member who is expected to die within 26 weeks. The definition of family is restricted to close relatives and does not include brothers and sisters. Further information is available at Government of Canada Employment Insurance offices or online at: www.hrsdc.gc.ca/asp/gateway.asp?hr=/en/ei/types/compassionate_care.shtml&hs=aed.

Useful websites and telephone-based services

Canadian Hospice Palliative Care Association

www.chpca.net. The Canadian Hospice Palliative Care Association website contains information for informal caregivers and is a good starting point for seeking information because of its links to many other web resources, including the provincial hospice palliative care associations. CHPCA offers a free guidebook for informal caregivers, *A Caregivers Guide: A Handbook about End-of-Life Care*, that can be ordered online. The website also has a directory of hospice palliative care services in Canada.

Canadian Virtual Hospice

www.virtualhospice.ca. The Canadian Virtual Hospice offers information for informal caregivers, chat rooms, bulletin boards and the ability to ask general questions online of a health care professional.

Living Lessons

www.living-lessons.org. This website has information about hospice palliative care and offers resources for informal family caregivers. The Living Lessons handbook, *A Guide for Caregivers* and *10 Tips for Caregivers*, are available on the website. A printed copy of the guide for caregivers can be ordered from the Living Lessons telephone information line. The national toll-free information line is 1-877-203-4636. This line is staffed during weekday working hours in the Eastern Time zone and has an answering machine to take after-hours messages.

Hospice Association of Ontario: End-of-Life Information Service

www.hospicelifeline.com. This website has on-line information for informal caregivers and offers confidential telephone help and information during weekday working hours. Messages can be left on the answering service at other times. The toll-free (in Ontario) number is 1-800-349-3111, ext. 28 or (416) 979-9779.

Books, videos and films

The best advice is to consult a trusted professional or volunteer or a library or bookstore for current titles because new books on end-of-life care and informal caregiving are released each year. Several internet-based bookstores such as Chapters.ca or Amazon.ca sell resources. Canadian Harry Von Bommel has written several books about informal

caregiving end-of-life caregiving and provides references to other books and resources on his website at *www.legacies.ca*.