

**COPING AND HELPING WITH ALZHEIMER'S DISEASE**

**by**

**Walter Lyons**

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**National Advisory Council on Aging**

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The Writings in Gerontology present in-depth examinations of topical issues in the field of aging. The opinions expressed are those of the authors and do not necessarily imply endorsement by NACA.

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## **WHAT IS THE NATIONAL ADVISORY COUNCIL ON AGING?**

The National Advisory Council on Aging (NACA) was created by Order-in-Council on May 1, 1980 to assist and advise the Minister of Health on issues related to the aging of the Canadian population and the quality of life of seniors. NACA reviews the needs and problems of seniors and recommends remedial action, liaises with other groups interested in aging, encourages public discussion and publishes and disseminates information on aging.

The Council has a maximum of 18 members from all parts of Canada. Members are appointed by Order-in-Council for two- or three-year terms and are selected for their expertise and interest in aging. They bring to Council a variety of experiences, concerns and aptitudes.

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## FOREWORD

The *Writings in Gerontology* Series is intended as a vehicle for sharing ideas on topical issues related to the quality of life of seniors and the implications of an aging population. It is produced as part of the National Advisory Council on Aging's mandate to publish and disseminate information and to stimulate public discussion about aging.

The Council endeavours to ensure that the articles in the series provide useful and reliable information. Most of the texts are original manuscripts. Some are written by Council staff, others by experts in their fields.

This series is addressed to seniors and the people who care about their well-being. It is hoped that readers will find the *Writings* useful.

The Council welcomes comments on the topics selected as well as on the contents of the articles.

Susan Fletcher  
Executive Director  
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## PREFACE

This paper is based on a speech that was first presented in June, 1981 at the *Social Work Clinic Day* at the Baycrest Centre for Geriatric Care in Toronto by the late Walter Lyons, then Director of Baycrest's Department of Education.

First published as a report in 1984, it has become widely read and has been reproduced many times. The National Advisory Council on Aging has reviewed its contents and has found that although medical research on Alzheimer's disease is now more advanced, no similar publication is available. The author's discussion of the problems caused by chronic irreversible brain damage remains as compelling a reading today as it was over a decade ago.

Lyons' narrative of the family's reactions when one of its members has Alzheimer's disease and his description of the patient's expectations and those of the spouse clearly show that he favours the human aspects over clinical considerations. He addresses the reader as the patient, the spouse and the social worker.

The Council is indebted to the late Walter Lyons for use of his material. No doubt everyone, whether lay person or specialist, will benefit from the lessons offered.

John E. MacDonell, M.D., FRCP(C)  
Chairperson

## **INTRODUCTION**

What we are talking about today is mental impairment caused by chronic irreversible brain damage, whether that damage is caused by multiple strokes or a deterioration of the brain cells of the Alzheimer's type. What terrible conditions they are—terrible because of what they do to the affected individual. It could happen to me. A sudden hemorrhage or blockage in circulation in my brain could slash and rend parts of that marvelously complex computer, my brain. Or Alzheimer's disease could eat away slowly, destroying brain cells bit by bit.

Whether it is by tearing or slow erosion, the effect is to loosen my grasp on my world—humbling and confounding me, as it narrows the portals of my brain; scrambling and distorting my communication with the things and the people around me; depriving me of my ability to recall what has transpired a short time ago, but leaving intact my emotions, my feelings, and affecting my other senses in ways that we do not always know. My ability to taste, to hear, to feel by touching, seem to be intact, but in the rare instance even my eyesight may be affected. There is a fluctuation and a variability in my performance which neither you nor I can explain.

### **1. THE IMPAIRED PERSON'S PERSPECTIVE**

#### **1.1 Self Struggle**

You only know me from the outside, through my 'abnormal behaviour'. Will you see me inside, struggling to maintain my assaulted personhood? Will you mistake my struggle to retain some dignity, some feeling of self, for organic disease rather than its consequences? For me, this is a life and death struggle from which I can collapse into crushing defeat and withdrawal, or I can be aroused to a fever pitch of agitation and frustration expressed in pacing, in tearing at my clothing, repetitive movements or sounds. You may think I am 'completely out of it', but if you watch me closely I may startle you with my awareness of, for example, the danger of walking down steps or the presence of a person, or I may be searching for a person or an activity which I



usually do around this time of day. My attempts to indicate to you that I am missing something may not make sense, and you may write off my behaviour as the meaningless actions of a person who lacks memory and does not know what time it is, or where he is. Yet, inside, in my own perception of things, I am reaching for something very real, and trying in my own way to find it or to get you to help me.

What a terrible condition it is which malignantly erodes my normal competence, reducing me to increasing degrees of dependence upon others to supply what I cannot provide for myself, whether it be protection against danger, supplying or preparing food, finding the toilet or putting on or taking off my clothing, actions which seem so fundamental that when I cannot do them, you cannot picture me as having any brains or ability left at all. But you may have too superficial a view of my capabilities. When, seemingly, I do not eat the food placed in front of me, all I may need is just a little help in starting, by putting a spoon or cup in my hand, or maybe putting a piece of food on my fork. If you put all my clothing in front of me and expect me to dress, I may not be able to. But I may be able to do a fair part of it if you hand me one piece at a time and give me a little bit of guidance. Do you have any idea what it means to me to be able to do a little bit? Do you know how good it makes me feel when somebody understands that I want to do something and cannot, and they help me to do it?

## **1.2 Struggle Against Other People's Attitudes**

Yes, I have problems understanding and communicating. But, in addition to the problems within me, I have to face your attitudes, your ability to be blind to what is really going on in front of you, your distortion and warping of what I am like, your impatience with my slowness, with my difficulty in grasping what you are trying to do or say, with my inconsistency. Therefore, you may ignore what I can do. You may miss or dismiss the abilities I do have. You may fail to help me do what I can do, by not taking the time and trouble to discover this. It is much simpler to do things for

me, because that way is quicker and surer and more efficient. But, do you realize that this may make me more confused, frustrated, sometimes resistive and resentful. Sure I am cognitively impaired, but that means you have to use **your** ingenuity and **your** patience to help me to clue into what you want me to do and to try to understand what I want to do.

Then I face the opposite kind of problem in which, because of my inability, you may think I lack motivation and, therefore, you try to pull or push me into doing things in the belief that somehow, if I am not pushed into them and I am not engaged, you are colluding in making me more helpless. Indeed, I may lead you to that belief. Because at times I may seem more able than at other times, I can confuse you and mislead you into believing that I am more able than I really am. I may need activity, but activity with which I can cope, which I can enter easily, which does not strain my impaired cognition—'fail safe' activity which does not leave me frustrated. There is quite a difference between pushing and helping, just as there is between helping me to do something and doing it for me.

But it is not only your misperceptions of me which add to my problems. It is also what you are feeling deep inside of you, because I know you are terrified by my losses. You are well-meaning, well-intentioned, normally kind and considerate. But inside, you cannot help but feel not just pity, but some revulsion; not just empathy but also some rejection. If you are going to help me and my family, you will need to know and face this in yourself, and drop the self-deceiving belief that you can easily empathize with my state. You have to experience that painful and humbling struggle to find true identification with me, as it does mean being frightened, both by what you can see may happen to another person, and by the feelings which, loathe them though you may, are aroused in you. You, like anyone else, are frail and sometimes you will protect yourself with unintentional callousness. When I am incontinent, I do not like it. I can still experience shame and embarrassment. But I am helpless to protect myself against it, especially when you are not tuned into my signals when I want to

go. I am also helpless to protect myself against your annoyance and disgust. Do you know how dependent I am upon you to protect my dignity which is so often assaulted?

### 1.3 The Isolation Barrier

Those are some of the things you will have to accept within yourself, if you are going to tap your own capacity to reach out with emotional feeling, and try to make connection with my struggling self. It is largely on the emotional level because, with my damaged brain, it is my emotions and feelings which remain intact, and of which I have the most use. Therefore, those of you who are more practised in using your feeling self will be better at making a connection with me and my situation, than those whose intellect is your main means of engagement.

You have to be able to sense my fear, and connect with it, not by reasoning or trying to argue me out of it, but by being with me in ways which help me to feel less alone and help others to make that kind of connection with me too. How much better that feels, than to have you 'yacking' away, trying to tell me I have nothing to be afraid of, when I am shaking inside and only feel your separation, your annoyance, your not understanding and, therefore, your lack of support. Help me to understand that you are with me and that I am not alone; that you are with me to protect me.

I know that you really cannot cut down all the barriers that isolate me. But you can look for those things which reduce my frustration, which help smooth the way in the face of what confounds me, if you take the time and make the effort to help me bridge, at least partially, that cognitive gap which separates me from outer reality. "I am not gone, I am here." Do you really know how terribly **alone** I am, closed in and cut off from so many people and so many things around me? How I try, and why I cry? For God's sake, help me in my terrible isolation. That is my cry and my pain at its most raw and elemental level.

## **2. THE FAMILY'S PERSPECTIVE**

### **2.1 Reactions of the Family**

Speaking now as a social worker, I have to admit that the condition of cognitive impairment is really terrible. Yes, we helpers can and do pull out of contact. After all, our contacts are, at best, partial. But what of the families of mentally impaired people, who are connected and tied with multiple strands of attitudes, emotions, responsibilities and well-worked and established habits of relationship to an individual who once was fully functioning?

They have a web of practised roles and attitudinal relationships, born and nurtured over time, in a multitude of experiences. The impairment of their relative, the gradual failure of that person to carry his part and to fulfill his accustomed role, is experienced, especially by those closest to and dependent upon him, as a one-sided, unearned, unsolicited, arbitrary change, which upsets the balance achieved between them, inevitably producing protest and anger. Seemingly, without reason or provocation, the rules of relationship are changed by the impaired one, by perhaps not wanting to do what 'they have always done', by leaving things for others to do, or by withdrawing from accustomed joint activity with unusual excuses, which often precipitate argument and then concern and pressure to right the balance. These encounters can cause increasing defensiveness and irritability and seeming irrationality on the part of the impaired person, and growing preoccupation with these changes, and reactions to them, on the part of the person or persons who are drawn into becoming the primary caregiver or caregivers.

Then there is the ripple effect upon the relationships and involvements with other members of the family, which calls forth their attention and their effort to respond, perhaps with helpful advice or direct intervention. Thus, gradually, the whole family system is affected. Each of its various parts, fitted together in accustomed roles

and stances, becomes individually reactive to this change, with a variety of opinions and differing assessments of the meaning and the source of the change in the affected individual. These very differences create new situations within and among the members of the family system, with which each must cope. Thus we see strain and/or strength in the relationship between the primary caregiver and their supportive network. The one who is primarily affected by the changes in the impaired person, usually a spouse, who is himself or herself struggling to find a new balance with the impaired family, may also be burdened with the concerns of other members of the network about either overprotection or underprotection or in some cases complete denial of any cognitive change. Such change may indeed be difficult for some to detect initially, because of the retained social ability. The relative who comes in asking, "Do you know who I am?" may deservedly get in reply, "Of course I know who you are. Why do you ask me?", even though names have been lost.

Some may regard the impaired person's behaviour as merely an extension of what they have experienced previously: "Mother could always fail to understand what she didn't like to hear. She's just manipulating again." Some will get stuck on blaming the source of the deterioration on past failures or strains. Others need to push therapies, like vitamins, diet or lecithin. Like chicken soup, they cannot hurt, and they may help, if there is an undiscovered deficiency along with the deterioration.

Some family members, whose separation from parents or other members of the family has been hard won and is still fragile, may have aroused in them the fear that they will be overwhelmed and sucked in, and therefore may respond with hurtful rejection. It may entrap a person deeply who is already carrying guilt for separation. The call and the need for help may be convenient excuses for a family member to withdraw from his/her own troubled family relationships.

One of the most common effects of the new demand is to expose old angers, rivalries, hurts and misconceptions among siblings, which have the potential to paralyze action, or make it labourious, circuitous and hazardous.

## **2.2 Role of the Social Worker**

### **2.2.1 Collaboration between family members**

Whatever are the reactions, it is certain that the onset of cognitive impairment has reverberations in the family that are disturbing. It is usually after this web of relationships has undergone strain and tension for a length of time that the situation comes to social workers. After all, there is always something which precipitates the decision to seek help, and it is always important to find out what that is. It is also essential to take pains to find out what is really going on and not come in like a knight on a white charger who will set things straight. Often, it may be clear to an outside observer that one or more members of the family are misguided in their assessment of the situation. The real task is to 'scout the territory' carefully, to understand where the problems are placed, and on whom, and test out how much room there is for individuals in the family group to listen to the other person, and accommodate themselves to the possibility that they might be wrong in their assessment. In the matter of cognitive impairment, there is lots of room on all sides for misinterpretation and for incorrect assessment. The first task is to help the family be ready to take account of different possibilities about illness, about what might be done and about each other.

In regard to the latter, the family members naturally look for familiar patterns of response in each other, to which are attached value judgements. The fulcrum for change lies in the worker's participation, holding to what each can contribute to the present situation, valuing it in this context, and not allowing attributions from the past to take over the stage. The fresh start and the necessity for, and respect for, each one

to share his ideas and his effort, form new ground upon which a way to act together can be found.

In this situation, like any other, it is important to have a basic clarity about our helping task. It is to help the family system and the members within it put together a framework of understanding among themselves and about the situation which enables them to act. This restores a sense of direction and at least a modicum of control, in what seems like a situation which is quite out of control.

It is important that this process we call 'assessment' really needs to be understood by the family as a beginning of a search and discovery in which all, including the social worker, can participate and share, the social worker bringing, hopefully, the advantage of the agency's accumulated experience. The objective is to sort out problems and work together on finding ways to deal with them.

This needs to be a mutual process, as in truth it really is, for the family is coming for help in arriving at their own assessment of their problem and what to do about it. Setting them up as spectators and information givers who hand over everything they can to an expert panel, who in due time will hand down their supreme court decision, is not a social work helping model, although it may be a good medical one. Therefore, the help which families need to get a hold on their situation, help which gives them some direction, begins right during the initial assessment process.

### 2.2.2 Participation of the family in the medical assessment

It is within this framework that the importance of a full medical assessment and the family's participation in it is critical. If this has not taken place, or if it has, and the family has not really understood its results, it is important that they be helped to formulate and agree upon their own questions, so that they are together, both in asking

for and listening to the answers. The family may need help in how to negotiate the medical system in order to get a full and proper assessment.

One common complaint is the seeming lack of interest of some physicians. From one point of view, this is understandable. After all, patients with cognitive impairment are some of the most unrewarding patients to have. Statistically, there is about only a one-in-five chance that after intensive investigation something treatable will be found. The physician, most likely, will end up suspecting a deterioration of the Alzheimer's type, a diagnosis which is only definitive on autopsy, anyway. If he suspects it, he has no treatment or hope to offer the family and has to contend with their reaction to this.

But from a family and patient point of view, the one-in-five chance is critical and, even if nothing treatable is found, they need to get some reality-hold on what is happening. If their physician is not interested, then they need help to find one that is. The possibilities of concomitant illness along with a degenerative process is very real. Treating what has been termed 'excess disability' such as poor hearing, eyesight, circulation, glandular disturbances and metabolic imbalances, etc., can ease the situation significantly. Therefore, pressing for a thorough examination is both the family right and responsibility which the social worker can help them safeguard.

It is important to review what medical advice and assistance the family has had in the past, what their input into it was, and, most importantly, what they understood as a result of it. The social worker is not a substitute for a medical diagnostician, nor, of course, should there be any attempt to presume to enter such dangerous grounds. It is sufficient to be aware of different possibilities and help the family keep their minds open so that they realize the importance of giving a physician all the information that can assist him. That is their 'piece of the action', something concrete they can do, in what can be a baffling situation.



Approximately 60% of persons with cognitive impairment are found to have a cerebral degeneration of the Alzheimer's type, the onset of which is very subtle. The losses of brain cells occur gradually like a slowly dripping tap. The first sign may be seen, in hindsight, as a job dissatisfaction or a work problem or withdrawal from stressful or perhaps not apparently stressful activity or relationships. Sometimes retirement from employment or withdrawal from social activity is seen as the cause of progressive degeneration rather than its result.

Plotting the course of events and the changes over time can give valuable clues to the nature of the illness for the medical practitioner. The circumstances which surround sudden changes need to be carefully examined. Some are attributable to the buildup of strain, as the affected person struggles with increasing difficulty. Like the buildup of earth tensions in an earthquake zone, there can be shudders of change which mark the dropping from one level of ability to another. In degeneration of the Alzheimer's type, because change occurs slowly and progressively, there might be marked changes in some **behaviour** as a person gives up an accustomed activity. But a sudden drop in **cognitive capacity** should arouse suspicion about other factors. Of course, an obvious one is the physical assault of small or larger cerebral vascular accidents which hopefully have had medical investigation and treatment.

Physicians tell us that in 20% of situations presenting cognitive impairment, the cause may be one or more of some 60 different malfunctions which are treatable. Among them is depression. Here, a careful history becomes especially vital. In the absence of organic causes, a rapid deterioration in performance, perhaps within a month, suggests a functional cause and the psychological assaults and stresses and frustration which might have precipitated it need to be searched out.

If the social worker can help the family put together a careful, accurate, comprehensive history, it is of value not only to the diagnostician, but also to the family. Here is where the participation of all of those who are close to the affected

person can be both useful and meaningful. Both relatives and special friends may be usefully involved. There is a rich potential in such a meeting to sort out facts, because time and pressure can distort the sequence, timing and nature of events. A multi-sided ironing out of differences in memory of events not only helps to produce accuracy in history but, just as importantly, if not more importantly, co-operation in planning. It helps the family network sort out varying interpretations and locate pressures and get some initial basic plan of action worked out, with a list of items and concerns to be worked on in the future. For a distraught family to emerge with some step-by-step plan and agenda for action, which they all understand and support, is a relief and restoration of hope and purpose which has to be experienced to be appreciated.

### **3. THE SPOUSE'S PERSPECTIVE**

#### **3.1 Reactions and Expectations of the Spouse**

Speaking as a family member, faced with the diagnosis of a deteriorating process about which nothing can be done, I may well experience the shock of a person who has had the ground cut out from under him. I may experience a sense of both helplessness and panic, which sends me into a state not much different in some respects from my affected spouse. I need both the rallying around me of family supports and the time and opportunity to both talk out my confusion and get gentle but firm insertion by you of some challenging difference which gives me a better perspective, and some beginning steps I might take to deal with my confusion.

I might find joining a family support group to be helpful, especially when one of my children comes along with me. Finding there are others in the same boat can make me feel less alone and somehow more hopeful that I can survive. It helps being able to share what I thought were crazy concerns, only to find others have had them too. I thought for a while I was losing my grip and in fact I really was. I had to be pushed by you and pulled by my children to take any step. But making a start put me

on the road to recovery from those awful feelings of fear and despair, with accompanying knots in my stomach and fatigue from lack of sleep. When my doctor wanted to give me medication `for my nerves', I regarded it, at first, as a sure sign that my worst fears about myself were being confirmed, instead of realizing it could be useful in helping me calm down and think out what I could do. It was not for lack of things to do. It was because I felt overwhelmed and unable.

There are many practical, helpful things you can do, like helping me deal with my brother-in-law, who has his mind made up that I made a terrible mistake by moving from my house to an apartment. He believed it caused my wife's disorientation. Help me and/or help him, to understand my need to simplify my living and that my wife was losing her grip anyway, although he did not notice it. Maybe I did not realize how carefully such a move needed to be planned, or the preparation and support my wife needed. But I was so busy, and where was he at that time anyway?

Yes, it is true, I did not reach out to ask for his help. Maybe he would have felt differently had I given him, or allowed him to have, a useful role. Yes, you are right. I have to learn to respond differently when someone asks, "Is there anything I can do?" I tend to feel there is nothing they can do to change the situation and, in my anger, I tend to hit back by asking, "Why didn't you visit last year?" or "What can you do—make my wife better?"

You are right, I have to learn that they, too, feel helpless and, in their helplessness, feel anger and withdraw and pay a price of guilt and resentment. I have to learn, as I go about my daily tasks, to be aware how a helping hand can be useful, whether it be to do a message, to visit or to help me look after finances or legal problems. Yes, even pick up something at the store or buy a piece of clothing or have us over to dinner. It is true, I can see now, how I have closed myself off. But, after all, I really do not want to impose my problem on others. My problem? As if a piece of it was not theirs too.

Life could be easier if I learned to ask for help and involve others. It does build up a kind of safety net around me of people who are tuned in. The ones who find it too difficult withdraw. But, as I look back, some of the friends who withdrew did so because they had no role. Social life does change drastically. My preoccupation with care, my wife's inability to participate and feelings of helplessness of friends and acquaintances combine to create a real social isolation.

Time! Time! How do you fill in those hours we have together? What can I do that will bring some change, some pleasure to my affected spouse? How many day care programs are really set up to cope with the cognitively-impaired? How often I wondered how I could get some relief for myself. People say I should bring someone in to help me. Sure, aside from the money angle, that is easy for anyone to say; just "get someone in the house." It is not just a question of finding a person. Did you ever stop to think of the problem of getting my wife and that person to connect? I wish people would get down to helping me figure out how to find and screen such people, so that I'll have someone in the house with heart and willingness to listen to me and not someone who tries to reassure me by saying, "I know what to do. I have dealt with many cases like this." I feel like saying, "My wife is not a case. She is a person and different from all your other cases. Are you interested in my wife's ways and my ways of doing things so that you can fit in? Can we work together on what I can do and what you will do?"

Yes, it is true that you need understanding, too, about how difficult it is to enter a strange situation fearing that you might get stuck with a mess or be summarily dismissed. But, if we can work out an understanding that we will discuss problems as they happen and not store them up, it will help. Let us try to form a partnership between two adults. I need you and you need me, or you would not be here. Let's try to make it work for both of us. At least we will give it the best chance of succeeding that way. No, I will not try to paint a rosy picture and let you find out the grim truth

for yourself. Do not hide things from me either; I am too dependent upon you and need to trust you, just as you need to trust me.

Will you, my social worker, help me to organize my thinking so that I can begin to explain it rationally when it comes to what I want and need from others—for example, help in the house? Will you help me interview or do you not see that as helping?

### **3.2 Interpretation of the Sick Person's Behaviour**

Problems! I am loaded with them. For example, medication. In my desperation one time, I told my doctor he just had to give my wife something. He wanted to help me and he obliged, telling me first what I already knew, namely that he had no medication that would cure or even slow down the disease. But I did not listen carefully to what the side effects of the medication might be, and I had more problems.

There were a lot of things that I never thought of. For example, I never thought to ask if I could or should vary the dosage, either by giving more or less, or giving more or less frequently, or whether I could vary the times of day, or what the maximum dosage was in a 24-hour period, or whether it was best to get two or three prescriptions of various strengths, if I could be counted upon not to exceed the limits my physician prescribed. I never thought to ask him or my druggist whether the medication comes in liquid rather than in pill form, because sometimes that is easier to take with orange juice or something like that. Will you help me to take the time and trouble to learn how to work out a co-operative relationship with my physician like I have to work out with any help in the house; like I have to work out with friends, thereby building another strong rope in my safety net?

Problems—I often do not even remember to tell you about them and sometimes I feel "What can you do anyway?" There I go again. When I am stuck, please do not

sit back smugly, like I am on a psychiatrist's couch, waiting for me to locate my problems. "I can only help you if you want help. If you don't tell me, then I don't know." I know now you did not mean it that way, but at the time it felt like a cop-out. Please stick with me and structure it so that I cannot cop out too, because I am so burdened. Can you put yourself in my place and picture some of the problems I might be having, and hold me and help me to review and locate them? Sure, I think some problems are petty and too ordinary, but then my view gets warped too.

What **do** I do about neighbours, shopkeepers and acquaintances who look at my wife askance. Something 'peculiar', they think. Lord knows what they think. Who gives a damn anyway? I have more important things to worry about. But it does cramp my style when we go shopping or walk together. No, I'm not embarrassed. Well, maybe I am too, but it's not only that. I can't bear them looking down on my wife. If they only knew what she has gone through and is going through and that there is a person there still, not an object, maybe of pity or humorous comments. Sure, I'm resentful, but you are right. How the hell are they to know if I don't tell them. But, then, what should I tell them? I can't go into a whole song and dance about her condition. Well it's true, they don't need that. I guess I could tell them simply that she has a brain condition and it's hard for her to understand or speak, or whatever.

That reminds me about the members of the club my wife used to belong to until she stopped going. I should call one of them and explain the situation. They might come to visit. That would be nice. But oh, wait a minute, visiting—that is a problem too! Not even my family knows how to visit. They come three at a time and my wife can't make head or tail of what's going on. It's hard enough when one person visits and they get to talking to me because it is easier. If they don't look at my wife and get directly in her line of vision and catch her eye and talk simply and slowly, she just will not understand. A lot of the time she is so happy to see a visitor and then, because the talk flows past her between them and me, she feels out of it and gets

frustrated and angry and withdraws and then the people say, "It's impossible to have any conversation with her."

You say stop? There I go again? Oh yes, I guess they, too, need help from me to know how. Now that I come to think of it, I had to learn, and I guess I am going to have to explain it to them. You have to be satisfied with talking less because verbal messages, by themselves, often do not get through. A person has got to learn that it is also how you feel that gets through. Sometimes it is just talking and holding a hand and saying something simple, like "It is good to see you," and trying to bring back old times with simple sentences or words that you know can trigger images of past events and good or important times together.

The problems? Now that you have got me going, I am running over at the mouth, like how do I tell what is happening with my wife anyway? Sure, I have heard you say her behaviour has meaning. It serves a purpose for my wife, whether you or I understand or not. But then other people tell me, "Well, that is just part of the disease." Is it an automatic organically-caused reaction or is it the psychological expression of my wife's attempt to cope with the disease? I get confused by these different messages.

Some say my wife is regressing to childhood because she says 'mama' and wants to go 'home'. I thought so too for a while. I have come to regard that explanation as superficial and incorrect. She kept asking for 'mama' and, when her sister came one day, she was delighted, and I began to realize she cannot find the right word and used mama to cover a female who is close to her. At the beginning, when I told her her mama was dead, she was terribly upset.

It is the same thing with her saying, "I want to go home". That happens when she is especially confused. Some experts told me that it is another indication she is regressing to her childhood. Well who wouldn't? It probably has a lot more warm

comforting associations than the difficult, frightening present. But that explanation left me feeling helpless and I am not so sure it was correct. I believe this is an indication that she is feeling lost and wants and needs to get connected. If I ignore it, she only gets more agitated. I have learned to stop arguing with her that she is at home, and concentrate on doing something that is very familiar, like having a cup of tea at the table or anything else. Sometimes it is taking her out for a walk and coming back and sitting and talking. Sometimes it is just a matter of holding on until medication helps reduce her anxiety, because the anxiety saps her energy, and for sure she does not have enough going for her to hold on to time and place, and to cope with anxiety too.

Those Freudian interpretations, such as infantile regression, do not really help me.

I remember in the beginning when we first noticed the trouble. My wife asked if she was crazy. So did some of our relatives, the ones who were honest enough to ask. Well, I had to go over and over the fact that she was not crazy and that she was suffering from damage to her brain, as if her brain had been hurt. I do not know how much difference it made to her. I think it did. But it sure made a difference to me to be able to say just what it was.

Well, I am wandering again. That is the way I am. One thing leads to another. Let me see—oh yes—about her behaviour. I have had to learn the hard way that you are right. Behaviour does have meaning. It does serve a purpose for the individual. Like the times when she became more agitated and restless and disoriented and I could not figure out what the matter was and could not seem to reach her as I usually could. What a time I went through. I was hollering at my doctor, "Let me give her more tranquilizers" and thank God—or rather thank him—he was smart enough to want to see first whether something else was the matter. One time, we found out she was so constipated she was in pain and couldn't tell me. Another time, she had a terrible corn on her foot. Still another time, we found that she had a hiatus hernia and had real



gastric distress. Now I know that behaviour does have meaning whether we understand it or not. I watch like a hawk for colds and infections and half the time I can't tell what the matter is, but the important thing is that I have learned not to write off her behaviour as meaningless.

One time she kept banging her hand on the table over and over again, and another time she went through a period of making repetitive noises. One therapist told me it was just an automatic brain reaction. But I think it was the only way she could relieve her tension. Thinking about it that way helped me to stay connected with her. If you think it's an automatic reaction, you know you cannot do anything about it. It makes you feel helpless and you withdraw, which is what she does not need. It only makes things worse, because she needs to feel connected, to be able to trust that someone is with her in a world which is confounding. It is like being her lifeline against drowning. That is why she gets anxious if I am out of her sight for too long unless she is connected with someone else she can trust. Whether friends or relatives, those people with whom she feels safe are like irreplaceable jewels.

That reminds me of the first time she got suspicious of me. I was furious. Here I am, the one whom she doesn't want to let out of her sight. I do everything to protect her and then she looks at me as an enemy. Me! Of all people! If she regarded you that way, I would understand it. She really does not remember you. When she sees you, she has got to get reconnected with you all over again. She has to do this, even with her own brother. He was so upset about that. I want to thank you for helping him understand how this can happen and that it does not mean she does not love him, or need him.

But me! How can she turn on me? Well she did, more than once, and I really messed things up but good by getting furious, which only convinced her that she was right, that, indeed, I was dangerous. After that horror story, I learned to look for clues. For example, had I been rushing her, or ignoring her, so that she just lost touch and

got frightened, and was that enough to put her further out of contact and escalate fear into panic? At such times I had to ride it out, by not trying to feed the panic with any action which was in any way aggressive, but rather search for ways, especially people, that she could hang on to. A couple of times it was a neighbour. Sometimes it was a close friend. It was anything to give her an anchor and then some medication to aid the calming down process and, if I did not intrude too much, it would blow over. But I soon learned to watch closely for signs that she was pulling out.

Paranoid? Sure she was at times, but now I realize, why would she not be suspicious? I would be too, if things were not working for me and I could not figure them out. Everything outside is less manageable, less understandable, and therefore more dangerous. I have learned to understand that when she gets this way, it means that she is overstrained, that maybe I have been expecting too much, asking questions like, "Would you like this or that or the other?" or "What should we do about this or that?" Sometimes she misinterprets what I mean or she simply cannot cope with figuring out the answer. She is frightened about making some decisions. After all, she had plenty of experience with things not turning out as she thought. Then, in her fear, she gets suspicious. Learning to find and ease the pressures, wherever they come from, is important. But it sure is hard to try to keep some kind of balance between expecting too much and expecting too little.

Sometimes she would give me a lead, like wanting to cut the vegetables for salad. I had to learn to let her try but keep a careful eye that she did not hurt herself or get too frustrated. So what if the salad was not so great at that time? Oh yes, I had to learn how to cook too and I got a satisfaction out of doing it, especially when she enjoyed the meals.

There are not that many rewards, but you learn to enjoy them, like when she feels more calm and contented and is co-operative in what needs to be done. It's great when things strike her as funny and we have a good laugh, often over crazy little

things that I would not have found funny before. I have changed along with her, but I do not feel worse for it.

But I am not trying to kid you. This cognitive impairment business is the pits. It even creates havoc with your sex life, piling on more deprivation. You can't help but feel really low at times. You remember how things were and think of what they could have been. Then you can't help mourning for your lost and spoiled life together. Mourning, yes, that is what it is: mourning like at a funeral. The things that are gone are gone. But there is the prospect of further loss. How do you know how it will all end up? And, if you knew, would it help? You're right. The only thing that really makes a difference is doing what you can now to make life liveable. At least it is a hell of a lot more satisfying than sitting round in a blue funk. But you can't help cursing the damn disease. One time when I did, my wife thought I was angry at her. The hurt in her eyes was awful to see, because she couldn't figure out why I would turn on her. She is so dependent and vulnerable that you can't forgive yourself for hurting her. She counts on me so much and the thought of what would happen to her without me makes me feel awful. Damn it, I'm not trying to blow my own horn. You just have to be in my position to feel it, and to feel how important it is that you never let her down. If there is anything which makes me feel cold all over, it's the very idea of her going to an institution. How can I ever do that to her?

#### **4. THE POSSIBILITY OF INSTITUTIONALIZATION**

Speaking once again and in conclusion as a social worker, there are multiple helping tasks which present themselves as we get connected with families of cognitively-impaired persons.

Elaine Bourke, our Chairperson today, wrote in a note to me:

The social worker's role requires a tremendous amount of skill in working with these families in helping them to understand the meaning of behaviour: how to listen and engage with it; how to ask for and take help; how to understand and cope with their feelings about the losses and the resentment; how to understand their own and their siblings' projections and to form a working relationship around the victim's care; how to find pleasure and success in small things; how to recognize and live in the inevitable deterioration; and how to face and prepare for institutionalization.

In facing the possibility of institutionalization, all or many of the intra-family problems that were present at the beginning may be reactivated. The differing views about the affected person's state and readiness for institutionalization, the suggestions for non-institutionalizable care, the differing assessments of the primary caregiver's ability and willingness to carry on, all are rife with possibilities for conflict, obscuring the main deciding fact which lies squarely with what the primary caregiver can really sustain, and the support which is necessary for that person or those persons to work out their decision against the reality of the best placement the family can find.

The investment caregivers make in sustaining the impaired person inevitably leads to ambivalence about placement. They need consistent help in sorting out and owning what are the needs of the person giving care and needs of the person receiving

care and accepting that they do not necessarily coincide. In the face of the pain and guilt which this arouses, some caregivers want to avoid carrying the responsibility for separation by overextending themselves, so that 'circumstances beyond our control' bring separation about. The helping role is obvious. Caregivers must accept the fact that protecting themselves is also protecting the person who depends upon them. The role of the social worker is to help, first, the caregiver, and then the family, really to look at what is pushing the need to examine institutional care as a possibility, and then work out a plan which they can understand as leading to resolution for the **time being**, with a date for review. This breaks up the decision-making into manageable parts.

Should placement be the direction, then the task becomes helping the impaired person, the caregiver and the family to make and enrich connections with the institution so that the transition is smooth for all parties concerned and so that a continued family supportive role can be implanted firmly within the care situation. Easy words, but taxing responsibilities.

But that is true of helping, which aims at enabling the individual and the family to find and use what they have within themselves and their community so that they emerge more able, not only to cope with what life brings them, but also to be a purposeful creative force in shaping that life.

In the face of the frustrations, the sudden changes and challenges which coping with cognitive impairment produces for family, a social worker must have advice and other practical assistance to give but, more importantly, the heart to bear with the inevitable pain, and still find a compassionate way to hold the person to the choices that confront them—heart which can bear and understand the anger which at some point needs to fall on the helper, just because being in the position of needing and taking help produces anger.

## CONCLUSION

In helping the families of cognitively-impaired persons, one central fact keeps emerging: just as the victims of the disease become increasingly dependent, so, too, do the families and especially the primary caregivers.

They become dependent upon physicians, upon other family members, upon friends, household help, a variety of health and social services and finally institutional services, with all the mixed feelings which are engendered by entrusting the care of a helpless relative to strangers over whom one has little control. Varying in individual capacities and vulnerable, families are under unrelenting strain, coping with the many-sided responsibilities which are thrust upon them, achieving a homeostasis with one set of problems, only to be confronted with new ones, gradually narrowing sights to a few days at a time, bearing the bad times and being grateful for the good.

Is it any wonder, then, that often when they meet social workers, primary caregivers may give only lip service to long-range planning, the necessity for which may be perfectly clear to the social worker and some members of the family. At such times we need to remind ourselves to begin where the caregiver is, and help the family pull together in that support, being sensitively attuned to the fact that the readiness, or unreadiness of the primary caregiver to seriously engage in long-range planning needs to be both understood and respected as decisive.

In their increasing dependence, families of the cognitively-impaired need from us social workers, a quality of locked-in dedicated support which can enable us to look in the mirror knowing we have done all that is in us and our communities to do.

I am reminded at this point of two quotations which perhaps apply equally to the situation of families and social workers.

The first is from Kahlil Gibran in a book called *The Prophet*: "Is not the lute which soothes our spirit, the very wood that was hollowed with knives?"

The other is from *The Wages of Sin* by Lucas Malet. The heroine asks her uncle, "What does one do when the sun of one's happiness is set?" He answers, "After a time—one lights a candle called patience and guides one's footsteps by that—remembering that you are not alone. More than half the noblest men and women you meet carry such candles."

In the darkness of cognitive impairment, we social workers do well when we help families to find candles to light.