



**Increasing Employability and Standards of Elderly Caregivers  
through Specialized Training and Innovative Empowerment**

**A Workbook for Informal Caregivers across  
Europe**



**Erasmus+**

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<b>Author(s)</b>	Dr Marina Lupari	
<b>Contributors</b>	Richard Bigger	
<b>Other Contributors</b>	I. Karaman, G. Billi, M.C. Ionescu, V. Seco, A. Pena Perez, S, Ioannou, A. Koppav, S.O. Petersson, F. Peptea	
<b>Contact name</b>	Dr Marina Lupari	
<b>E-mail address</b>	marinalupari@aol.com	
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## **Foreword**

Older citizens are more likely to be disabled or dependent due to medical problems. These problems change a person's relationships with family and friends. A husband, daughter, or friend may find that they are now also an informal caregiver. This simply means that they become the person primarily responsible for seeing that a care recipient's physical, psychological, and social needs are met. Another person now depends on them for basic physical needs.

Regardless of whether the disability is due to progression of a chronic illness such as heart or lung disease, stroke, dementia, arthritis, or the combined effects of multiple medical and social factors, the caregiver role is a profound change for both people. These adjustments are often stressful, as well-established patterns must be abandoned, and new adaptations need to be developed. This provides opportunities for personal growth, but also, invariably, causes emotional turmoil and distress.

Being a caregiver is rewarding, but also can exhaust a person physically and emotionally, leading to illness and inability to further provide care. However, if you reach out during this time for help and information, you might discover that the stories of other informal caregivers mirror your story. Start by working through the exercises described in this booklet and work with other members of this support group. Others in similar situations may be able to voice feelings you are unable to describe.

This book is for informal caregivers for frail and ill older people. Family members should also read this book to become more aware of the problems facing informal caregivers. This book offers practical approaches to common challenges faced by informal caregivers. Staying healthy, avoiding depression, remaining active, making friends, enjoying pleasurable activities are all essential parts of any human life, including those of informal caregivers. Serving as the informal caregiver for an ill loved one should not make life meaningless. Hopefully you will find this book useful in improving the quality of life for all concerned.

The final thought is reported from a participant in the Greek focus groups and it seems to highlight the most important need for informal caregivers. *“The point is that you live somebody else’s life... I created a net of people who would take care of my father, when I wouldn’t be at home...I gave duties assigned to each one...who will do this, in case that happens, when, under which circumstances...indeed, it helped... His life is entirely up to me...but my life is entirely up to him... too! ... there is no me...you have no identity”*

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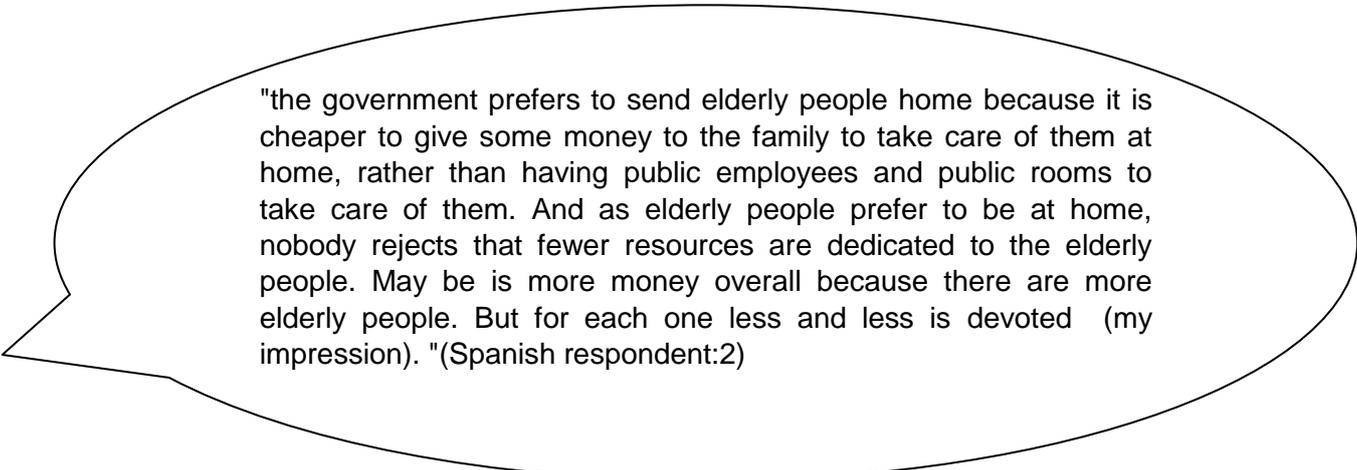
## **Introduction**

Few people are prepared for the responsibilities and tasks involved in caring for the older person. This handbook explores a number of different topics which include exercises and opportunities for you to reflect on your own personal experience which can make the role of caregiver easier, and at the same time, help the person receiving the care. Throughout this handbook, informal caregiving refers to the person giving care who does not receive payment, and care-receiver the person receiving the care.

In preparation for this workbook we carried out a series of Focus groups with informal caregivers across the 8 countries involved in this project. It is not our intention to reproduce all this information at this stage but we felt a summary of the main themes and most powerful quotes from informal caregivers would be helpful at this stage.

**The five main themes with poignant quotes identified were as follows:**

### **Theme 1: I'm not a care-giver...I'm family**



"the government prefers to send elderly people home because it is cheaper to give some money to the family to take care of them at home, rather than having public employees and public rooms to take care of them. And as elderly people prefer to be at home, nobody rejects that fewer resources are dedicated to the elderly people. May be is more money overall because there are more elderly people. But for each one less and less is devoted (my impression). "(Spanish respondent:2)

**Theme 2: Lack of support**

"Full dedication by someone totally dependent on us requires an effort that, as time passes, increases the physical exhaustion and psychological stress that together, day by day, are likely to turn into lack of dignity and ongoing unrest." (Portuguese Respondent 7)

**Theme 3: Feelings of loss of identity as a person**

"Sometimes I think who am I and what is my role in this all...I am the person who does...I am the daughter...the nurse with the tablets...the skivvy for my brothers and sisters...the wife for my husband...the mummy for my kids...pulled in all directions ...but who am I...you know what I mean (United Kingdom:1).

**Theme 4:**

"I fear that if I die who assist to my husband. Nobody gives a good care to my husband except me, because he is so nervous due to his illness.

Participant 11 says: "If my disease progress who help me and my husband."

Participant 1 express their fear as: "What happens to my wife if I die." (Turkish Respondents)

**Exercise 1** Please take 3 minutes to read and answer the questions asked in the box provided. It is important that you write the first things that come to your mind

**Who am I?**

1. Who are you?
  
2. What has been your biggest life achievement so far?
  
3. What is the thing that you would want to do most in future years?

This booklet is not about how to take care of a care recipient. Instead, it mainly provides ways for a friend or family member to take care of themselves while caring for someone. It gives you communication and self-care tips to focus on your needs while helping your loved one too.

**Exercise 2** Below are two checklists: one focusing on how you provide care for the care-receiver and the other one focusing on you as the caregiver. They are included as general guidelines to help Ensure an optimal level of health, safety and comfort for both your care-receiver and yourself, the caregiver. Please read the checklists and consider your responses.

**Check list for care provided to the care-receiver**

- The person I provide care for has the following needs met:
- All legal and financial matters are in order and available
- All health and physical related appointments are kept annually or

more often if needed

- The home environment is clean, safe and pleasant
- Nutritional needs, exercise, sleep and social activities are maximized to the degree possible
- Personal hygiene and grooming are done daily
- Respite services have been considered and are being utilized monthly/weekly
- Level of care is reviewed continuously to ensure care-receiver is able to remain safely in the home

### **Check list for the caregiver**

- I have the following needs met:
- I am getting out/exercising at least once a week
- I am getting at least seven to nine restful hours of sleep a night
- I take opportunities to talk with or visit with friends or relatives weekly
- I keep annual medical appointments
- I am taking only the medications as prescribed to keep up my health
- My legal and financial papers, including wills, are in order and available
- I have read and I am aware of MY relevant Caregiver's Bill of Rights
- I am eating three balanced meals a day.

This simple exercise allows you to identify early the challenges that you are facing as a caregiver. These exercises are included as general guidelines to help insure an optimal level of health, safety and comfort for both your care-receiver and yourself, the caregiver. Now take a few minutes and complete exercise 2.

**Exercise 3** Please take 5 minutes to consider your results from Exercise 1. Now in the boxes provided below please record the 3 main challenges that you face as a caregiver.

**Main challenges for care provided to the care-receiver**

- 1.
- 2.
- 3.

**Main challenges I face as the care-receiver**

- 1.
- 2.
- 3

You are ready to proceed through the workbook. You may find it easier to go through each section as they are presented or, use the Table of Contents to guide you to those parts that may be most helpful to you.

**Chapter 1 - Common Problems in Caregiving**

Caregiving presents considerable challenges—physical, emotional and economic. There is no reason to suffer in silence. If you take away one thing from this booklet, remember, it's always OK to seek and ask for help. Getting help can enable you to become a better caregiver. The process of educating and preparing yourself may help you reduce stress and better cope with the many challenges of caregiving. This booklet is designed as a place to start.

The first step in organizing a rational care plan is making a list of needs. As a care giver, several questions present themselves as set out in the next exercise:

**Exercise 4****Identifying the care-receiver needs**

1. What are his/her needs?
2. What kinds of care are needed to allow the elderly/impaired person to remain in the community?
3. Who is going to provide the care? When? How?
4. Should the care-receiver remain in his/her own home, live with the children or other relatives or move to other surroundings (retirement apartments, residential care, intermediate care, skilled nursing facility or other)?
5. How can living arrangements be changed to help the person stay in the home or become more independent?
6. If outside services are needed, does the impaired person have the resources to pay for them? How can they be obtained?
7. How can care be given to the person in need without denying attention to others (spouse or children) for whom the caregiver also has responsibility?
8. Do you as the caregiver feel tired or frustrated from caring for an older person?

In answering these questions you are developing an important list of needs of the impaired older person, and bringing into perspective your own needs as the caregiver as well. The questions do not have easy answers and the solution may vary in every situation. The care of an impaired older person can create stress that affects the ability of the caregiver to continue giving necessary levels of care. The stress experienced may be physical, financial, environmental and/or emotional in nature.

**Physical Stress** Providing physical care to an impaired older person can cause physical stress. General housekeeping activities such as cleaning, laundry, shopping, and meal preparation require energy and can be tiring, particularly when added to existing responsibilities in one's own home.

Personal care required for the supervision of medications and the maintenance of hygiene can also be stressful, particularly in situations of very personal behaviours- incontinence (loss of bladder or bowel control), colostomies, or assistance with bathing. Lifting and transferring individuals with limited mobility is not only tiring, but also can result in injury to the caregiver or the impaired person. In some instances there is the additional responsibility of maintenance of equipment such as wheelchairs or hospital beds.

**Financial Stress** The care of an impaired older person has many financial dimensions. For those services that cannot be provided by family members (medical, pharmaceutical, therapeutic, etc.), decisions will have to be made as to where service will be secured and how they will be paid. When money is limited, many families assist with the cost of care, causing financial burdens on all family members.

**Environmental Stress** The proper home setting has to be chosen. If the care-receiver elects to remain in his/her own home, modifications such as railings and ramps may have to be installed. If the person cannot remain in his/her own home, alternative arrangements must be sought, such as moving in with a friend or relative or specialized housing (retirement hotels, senior apartments, residential care homes, intermediate care facilities, or nursing homes). If the care-receiver is to remain in the home, some major adjustments in the living arrangements and patterns of daily living may be necessary. Sometimes the caregiver may need to move into the care-recipients home to provide them with the level of care required.

**Social Stress** Providing personal care up to 24 hours a day can cause social stress by isolating oneself from friends, family and a social life. The caregiver may find himself/ herself becoming too tired or unable to have an evening out even once a week, or once a month. What can result is a build-up of anger and resentment toward the very person receiving the care, as the care-receiver is the cause of social stress.

**Emotional Stress** All of these factors often result in tremendous emotional stress. Compounding these sources of stress are the difficulties in managing one's time, juggling multiple responsibilities, and feeling the pressure of the increased dependency.

**Exercise 5** It is clear that informal caregivers experience various forms of stress. In the next exercise please take 5-10 minutes and read through the descriptions of the various stresses that you may be experiencing. Then please rank the different kinds of stress using 1-5 with 1 being the highest stress being experienced.

#### **Identifying your stresses as a caregiver**

Physical Stress \_\_\_\_\_

Financial Stress \_\_\_\_\_

Environmental Stress \_\_\_\_\_

Social Stress \_\_\_\_\_

Emotional Stress \_\_\_\_\_

For family members providing care, the various forms of stress can result in different feelings. Anger, resentment and bitterness about the constant responsibilities, deprivation and isolation can result. This is also a time when many of the unresolved conflicts from parent-child relationships resurface and can intensify, causing anxiety and frustration. There might even be the unspoken desire, at times, to be relieved of the burden through institutionalization or even death of the care-receiver. This desire is frequently and swiftly followed by feelings of guilt. All of these can be felt, and then denied because they seem unacceptable.

**Dealing with help you don't need** Sometimes people offer help you don't need. Thank them for their concern. Tell them you'll let them know if you need anything. Some people may offer unwanted advice. They may do this because they don't know what else to say. It's up to you to decide how to deal with this. You don't have to respond at all.

Otherwise, thank them and let it go. Tell them you are taking steps to help your family.

## **Conclusion**

The life of the person you are caring for has likely changed forever. Likewise, yours may change, perhaps dramatically, as you adjust your already busy life to include caring for another person. You may feel socially isolated, as if you are the only person in the world facing the struggles of caregiving. As a caregiver you need to be assured that, in fact, these feelings are common even though they may not be expressed. Many informal caregivers find comfort in knowing they are not alone.

The remainder of this book will address those resources that may help you adapt and to adopt the caregiver role. The most important message is that you need to care for yourself as the caregiver.

## **Chapter 2 - Types of Help Available**

Many people who were once informal caregivers say they did too much on their own. Some wished that they had asked for help sooner. Accepting help from others isn't always easy. When tough things happen, many people tend to pull away. They think, "*We can handle this on our own.*" But things can get harder as the care recipient gets older. As a result, many informal caregivers have said, "*There's just too much on my plate.*" The following section highlights some of the help that may be available to you.

**Community Agency Help** When family or other volunteer help is not available or cannot meet your needs, informal caregivers or care-receivers may wish to seek help from agencies. A wide range of help may be available. Some may be covered by private insurance, Medicare (and/or a supplemental program of your State). All of it can be purchased. Sometimes the service costs may be based on the income of the care-receiver.

**Services for Impaired Elderly** Adult Day Health Care: This is for people who are physically and/or mentally frail. It offers a range of therapeutic, rehabilitative, and support activities, including nursing, rehabilitation,

assistance with life activities, social work services, meals, and possible transportation, provided in a protected setting for a portion of the day, one to five days a week, usually during weekdays.

**Chore Workers/Handypersons Services:** Includes heavy-duty housecleaning, minor home repairs, yard work, installing safety devices, and winterizing homes.

**Companionship Services:** Companions visit isolated and homebound individuals for conversation, reading, letter writing, and general light errands.

**Escort Services for the Elderly:** These services provide personalized accompaniment to service providers as well as personal assistance.

**Geriatric Assessment Units and Special-Care Units:** Specialized geriatric units, both in-care recipient and out-care recipient, exist in some hospitals and medical centres. They provide coordinated multi-disciplinary diagnostic services to older care recipients.

**Home Delivered Meals:** Some nutritional programs as well as well as specialized meals-on-wheels programs offer home delivered meals to the frail, homebound aged. Subsidized programs ask for voluntary contributions, while others may require full payment cost for delivery of a hot, well balanced lunch, and sometimes cold evening meal.

**Home Health Aides:** Provide personal care to individuals at home (These services may be covered by health insurance if ordered by a Doctor.) Aides assist with eating, dressing, oral hygiene, bathing, colostomies, administering medications, etc., as well as light household tasks.

**Home Health Care:** Organized programs of nursing, social work, occupational therapy, physical therapy, and other rehabilitation services to individuals in the home.

**Homemaker Services:** Provided by non-medical personnel, services include shopping, laundry, light cleaning, dressing, preparation of meals, and escort services on medical visits. Homemakers can be of great help in supplementing help provided by family members, or providing relief when family informal caregivers need a break. Homemakers can be secured through in-home health care agencies, the Area Agency on Aging, the Department of Social Services, and religious groups and organizations. Some agencies provide bonding and training for their homemakers while others provide only a registry of homemakers' names and phone numbers, in which case you must

thoroughly check references and draw up a contract for the required services.

**Hospital and Surgical Supply Services:** Supply houses rent or sell medical supplies and equipment like hospital beds, canes, walkers, bath chairs, oxygen and other equipment. Consult your Yellow Pages.

**Housekeeping Services :** These usually include cleaning, shopping, laundry, and meal preparation.

**Housing Assistance:** Housing assistance programs exist to help in the search for senior housing, shared housing, and finding emergency shelters, such as Heartland Human Relations and Area Agency on Aging.

**Nutritional Programs:** Congregate meal programs feed many older adults as a group in a senior center, community centre, or school. A noonday meal is provided, containing one-third of the recommended USDA dietary allowance, usually for a voluntary contribution. Additionally, some centres provide recreational and educational activities.

**Occupational Therapy:** Occupational therapy, or OT, is restorative, to enhance or restore skills necessary for daily living. It should be provide by a qualified occupational therapist who is referred by your doctor.

**Physical Therapy:** Physical therapy, or PT, is rehabilitative therapy to maximize mobility. It should be provide by a qualified physical therapist, usually recommended by your doctor or hospital.

**Respite Care Services:** Respite care programs provide temporary and in some instances up to twenty-four hour care to give relief to primary informal caregivers. The care may be provided in the person's home, at an adult day care center, or other facility.

**Senior Service Teams:** Regional/County Mental Health teams working together to provide mental health screening, needs assessments, and short-term counseling services to seniors.

**Skilled Nursing Services:** These specialized services are provided for specific medical problems by trained professionals through local home care agencies. Your doctor must prescribe nursing services.

**Speech Therapy:** Speech therapy is provided by a qualified speech therapist to overcome certain speech and communication problems. The doctor usually recommends this.

**Social Day Care:** Provide supportive but not rehabilitative services in a protected setting for a portion of the day, one to five days a week. Services may include recreational activities, social work services, a hot meal, transportation, and occasionally, health services.

**Telephone Reassurance:** Friendly telephone calls are provided by agencies or volunteers offering reassurance, contact and socialization. Telephone reassurance can be a lifeline for older people who must be left at home alone during the day.

**Transportation:** Transportation services provide travel by automobile or specialized vans to and from medical care. Community agencies and service providers such as Dial-a-Ride, Red Cross Wheels, Cancer Society, and Life Line are but a few.

**Exercise 6** Take a look at how busy you are now. Be honest with yourself about what you can do. Think about tasks you can give to others. And let go of tasks that aren't as important right now. Asking for help also helps your loved one. In this exercise please identify 3 things from this section that would help you in your caregiving role.

### Getting help

1.

2.

3.

The most important asset we have are our family or friends. However this is the asset we use the least.

For **Exercise 7** firstly make a detailed inventory of any assets individual family members and friends can contribute, including the assets of the impaired older person needing the care. Assets include available time,

skills, space, equipment, the strengths of the person in need care, and most important money. Sit down with all the family members (or at least as many as are agreeable) and work out a plan for giving help. This involves defining and agreeing upon what tasks will be performed, by whom, on which days, and so forth. For example, can cook, Uncle Peter can mow the lawn and Mary can check on Mom twice a day.

<b>Available assets</b>	<b>Family member</b>
e.g. Cooking  Gardening	Aunt Martha  Uncle Peter

## Conclusion

Being a caregiver is hard work. You may feel that your needs aren't important right now. Or that you've spent so much time caring for your loved one, there's no time left for yourself. Don't be afraid to ask for help. Remember, if you get help for yourself:

- You may stay healthier and have more energy.
- Your loved one may feel less guilty about your help.
- Other helpers may offer time and skills that you don't have.

## Chapter 3 - Caring for the Caregiver

Informal caregivers experience mixed emotions. Love for your family member and the satisfaction you derive from helping may coexist with feelings of resentment about the loss of your privacy and frustration at believing you have no control over what happens. You may find it hard to accept the decline of the special person for whom you are giving care. Such feelings will depend in part on your prior relationship with your care-receiver, the extent of your responsibilities as a helper, and daily activities in your life (professional, social, and leisure pursuits). Your conflicting emotions may cause guilt and stress.

### Understanding your feelings

You probably have many feelings as you take care of your loved one. There is no right way for you to feel. Each person is different. The first step to understanding your feelings is to know that they're normal. Give yourself some time to think through them. Some feelings that may come and go are:

- **Sadness.** It's okay to feel sad. But if it lasts for more than 2 weeks, and it keeps you from doing what you need to do, you may be depressed.
- **Anger.** You may be angry at yourself or family members. You may be angry at the person you're caring for. Know that anger often comes from fear, panic, or stress. Try to look at what is beneath the anger.
- **Grief.** You may be feeling a loss of what you value most. This may be your loved one's health. Or it may be the loss of the day-to-day life you had before the caregiver role was required. Let yourself grieve these losses.

■ **Guilt.** Feeling guilty is common, too. You may think you aren't helping enough. Or you may feel guilty that you are healthy.

■ **Loneliness.** You can feel lonely, even with lots of people around you. You may feel that no one understands your problems. You may also be spending less time with others.

To guard against becoming physically and emotionally drained, you must take care of yourself. You need to maintain your health and develop ways to help you cope.

**Exercise 8** Take 5 minutes and think about your feelings. In the box below write the feeling that you are experiencing most today. Remember feelings change.

### Understanding your feelings

**Exercise 9** Below is a scale to evaluate your level of caregiving. It is an excellent effort to provide some guidelines for informal caregivers and to evaluate your level of care and value which you give your care-receiver and yourself. Put a number from 1 to 10 to best describe your feelings. Number 1 is no feeling, numbers between express stronger feelings with 10 being strongest feeling.

You can place yourself on the Scale of Caregiving to determine how you value your care-receiver as compared to yourself. The low numbers give little or no value (honour) to the needs of your care-receiver. The high numbers (8, 9, 10) give little or no value to your own needs as an individual and as a caregiver. The numbers in the middle are where you find a balance between too little care and too much care. Neither of the two extremes is healthy; they represent positions where you are not helping your care-receiver.

<b>Caregiver's Self-Rating Scale:</b>	
<b>Your Feelings</b>	<b>Score 1-10</b>
Abandonment to withdraw protection or support or to actively abuse your care-receiver.	
Neglect to allow life-threatening situations to persist or to display consistent coldness or anger.	
Detachment/Aloofness to maintain an air of detachment or being aloof, perfunctory in your care, no genuine concern, only obligation. Concerned only with physical well-being of your care-receiver.	
General Support given freely, with a guarded degree of warmth and respect, occasional feelings of manipulation. Concerned with both emotional and physical well-being of care-receiver.	
Expressed empathy the ability to feel what your care-receiver feels. a quality relationship where feelings can be freely expressed and caringly received with non-judgmental positive regard.	
Sympathy feeling sorry for care-receiver, giving sympathy, focusing on the losses experienced by care-receiver.	
Occasional over-involvement care characterized by periodic attempts to do for rather than be with.	
Consistent Over-involvement care-receiver regarded as object of series of tasks which must be performed.	
Heroic Over-involvement care characterized by sometimes frantic and desperate attempts to provide for every possible need your care-receiver has; increased dependence, care-receiver not allowed independence.	
Fusion of personalities between caregiver and care-receiver. The caregiver's needs no longer have any value or meaning; the caregiver has abandoned him/herself to needs of the care-receiver.	

**Exercise 10** This exercise will help you understand how much stress you are under and will help you become aware of your feelings, pressures and stress you currently feel. Take 5-10 minutes and in the space provided record if the following are seldom true, sometimes true, often true, or usually true?

<b>Caregiver Stress Test</b>	
I find I can't get enough rest.	
I don't have enough time for myself.	
I don't have time to be with other family members beside the person care for.	
I feel guilty about my situation.	
I don't get out much anymore.	
I have conflict with the person I care for.	
I have conflicts with other family members.	
I cry every day.	
I worry about having enough money to make ends meet.	
I don't feel I have enough knowledge or experience to give care as well as I'd like.	
My own health is not good.	
I find I can't get enough rest.	
I don't have enough time for myself.	
I don't have time to be with other family members beside the person care for.	
I feel guilty about my situation.	
I don't get out much anymore.	

**What can I do to help myself?** Acknowledge your feelings: Your feelings have a lot to do with the way you view and cope with caregiving. All feeling are legitimate, even those that may seem disturbing to you (including anger, frustration, and sadness). Recognizing and accepting your emotions are the first step toward resolving problems of guilt and stress. Learn to express your feelings to family members, friends, or professionals.

**Benefits of being part of this Caregiver Group** In addition to offering useful information, this group will provide a unique forum for informal caregivers to come together and share their feelings in a supportive environment. It will help you as an informal caregivers feel less isolated and can create strong bonds of mutual help and friendship. Participating in the group will help manage stress, exchange experiences, and improve your skills as a caregiver. Sharing coping strategies in a group setting lets you help others while helping yourself. It may also help you to realize that some problems have no solutions and that accepting the situation is reality.

**Setting Realistic Goals and achieving them** Caregiving is probably one of the many conflicting demands on your time. It is important to set realistic goals. Recognize what you can and cannot do, define your priorities, and act accordingly. Turn to other people for help - your family, friends, and neighbours as discussed earlier in section b. Do not expect that others will ask if you need help. It is up to you to do the asking. Turning to family members or friends for emotional support and help can be a mixed blessing. Their visits may make you feel less alone and better able to deal with caregiving responsibilities. They can give you a break by spending time with your care-receiver.

However, other relatives or friends can be critical of the way you provide care. They may feel the house is not kept clean enough; or they may not like the way your care-receiver is dressed. Recognize that they are responding to what they see at that time and are lacking the benefit of experiencing the whole picture and any gradual changes in your care-receiver's condition. Harsh criticism may be a response to their own guilt about not participating more in the care process.

Try to listen politely to what is being said (even though this might not be easy). However, if you and your care-receiver feel comfortable with the way you are managing the situation, continue to do what meets your needs. Schedule a family meeting from time to time to help other family members understand the situation and to involve them in sharing the responsibilities for caregiving.

**Use Respite Care Services** When you need a break from providing care to your care-receiver, look at respite care. For example, a companion can stay with your care-receiver for a few hours at a time on a regular basis to give you time off. Or have your care-receiver participate in an

adult day care program where he or she can socialize with peers in a supervised setting; this gives your care-receiver a necessary break from staying home all the time. Hospitals, nursing homes, and particularly residential care homes offer families the opportunity to place older relatives in their facilities for short stays.

**Maintain your Health** Your general well-being affects your outlook on life and your ability to cope. Taking care of yourself is important and involves these four simple measures:

- eating three balanced meals daily,
- exercising daily,
- enough sleep/rest,
- allowing yourself leisure time.

Food is fuel for your body. Skipping meals, eating poorly, or drinking lots of caffeine is not good for you. Learn to prepare and eat simple, nutritious, well-balanced meals. Avoid alcohol above 2-3 ounces daily.

Being physically active can provide you with an outlet that is relaxing and makes you feel good. Stretching, walking, jogging, swimming, or bicycling are examples of invigorating exercises. Consult your doctor before starting an exercise routine. Your doctor can help design a program that fits your individual needs.

Leisure time allows you to feel better and more able to cope with your situation. Having time to yourself to read a book, visit a friend, or watch TV can also bring enjoyment and relaxation, and break the constant pattern and pressure of caregiving.

Sleep refreshes and enables you to function throughout the day. If your care-receiver is restless at night and disturbs your sleep, consult your doctor and fellow informal caregivers on possible ways to handle the situation. You may need to have outside help in the evenings to allow you time to sleep.

If you are unable to sleep because of tension, practice relaxation exercises. Deep breathing or visualizing pleasant scenes can be helpful. Continued sleep disturbance may be a sign of major depression, which needs medical attention.

**Laughter is the Best Medicine** This is an old expression and in short, identifies that humour therapy is valuable and it helps us through difficult or stressful times. So for yourself and your care-receiver:

- try to see the humour in being a caregiver;
- write on a card *Have you laughed with your care-receiver today?* and place it in a conspicuous place in the bathroom or kitchen;
- read funny books or jokes, listen to funny tapes or watch humorous movies or videos that make you laugh;
- share something humorous with your care-receiver, a friend, or relative;
- attend social groups where there is a lot of camaraderie, joy and fun;
- be aware of how often you smile; it takes much less energy to smile than to frown.

If you find that you are feeling hopeless, and humour or laughter is not affording you the up-lift you want, contact a counsellor. And remember, laughter is the best medicine. Try it, you'll like it!

**Avoid Destructive Behaviour** Sometimes people handle stressful situations in ways that are destructive. Instead of openly expressing feelings, they overeat, use alcohol, drugs, or cigarettes to mask their difficulties. Such escapes do not solve the problem and are harmful to health. If the strain results in neglecting or abusing the care-receiver, it is a very serious problem. It is also against the law!

**Seek Help** You do not have to go it alone. Turn to family members, friends, clergy members, professional counsellors, or a caregiver support group for help and support.

**Build your Self-Esteem** Continue to pursue activities and social contacts outside your home. Do what you enjoy. Go to a movie, play a musical instrument, or get together with friends. It may not be easy to schedule these activities, but the rewards for having balance in your life are great.

**Caregiver's Bill of Rights** You have rights, too. Find the relevant Caregiver's Bill of Rights for your country. After you read them, post and keep them fresh in your mind

**Exercise 10** For the next exercise think about what you have read and the stressors that you have identified and set out three actions that you help you in your caregiver role

**Three actions to ease caregiver role** e.g Find nice things you can do for yourself. Even just a few minutes can help. You could watch TV, call a friend, work on a hobby, or do anything that you enjoy.

1.

2.

3.

The final **Exercise 11** in this chapter aims to help you to use relaxation to assist you in your caregiver role. For this exercise follow the steps clearly set out below.

**Relaxation Exercise:**

Sit or lie down in a comfortable position. Close your eyes. Allow your mind to drift a few seconds, go with it wherever it goes. Wiggle your fingers and toes, then hands and feet, ankles and wrists. Loosen tight clothes, belts, ties. Sway your head from side to side, gently, gently. Now you have prepared yourself to relax physically and psychologically.

Now concentrate, still with your eyes closed, on someone pleasant thing you really want to think about; maybe it is a place you have visited in the past, or your dream place of your own imagination. It might be the seashore, or high on a hill, or in a field of grass and flowers. Become totally immersed in the place. Smell the smells you best remember. See the sights it offers. Hear the sounds. Feel it, whether it be water or sand or soil or snow. Fully realize this place or situation you are in: if it is on the sandy beach, sift your fingers through the warm sand and smell it, hold the sand to your cheek, smell the salt of the sea, search the skyline for gulls and terns and low clouds in the distance. Your body is totally

weightless. You are totally in control of this scene. It is so relaxing and pleasant and beautiful, you are breathing slowly, peacefully. This is YOUR place and no one can take it from you.

After you have sufficiently experienced your peaceful imaging, whenever you have a chance, return to your special place, close your eyes again, tune in, relive those these special few moments in the world of your choosing where everything is perfect and everything is yours. This relaxation exercise can benefit you all day.

### **Conclusion**

It's common to feel stressed and overwhelmed at this time. Like your loved one, you may feel angry, sad, or worried. Try to share your feelings with others who can help you. It can help to talk about how you feel. Do something for yourself each day. It doesn't matter how small it is. Whatever you do, don't neglect yourself. Taking time for yourself can help you be a better caregiver. Caring for your own needs and desires is important to give you strength to carry on. Meeting your own needs will satisfy you and give you additional strength and vigour to bring to your caregiving tasks.

## **Chapter 4 - Caregiver Training**

You may not be immediately skilled in all of the duties involved in caregiving. While bathing and feeding someone may seem like simple tasks, there are tips and tricks you can learn to make assisting in the activities of daily living easier. Safety is also an issue, especially since most care recipients are elderly or disabled in some way. This section aims to help you understand two important aspects of caregiving—personal care and nutritional care.

### **Section A: Personal Care**

Personal care activities include eating, bathing, shaving, caring for the skin, hair and mouth, and transferring (moving from chairs, toilets or bed). During the course of our daily lives these activities are taken for granted until weakness or a disability makes them difficult to accomplish independently or safely. Providing assistance requires knowledge, patience, skill and physical strength.

**Bathing** Bathing an older person may require strength, special equipment and skills. It is advised that informal caregivers ask the older person's doctor and/or physical therapist for special instructions on how to safely bathe the care-receiver.

**Shampooing and Shaving** Visits to a barber or hairdresser are very positive experiences. Individuals who provide this service will often come to the home. Wetting hair with alcohol or cream rinse helps to remove the snarls. Dry shampoos are available if your family member is bed bound. People who are diabetic or on medication to thin the blood (anti-coagulants, i.e., Coumadin) should use an electric shaver to reduce the risk of cuts. It is much easier and safer to shave another person with an electric razor.

**Skin Care** The main care required for the care recipients skin is set out below.

- Keep skin clean and dry, especially when people are having problems with bowel and bladder control. When washing, use a mild soap, rinse well, and dry thoroughly.
- Keep bed linens clean, dry and free of wrinkles. Disposable bed pads can be purchased at a drug store and can keep sheets dry so that the caregiver does not have to change sheets so often.
- Massage skin gently using a light, circular motion. Change the position of older people at least every two hours, particularly for those confined to a bed or wheelchair. Encourage them to shift their weight between position changes to redistribute pressure onto other areas.
- Encourage good nutrition and adequate fluid intake. As a supplement to your family member's diet, give a multi-vitamin every day to ensure proper nutrition. Check with the Doctor as to the appropriate supplement.
- Use mattress and chairs that are soft and form-fitting rather than rigid and hard. (Example: egg crate mattress and sheep skin). This spreads the weight over a larger skin area, decreasing the pressure under the bones.
- Encourage movement or mild exercise; this helps stimulate circulation which is good for the skin. Combing hair and helping with bathing and dressing are good ways for frail people to get exercise and be more independent.

- Watch for possible sources of pressure on anything that would interfere with good circulation, such as tight shoes, elastic cuffed socks or tight undergarments.
- Bony prominences are prone to skin breakdown. They are heels, feet, behind the knees, hips, buttocks, sacrum, elbows and shoulder blades. A special air mattress may be ordered by the doctor to prevent skin breakdown.
- Watch for any redness or a break in the skin and report it immediately to the doctor or nurse, and keep the care-receiver off the affected side.

**Toileting** Main consideration for toileting is as follows

- Safety features in the bathroom, such as grab bars and raised toilet seats, make using the bathroom safer.
- A commode or urinal may be necessary when flexibility and distance to the bathroom are a problem. They may be especially helpful at night.
- Lack of control over bowel or bladder functions can be embarrassing and older people may try to hide it from informal caregivers and professionals. Be sensitive to the older person's feelings, and mention this to the doctor. Loss of bowel and bladder control is not a part of normal aging and often can be controlled.
- For the care-receiver with bowel and/or bladder problems it may help to take them to the bathroom every 2 hours. Specialized programs exist to retrain a bladder and bowel function. Check with your doctor or nurse for a program in your area.
- Constipation or Irregularity: Many elderly become constipated due to medications and inactivity. If your care-receiver is experiencing this problem the doctor or nurse can suggest a stool softener. Other important factors to manage constipations are:
  - ✓ Eat plenty of fresh fruit, vegetables and foods high in fibres.
  - ✓ Drink at least 8 glasses of water a day.
  - ✓ Avoid constipating foods like cheese, rice, bananas, etc.
  - ✓ Exercise as much as is tolerated.

- ✓ Be sure your doctor is aware of all the medications being taken.

**Assisting with Eating** Eating can be very time-consuming, especially if the older person must be fed. Encouraging independent eating saves time for informal caregivers, and promotes the independence and self-worth of the older person. Try to relax yourself and enjoy the time spent with your care-receiver. Here are some suggestions for encouraging independence:

- Check gums for areas of redness. Dentures may not fit correctly and cause the family member pain when chewing.
- Provide adaptive equipment such as plate guards or special silverware with built-up handles. These can be purchased from medical supply houses (listed under Hospital Equipment and Supplies in the Yellow Pages). An occupational therapy evaluation can recommend the best for each individual.
- Prepare finger foods which may be easier to eat than those requiring utensils.
- Encourage older people to use a straw, cups with 2 handles, or a glass with ribbed surface for independent drinking.
- If the older adult has limited vision, consistent place setting of food and utensils helps to know where to find silverware, beverage, etc. Using the clock method to locate food may be helpful; for example, Your meat is at 9 o'clock, your potato is at 12 o'clock and your carrots are at 3 o'clock.

*Reminder:* Treat older people who are being fed as adults, not children. Disciplining poor eating habits should be avoided. When they lack interest in food, try to learn the reason.

**Mobility and Transferring** Moving people who cannot move safely by themselves requires skill, knowledge, and some strength. For every type of disability, there is a specific technique to use. Ask a doctor, therapist or attend caregiver training for specific techniques. In all cases, remember:

- When lifting, do not add your own weight to whatever you are lifting -- get close and keep balance centred.
- Do not use weak back muscles to lift - use your leg muscles because they are much stronger.

- Do not twist when you are lifting - instead, change the position of your feet so that you face the older person, keeping your spine straight.
- Balance is vital - spread your feet to serve as a base for support.
- Your doctor can refer you to a physical therapist who can teach you to transfer safely.

**Rest and Sleep** As we age, our sleep patterns change. The elderly require less sleep time. It takes longer for them to fall asleep. Also, awakenings during the night increase. Scheduled rest times are important. A few naps during the day can refresh and revitalize the care-receiver. However, if you notice that your care-receiver is sleeping for brief periods during the night, it could indicate a problem. Notify your doctor and discuss your concerns.

**Tips for Encouraging Self Care** Allow the care-receiver to do as much as possible; provide only as much help as needed. When older people do all or part of their own personal care, it is a form of exercise that will help maintain strength as well as promote independence. Here are some simple tips for you to remember:

- No matter how small the activity (holding the soap, combing the front of the hair, etc.) it is important that the person be able to participate.
- Adapt the home to allow the care-receiver to do more things. Install equipment such as grab rails in the bathroom, wheelchair-accessible sinks and lights with switches that can be easily reached.
- Seek the aid of therapists or nurses to teach you how to perform personal care tasks safely and effectively.
- Learn about the care-receiver's disability and what you and others can do to help him/her function as independently as possible. If the older person cannot perform a certain activity, see if there is a part that can be done.
- Whenever possible, include the care-receiver in making plans for his/her care. Take suggestions and feelings into consideration and encourage involvement in his/her own care. Sometimes, slowing the pace of an activity is helpful

- Be aware of changes in the care-receiver's health and abilities. Your plans for care will change as the care receiver changes.

**Exercise 12** Thinking about what you have read in this section please record three actions that you will undertake that will help you in your caregiver role in the box below

**Three actions to assist in personal care**

1.

2.

3.

**Section B: Ensuring good Nutrition**

Good nutrition is important in order that people live life to its fullest. Good nutrition is a balance of proteins, carbohydrates, fats, vitamins, minerals and water in the foods we eat. A healthy diet helps to (1) provide energy; (2) build, repair, and maintain body tissues and (3) regulate body processes. When meals are eaten in the company of others, people not only benefit from the nutritious foods, but also enjoy the chance to socialize. This encourages good eating habits and promotes good mental health

**Understanding good nutrition** The Four Basic Food Groups are detailed for you.

- 1) *Meat Group*: Provides protein, niacin, iron, and Thiamin-B1. 2 servings daily. Dry beans and peas, soy extenders, and nuts combined with animal or grain protein can be substituted for a serving of meat. 2 ounces of cooked, lean meat, fish or poultry have the same amount of poultry as: 2 eggs; 1 cup cooked dry beans, peas, or lentils; 4 tablespoons peanut butter; 1/2 cup cottage cheese.

- 2) *Grain Group*: Provides carbohydrates, Thiamin-B1, iron, and niacin. 4 servings daily. Whole grain, fortified, or enriched grain products are recommended. 1 adult serving is: 1 slice bread; 1 cup ready-to-eat cereal; 1/2 cup cooked cereal, pasta, cornmeal, rice or grits; 1 small muffin or biscuit, 5 saltines, 2 graham crackers.
  
- 3) *Milk Group*: Provides calcium, riboflavin-B2, and protein. 2 servings daily: Foods made from milk contribute part of the nutrients supplied by a serving of milk. 1 cup milk has the same amount of calcium as 1 cup yogurt, 1 and 1/2 slices (ounces) cheddar-type cheese, 1 and 3/4 cups ice cream, 2 cups cottage cheese.
  
- 4) *Fruit-Vegetable Group*: Provides vitamins A and C. 4 servings daily: Dark green leafy or orange vegetable and fruit are recommended 3 or 4 times weekly for vitamin A. Citrus fruit is recommended daily for vitamin C. 1 adult serving is: 1 cup raw fruit or vegetable, 1/2 cup cooked fruit or vegetable, 1 medium fruit, such as an apple or banana, 1/2 cup juice.

The list that follows summarizes essential nutrients (which you may also find listed on food labels) and their functions. A simple approach to understanding what food is nutritious is to look at the nutrients listed on food labels.

### **Nutrients on Food Labels and their Function**

- Protein: For preservation and repair of tissue; formation of antibodies to fight infection.
- Carbohydrates: For energy; fibre to help prevent constipation.
- Fat: For energy; healthy body and skin.
- Vitamin A: For healthy eyes, skin, hair; resistance to infection.
- Vitamin C: For healthy gums, skin; healing of wounds, bones; resisting infection.
- Thiamine (B1): For digestion; healthy nervous system.
- Riboflavin (2): For healthy eyes, skin, mouth; use of oxygen from air.
- Niacin: For healthy digestive tract and nervous system.
- Calcium: For preservation and repair of bones, teeth; muscle contractions; blood clotting.

- Iron: For building red blood cells to carry oxygen to all parts of the body.

### **Adapting Meals for People with Dietary Restrictions**

If the care recipient is on a special diet (low salt, diabetic or low saturated fat), the Basic Four Food Groups Guide (as detailed below) can still be used. However, because diets are prescribed to control a specific medical condition, certain foods may have to be eliminated, modified in the preparation, or limited in their intake. It is important that informal caregivers obtain specific instructions from a registered dietician or their doctor on which foods are allowed, how much, and how they should be prepared. Since some foods or medications may interact with other medications and/or foods in a harmful way, check with the pharmacist as to restrictions in any medications' use before it is applied.

**Common Problems Interfering with Good Nutrition** Illness, disability and depression can affect an older person's desire and ability to eat properly. The following suggestions deal with common problems that interfere with good nutrition.

#### ***Food tasting strange***

- Check teeth for tooth decay or gum infection,
- Avoid alcohol,
- Marinate meat, poultry and fish in sweet fruit juices, Italian dressing, or sweet or sour sauces,
- Drink plenty of fluids or suck on candies to get rid of bad tastes,
- Serve foods at room temperature or cold (Try milk-shakes or cheese),
- Use stronger seasonings such as basil, oregano, rosemary, tarragon, lemon juice or mint when cooking,
- Try new foods.

#### ***For Cramps, Heartburn, Bloating:***

- Eat slowly,
- Eat small meals frequently,
- Avoid gas-forming foods, e.g., cabbage, onions, nuts, beer, cola drinks,
- Avoid lounging immediately after eating; stand or sit upright for one hour after eating,
- Avoid fried, greasy and heavily spiced foods,

- Try bland, low-fat, easily digested foods,
- Chilled antacid may help, HOWEVER, check with your doctor regarding the brand of antacid to use.

***For Constipation try:***

- Take high-fibre foods and plenty of liquids,
- Exercise,
- Add bran when cooking or baking (1 - 2 tablespoons of bran for each cup of flour),
- Drink hot beverages which act as stimulants.
- Diarrhoea
- Eat small meals frequently,
- Drink clear liquids,
- Avoid high fibre and greasy foods,
- Replace fluid loss with liquids between meals.

***For Nausea and Vomiting***

- Avoid unpleasant odours
- Eat small meals frequently,
- Chew slowly and thoroughly,
- Sip cool, clear liquids between meals,
- Rest after meals with head elevated,
- Avoid hot, spicy, strong-smelling foods or fried, greasy foods,
- Try foods which are cold or at room temperature, and low-fat food,
- Eat dry or salty food,
- Try fresh air and loose clothing.
- Dry or Sore Mouth
- Drink plenty of liquids,
- Suck on ice chips,
- Suck on popsicles made of milk or non-acid juices,
- Dunk or soak foods in liquids,
- Use extra gravies, sauces, salad dressing,
- Rinse mouth frequently,
- Suck hard candies or chew gum,
- Eat sweet or tart foods if no sores in mouth,
- Artificial saliva can be used.

**General Tips for Helping the Older Person to Eat Well**

- Plan meals and snacks to include the person's favourite foods.
- Use a variety of foods from each of the four food groups,
- Prepare foods that provide a variety of texture, colour, and temperature,
- Provide a pleasant setting, i.e., flowers, place mats, matching dishes, good lighting.

**Exercise 13** Thinking about what you have read in this section please record three actions that you will undertake that will help you in your caregiver role in the box below

**Three actions to assist with nutrition**

- 1.
- 2.
- 3.

**Chapter 5 - Medical Aspects of Caregiving**

As a caregiver, you are in a position to help your care-receiver along the road to good health care by encouraging routine physical examinations. You are valuable in helping the care-receiver talk to their doctors and other medical personnel. You can follow through with their medical treatment at home. However, it is important to remember that the primary responsibility for medical treatment rests between the doctor and the care recipient. If there is any doubt about what you should or should not do, the doctor should be consulted.

You can help your care-receiver to understand his/her medical treatment and encourage the care-receiver to be involved in making decisions. In medical treatment, it is often tempting to decide what is best for the care recipient, but it is best to recognize the care-receiver's need to choose.

We all need control of our lives, and this is especially true for a person who needs the help of others. If there are serious concerns about decisions being made, informal caregivers should discuss the matter openly with the doctor.

### **Your relationship with the Doctor of the care-recipient**

The doctor is a valuable resource. Remember, Doctors are human beings, with individual personalities, enormous responsibilities, and only 24 hours in one day. No doctor will be right for all care recipients. Find a doctor whose skills and style of practice suits your current needs. All care-recipients should have one Doctor to coordinate their care. Frequently changing doctors is likely to result in poor quality care of chronic or complex problems.

If you are having a difficult time managing your care-receiver at home, or an acute illness occurs, the doctor may assist with related health care concerns. Your care-receiver may have to be hospitalized. The doctor may assist by making a referral. Once hospitalized, the doctor can assist in placement issues or home health care upon discharge. If he/she doesn't offer it, you may request it.

If you are dissatisfied with your doctor, consider:

- What do you want from your doctor?
- Are these wants realistic (e.g., cure of an incurable disease)?
- Have you discussed them with your doctor and/or staff?
- Do you have a Doctor who oversees your overall medical care? (Often, sub-specialists such as cardiologists or orthopaedists focus on one organ system, and do not try to coordinate the care recipient care.)
- Do you keep your appointments for the care-recipient?
- Does the care recipient take medications as prescribed?

Older individuals with multiple medical problems or difficulties with memory or intellectual functions may benefit from a comprehensive geriatric assessment program. Your Doctor may have information on comparable programs in your community.

## Keeping Records and Managing Medications

Informal caregivers can help older people maintain medical records for use by the doctor. The same medications that are helpful in easing pain, stopping infection, controlling heart rate and keeping people healthy can also cause serious problems. Because many older adults take several medications at one time, it is possible that these drugs can interact with one another and be a danger. If more than one doctor is prescribing medications, it is important to keep each doctor aware of the drugs that are being taken. You can keep them informed by taking all your drugs in a paper sack or a list of all your drugs to each doctor. Having one pharmacist that fills all of your prescriptions is a way to prevent taking drugs that interact and cause problems. Over-the-counter or non-prescription drugs also can cause problems. Talk with your pharmacist before using them. If you find the medicine schedule confusing or difficult to follow, ask your pharmacist about preparing all medicines in blister packs.

**Arranging the Doctor Appointment.** Some things to remember for the visit to the doctor, the care recipient's list of current medications (Exercise 14) and previous medical records should be given to the doctor. If the visit is for a specific problem, have the following information for the doctor:

- the symptoms,
- how long they have been present,
- how often they happen, how bad they are.
- Reviewing this information before the visit will help.

And remember, it is important that the care recipient have a chance to visit with the doctor privately to discuss confidential information. Before leaving the doctor's office, meet with the doctor or the nurse to find out how you can help with treatment and what your role as caregiver should be.

**Exercise 14** This exercise will help you with the care-recipients medication. In the box provided record the essentials: name of medication, the reason for the medication, the dosage and the time the medication is taken. List all Medications for Each Time Morning/Noon/Evening/ Bed Time.



## **Common Medical problems faced by care recipients**

Research shows that reaction time may be slower in older people but they can still learn. Families and friends may need to be care recipient in waiting for responses. It is also important to remember that short-term memory may not be as good as it was. Sometimes older people are incorrectly labelled as "senile"; the misconception is that they are no longer able to think for themselves. However, for the most part, older people continue to make good use of their creative powers, and as is true for all parts of the body, the brain usually will function better if it is used regularly.

Lifetime learning means exploring new ideas, whether this is from reading, listening to radio or television, trying a new hobby, or trying a new recipe. It can include lively conversation with friends and family. What it boils down to is a willingness to keep exploring the many adventures that life has to offer. The benefits of lifetime learning include more enthusiasm for life, less boredom and depression, increased feeling of self-esteem and self-respect, more interest in the surrounding world, and new ideas to share with family and friends.

**Memory Problems:** Memory loss can be one of the hardest problems for both the care-receiver and the caregiver. Some memory problems are treatable, some are not. Therefore, it is important for the doctor to determine the causes of memory loss in the individual. Forgetfulness, even inability to recognize familiar faces and places, might result from such treatable causes such as malnutrition related to improper eating habits, alcohol, side effects of medications, loneliness, isolation, few chances to socialize with others, sensory impairment (decreased vision, decreased hearing), surgery or accident resulting in injury to body, viral infections or other illness, or depression or other mental illness.

**Sensory Problems** People who have losses in hearing and vision may have trouble understanding things consequently negatively affecting their emotional well-being. Basic aids to hear and see are vital. At times an older person may be cut off from the world because of wax in the ears or worn out hearing-aid batteries. Glasses may need to be adjusted or perhaps just cleaned. Good lighting, without glare, is important. Magnifying glasses or large print can make reading easier.

**Confusion** For people who are confused, the following tips can be useful:

- Make changes in routines gradually,
- Be clear about reminders for appointments or meetings,
- Write simple directions in large, clear print,
- Use large labels (words or pictures) on drawers and shelves to identify contents, have clocks and calendars clearly visible and mark off passing days,
- Make certain that medicine is being taken regularly,
- Confused or forgetful care recipients must have assistance with their medications,
- Encourage consumption of nutritious foods,
- Encourage movement and/or exercise as this will increase circulation of the blood and help improve bodily functions, including the ability to think.

**Behavioural Problems** For people who are acting out, being disruptive, or have other undesirable behaviours, it is best to not antagonize or confront but to temporarily remove your presence from the person, giving the message that "*I love/care for you but not this behaviour.*" Below are some suggestions to minimize undesirable behaviours:

- Avoid confrontation. If the behaviour deals with disrobing, offer brightly clothes which make the person feel good.
- Don't argue. If the person becomes too agitated, change the subject/object to something completely different.
- Reduce stimulation. Lower lighting, reduce noise (radio, TV) to soothing music, minimize items in the area to a few possessions known to the person, and avoid clutter.
- Promote familiar objects, pictures.
- Walk slowly with the person to reduce anxiety and stress the muscle tension.

**Mental Stimulation** Because many older people enjoy recalling events from past years, families and friends should encourage the sharing of stories. Activities which stimulate the brain (visiting others) can contribute to the goal of continued lifetime learning. Often, older people can become happier, more productive individuals when they

are encouraged to perform fun, brain-stimulating activities. People who are physically able should be encouraged to participate in swimming, bowling, nature walks, and other activities outside the home. Drawing, writing, reading, crafts, taking classes, and other hobbies encourage creativity. Indoor games including chess and checkers provide interesting relief from boredom as well.

### **Caring for persons affected by dementia**

Alzheimer's Disease is the most frequent form of dementia in industrialized nations. This disease causes a slow, but progressive deterioration of an older person's cognitive functions and physical capacities, including the loss of memory, reasoning, language skills, the sense of orientation, the ability to carry out routine daily activities such as managing a household, grocery shopping, selecting clothing and dressing, etc.

The memory of a person affected by Alzheimer's is severely impaired. These individuals do not remember things and even the simplest actions become difficult. They sometimes repeat the same questions continuously and they may not even recognize their own relatives or close friends.

There are evident changes in the care recipient's behaviour. Family members or close friends may occasionally note something in these care recipients that seems strange to them, with behaviour that is inappropriate in situations or circumstances (because the dementia care recipient confuses persons or places and exhibits embarrassing behaviour). The care recipient may also display nervousness, restlessness or aggressiveness for no apparent reason.

Recognizing the early signals of this disease in a member of the family is a difficult matter, as is acceptance of the diagnosis. This is also because it is commonly thought that natural aging inevitably leads to the loss of many functions, including physical and mental skills. Actually, the deterioration of cognitive skills, which part of our culture continues to consider as a natural event, is in fact more often than we believe caused by various degenerative diseases, among which Alzheimer's also figures. Family members are faced with a long and difficult road ahead, as changes in personality (indifference, lack of interest,

irritability, mistrust, social isolation and depression) and cognitive impairment are the symptoms that are the hardest for family members to accept - it is painful not to be recognized by loved ones and to accept this situation.

Over time, Alzheimer care recipients require constant assistance in personal hygiene, to dress, eat, go outdoors and in moving about their own homes. Learning and staying informed about the disease and its future course is very important for understanding the care recipient's behaviour, for it makes it possible to identify the real problem and to understand what to do to help the older person. Communication and empathy at the affective level (love, gentleness, caring, affection, smiles and kindness) are essential for a supportive relationship with the care recipient. Unfortunately, there are no pharmaceutical drugs that serve for complete recovery in the case of Alzheimer's disease. However, there are drugs that can slow down the progressive course of the disease and reduce some of the symptoms, such as aggressiveness, anxiety, delusions and hallucinations, depression and problems with sleeping.

### **How you can help an older person who is suffering from loss of memory**

Older person with Alzheimer's tend to remember things that happened many years ago, but they forget things that have happened recently, just a few days or hours before. For example, they may not remember whether they have eaten, get upset because they cannot remember the name of their caregiver, worry because they do not remember where the house keys are, or they may not remember what day, month or year it is. In such cases, the caregiver should:

- Always respect the older person, remember that he/she is suffering from Alzheimer's
- Be calm and reassuring; do not lose your patience
- Suggest that the family contact a dementia care centre, if the care recipient can no longer be managed alone

The care given must be of a practical nature. In other words, the caregiver should intervene with the aim of helping the elderly care recipient carry out daily activities, without taking over completely if the care recipient is still able to do something on his/her own.

### **Talking and communicating with elderly Alzheimer care recipients**

Alzheimer care recipients gradually lose the ability to understand spoken and written language. They have trouble finding the right words (parole), make mistakes and mix words up. These problems make communication difficult. The caregiver must try to understand their needs and desires and to help them converse, the caregiver should:

- Stay calm, relaxed and cheerful
- Sit down facing the care recipient and try to understand what he/she is trying to say
- Do not criticize or ridicule the care recipient if he/she makes mistakes
- Look directly into the care recipient's eyes
- Check for any physical problems, example: a need to go to the bathroom to urinate
- Do not shout or raise your voice because it could frighten the care recipient
- Try to understand even on the basis of the older person's gestures
- Try to understand the older person based on his/her facial expressions: Is he/she sad? (triste) Angry? Worried? Feeling pain?

The behaviour of the elderly individual with this disease can sometimes make him/her seem like a young child in need of attention and reassuring tender loving care. Some care recipients may like physical contact and thus holding the care recipient's hand or a reassuring pat could be of help in caring for the care recipient. However, some care recipients may not appreciate contact of this sort. Therefore, thorough preliminary information about this aspect is required and can often be supplied by the family member who is closest to the care recipient.

### **How to approach personal hygiene with the care recipient**

The care recipient has an increasing need for assistance with personal hygiene. He/she may have problems holding a bar of soap or remembering what the soap is used for. The care recipient may not understand what a faucet is or how to open it and also lose interest in taking care of themselves and their personal hygiene. When an older person has to bathe, there may be a fear of water or of falling in the tub. The caregiver should:

- be relaxed and cheerful
- make the room where the older person bathes safe

- use water that is not too hot
- make the bathing routine pleasant, without forcing the care recipient because he/she could get angry - do not scold the care recipient
- use a mild, scented soap
- use a soft towel and gently dry the skin without rubbing because older person have very delicate and sensitive skin
- always check and clean fingernails and toenails and remember to trim them.

It is not always easy for Alzheimer care recipients to dress themselves because of their loss of memory. They may not remember how to put on their clothes or how to button them. The caregiver should always check to ensure that the elderly care recipient looks tidy and well groomed - this can help to make the person feel better about him/herself.

**How to approach diet and eating issues** Mealtimes can become difficult because the care recipient may not remember to eat or drink. The care recipient may not recall previous meals because of memory loss and ask to eat constantly. Some care recipients may not be able to hold or use a fork or spoon. If the case is severe, the care recipient may have problems chewing and may keep food in his/her mouth without swallowing it. The caregiver can follow these recommendations:

- prepare foods that the older person likes
- have the care recipient sit correctly - the care recipient should be comfortable and at ease
- let the care recipient eat with his/her hands if he/she wants to
- place a napkin on the care recipient's lap
- do not scold the elderly care recipient if he/she gets dirty or if food falls on the floor
- remember to give the care recipient at least 8 glasses of water per day, tea (very little) and chamomile tea because the elderly tend to forget to drink
- cut the food up if the care recipient is unable to do so alone

**Advice and suggestions for informal caregivers** Some older person affected by dementia may not recognize where they are, places such as their own home and the street where they live. They may walk for hours, wander for miles and get lost, without being able to remember their own address. For these reasons, the caregiver must be very

watchful to prevent a care recipient from leaving home, as he/she may not be able to remember where he/she lives or how to return home.

Some elderly dementia care recipients are unable to sleep at night and remain awake. They become restless and get up from bed. It can help to offer some milk, let them move about and check to ensure there is no risk of falling or tripping, have them go to the bathroom and avoid naps during the day. Some care recipients are unable to distinguish daytime from night-time. Do not force the elderly care recipient to stay in bed because this could make him/her angry and upset, and calming him/her down could become difficult. The doctor can be called if the care recipient is not sleeping well or not sleeping at all.

As the disease progresses, the dementia care recipient may also suffer from urinary incontinence (the care recipient does not feel as if he/she has to urinate (pipi) or no longer understands when, is unable to verbalize it, or can no longer find the toilet). Help the care recipient change clothes if he/she wets him/herself. Do not scold the care recipient because he/she needs help and may feel embarrassed and ashamed.

It is important to monitor the older person's bowel movements for regularity because he/she may be suffering from constipation. This problem can cause stomach aches and loss of appetite. If the problem persists, the doctor must be contacted.

Call the doctor immediately and notify members of the family if you realize that the elderly care recipient is feeling ill, has a fever, has fallen and is moaning with pain, or is delirious.

**Daytime activities with the elderly care recipient** The caregiver can keep the elderly care recipient company and help him/her to perform small tasks to keep him/her from feeling sad or bored. Older person may still be capable of:

- Taking walks
- Folding laundry and dusting furniture
- Doing gardening if there is a garden
- Listening to music
- Keeping their hands busy with yarn, winding it into balls
- Sharing photographs

- If the care recipient has a cat, he/she can continue to keep the cat in the home; older person like to pat pets.

The elderly deserve care and respect and the work of care- givers is considered to be very important in making older person feel good in their own homes.

### Exercise 15

#### **Prioritise 3 things that you have learnt about physical health**

1.

2.

3.

**Planning For Medical Emergencies** Having an emergency plan is important, especially when a substitute caregiver occasionally takes your place in the home. Post phone numbers for the following agencies next to your telephone or a conspicuous place where they can easily be seen by anyone.

- The 911 number for emergencies (Medical, Fire or Police),
- The Doctor's number (emergency and office number),
- The name and number of the hospital the Doctor and the care recipient prefer,
- The number of the home health agency, if one is currently making visits to the home,
- The Poison Centre phone number,
- The 24-hour number of the medical or oxygen supplier, if one is being used,

- The telephone number where you (caregiver) can be reached.

Remember; observe changes and signs of illness in the care-receiver. They can help detect a medical problem. But if any doubts about health arise, call the doctor for advice; do not procrastinate!

**Exercise 16** It is useful to look at the following three areas and develop a plan

### **Medical Help plan**

1. What can be done now to help in the treatment of current medical problems
  
  
  
  
  
  
  
  
  
  
2. How to recognize problems that may arise

## **Chapter 6 - Emotional and Intellectual Well-Being**

Each human being is a combination of body, mind, and spirit; we should be aware of how these parts interact. For example, people may have powerful emotional responses while facing the many challenges which life presents. Thus, some may often appear cheerful and optimistic while others are anxious and unhappy. In later years, we usually continue our basic moods, but the ways we express our feelings often become more obvious.

**Depression: Signs and Causes** In the midst of losses, such as physical changes, death of friends or loved ones and reduction of income, older people may begin showing signs of depression. Some things to look for are:

- inability to concentrate or make decisions,

- lack of feelings of enjoyment, or enthusiasm even for doing those things that were favourites,
- little interest in eating (causing weight loss) or changes in eating habits (overeating causing weight gain),
- lack of interest in being with other people, or loss of sex drive (libido),
- feeling unwanted and worthless, sometimes leading to the thought that life is not worth living,
- sadness or crying spells for no apparent reason,
- problems with sleeping (sleeplessness during the night or excessive sleep during most of the day),
- feeling tired most of the time, regardless of adequate rest.

If older people brood about their unhappiness, much of their energy is focused on worry. Part of that worry may relate to the fear that they will become forgetful and unable to manage their affairs. This worry can lead down the path to more depression, which may cause physical problems.

**Exercise 17** In exploring the cause of depression, the following questions should be asked

**In cases of depressed mood consider**

- Is there a physical or medical problem causing the depressed mood?
- Have there been changes in hearing, seeing, moving, or other body functions?
- What social contact does the care-receiver have?
- What are the opportunities for usefulness?
- What kind of personal losses (death of friends, relatives, or pets) have occurred?
- Is the older person getting proper nutrition?
- What kind of mental stimulation is the person getting?
- Has there been a difficult adjustment following retirement?
- Is the focus entirely on the past or is there some enthusiasm about coming events?

Once these questions have been answered, steps can be taken to relieve the depressed mood. It will take some work from both the caregiver and the care-receiver to change habits and routines. Prolonged depression causes biochemical changes in the brain, usually requiring treatment with medication. The doctor is a good person the contact to find help for treatment of depression.

## **Suicide Prevention**

Suicide among the elderly is a significant and ever increasing problem. Unlike other segments of the population, the elderly do not often make threats or mention suicidal thoughts to others. Therefore, it is important that informal caregivers also know other warning signs:

- Depression - feelings of sadness, hopelessness, a sense of loss and statements as "Life isn't worth living" are common before a suicide.
- Chronic or terminal illness.
- Withdrawal and isolation - suicidal people may pull away from family, friends and others close to them.
- Behaviour changes - sudden changes such as irritability, aggressiveness or changes in eating and sleeping habits can signal problems.
- Making final arrangements - a suicidal person may give away valued possessions, making out a will, make a plan for suicide, or write a suicidal note in preparation. They may purchase weapons or stockpile medications.

Suicide can be prevented. If the person you care for shows any of the warning signs, you can:

- Ask - don't be afraid to ask directly if the person is thinking about suicide. It is not a taboo subject. You will not be putting ideas into the person's head. It can be a relief to the suicidal person to talk openly about their feelings.
- Listen - let the person express his/her feelings and concerns. Don't worry about saying the right things - just listen.
- Show you care - tell the person you care and want to help. Take active steps to make sure the person is safe; remove weapons, pills, etc., and stay with him/her.
- Get help - make sure the suicidal person gets in contact with a professional or other helpful person who will know what to do. A crisis counsellor can help figure out the best way to handle the situation and give referrals to other resources.

## **Death and Dying Interventions**

The terminally ill and older person who are nearing the end of their lives and often associated with states of illness, are reminders for the caregiver of an end, of the condition of being mortal. The usual attitude is to avoid them, to keep them at a distance, thus creating a context of isolation that accentuates a feeling of exclusion in the older person.

However, not all older people approach death with the same feelings as younger persons. In fact, some studies have demonstrated that older person do not have a fear of death per se, but rather a fear of ending up in a rest home and of prolonged illness accompanied by pain and physical suffering.

On the other hand, in addition to the physical and psychological burden involved in assisting an elderly relative, family members may have feelings of guilt before the death of their relative and thus wonder whether they can do more for the person who is ill. However, they may also have these feelings after the death of their relative and thus feel guilty about that inevitable sense of relief that follows a long period of care.

Despair and pain over the loss can be partially alleviated if the family member has someone to talk to about his feelings. It is also very important that the family member does not see his relative endure suffering, asking the family physician to alleviate the pain, and thereby preserving the care recipient's dignity down to the last moment when death occurs.

The terminally ill care-recipient and you as a caregiver can encounter anxiety and fear regarding death as follows:

- fear of the process of dying; will there be pain?
- fear of losing control; will I be at another's mercy?
- fear of letting go; I cannot leave family and friends to an uncertain future.
- fear of seeing how others will avoid me.
- fear of losing my caregiver; will he/she be turned off emotionally to me?
- fear of the unknown after death.
- fear that my "life's script" has been meaningless, unfulfilled, a waste.

**Exercise 18** Take 5-10 minutes and think about your feeling regarding the death of the care recipient. Be honest in your responses and write the three main feelings that you experience in the box provided

**Feelings about death of the care recipient**

- 1.
- 2.
- 3.

You may wish to ease these fears through an open discussion of these fears and intervening:

- Regarding the death process, a "faith system" may be of great help; if you can get the person involved in his/her religious faith, the subject of death is well covered.
- Regarding fear of letting go and isolation, assist then person to get his/her "house in order." This entails a will, funeral arrangements, burial plot, etc. Also attempt to have the person and family involved discuss the situation.
- Regarding meaninglessness of one's life, have the person do a "Life Script," whereby he/she writes all the good things done for others, all accomplishments, etc. Then discuss with the person that had he/she not been there to do what he/she did at that time, no one else would have, and society would have been the worse for it. So he/she did make a difference. Truly, no person is an island!

**Exercise 19** Now consider your feelings about what would happen if you were to die. Again be honest in your responses and write them in the box provided

**Feelings about your death**

- 1.
- 2.
- 3.

**Promoting Emotional Well-being** It is important to help the elderly remain involved in decision-making as long as possible. You must stress that needing help with everyday activities does not mean that they cannot make decisions for themselves. Also, granting others the right to decide does not mean you are ignoring or abandoning them. Informal caregivers need to be sensitive to the right combination of giving just the right amount of assistance and no more.

**Ways to promote good mental health in the elderly:**

- encourage socializing with friends and relatives through visits, phone calls or letters.
- arrange fun times such as parties or outings.
- help start new hobbies or revive old ones.
- listen, talk, and share feelings.
- assure privacy.
- treat with respect, not as little children unable to think for themselves.
- encourage movement and exercise.
- help find ways to be as useful as possible.
- strive to keep the lines of communication open.

## Chapter 7 - Legal and Financial Affairs

Older people continue to be concerned about management of their assets and property. However, they may be unable to participate because of illness, confusion or loss of memory. It is important to involve them whenever possible. This will reduce the stress that you will experience as a caregiver

**Compiling an Inventory** Develop an inventory which lists all assets and liabilities of the older person. The following items should be included: bank accounts, pass books etc. Location of the records for each asset and liability also should be included. Other important documents, such as birth and marriage certificates, social security numbers, etc should be listed and the locations designated. If able, the older person should compile the list. If unable, a family member, legal representative can help compile the inventory which should be copied and kept in a safe, obvious place, possibly with a relative or friend. It is important that the document be updated every year.

**Managing a Will and Financial Affairs** An objective of financial and estate planning for older people is to plan for the orderly distribution of the estate upon their death, according to their desires. Consequently, it is important for people to have a will drafted, which incorporates the

above inventory and states how property is to be disposed of upon death. Everyone over the age of 18 should have a will or a similar legal document.

If a person does not have a will, an attorney should be consulted immediately. Proper planning is essential and powers of attorney or trust agreements should be executed while a person is still competent. Otherwise, transfer of responsibility for management of the person's financial affairs to someone else must be completed through a court action, and costs spent in clearing up Probate problems come directly out of the person's assets, diluting whatever estate is left after death.

Remember, as informal caregivers concerned about the financial affairs of a care-receiver, ***you should not get directly involved without legal authority***. Acting without clear legal authority, even with the best intentions, can cause serious problems.

**Liability of Caregiving** Anyone who accepts the responsibilities of a caregiver must also understand that there are a number of legal duties or liabilities that come with it. Many countries have passed elderly abuse laws. Informal caregivers are bound by these laws in two ways: not to abuse the elder person (physically, mentally or monetarily) and report any incidents of abuse or suspected abuse.

As a caregiver, you must provide a clean and safe environment, nutritious meals, clean bedding, and clothes. At the same time, if you are in charge of the older person's finances, you must use that money properly, purchasing necessary services for the benefit of the person to whom care is given. Failure to provide care, failure to get care, and failure to purchase care are all forms of abuse or neglect.

In addition, informal caregivers may not physically, sexually or psychologically abuse the person receiving the care. Yelling, screaming, withholding affection, etc., are as much an abuse of the person as is striking the person with the hand or with objects. Therefore, if you are contemplating becoming, or are now a caregiver, you must be ready to accept the physical, psychological and legal duties to provide the necessary care. If you are reaching a point where you are no longer able, physically or emotionally, to provide the proper care, we urge you to consider the alternatives to personal caregiving and to seek help with this decision from a counsellor.

**The Financial Aspects of Caregiving** Caregiving is a complex and expensive endeavour. Caregiving itself can have financial consequences for the caregiver. For example, you may have to cut back on your work hours, from full-time to part-time, due to caregiving duties. That can have a negative effect on other benefits of

employment, such as promotions and retirement contributions. Consider the following actions:

**Review bank and financial arrangements.** You will need to review issues and perhaps change financial arrangements between yourself as a caregiver and the care recipient.

Look into Social Security and pension benefits. You may need to determine and make arrangements regarding Social Security and pension payments for the care recipient.

**Manage family financial planning.** Plan for care options now, and in the future. There are many care options and services available. These include adult day services, supplemental home-based care, occupational and physical therapy, respite care, assisted living and long-term care. All of these care options require financial planning and arrangements.

**Exercise 20** Thinking about what you have read in this section please record three actions that you will undertake that will help you in your caregiver role in the box below

1.

2.

3.

## Chapter 8 - When is It Time to Stop Caregiving?

As we have stated repeatedly throughout this booklet, caregiving is a very stressful situation. Stress either causes or exacerbates some 70 to 90 percent of all medical complaints, including tension and migraine headaches, high blood pressure, asthma, nervous stomach, bowel problems, and chronic lower back pains. There is research evidence indicating stress plays a role in a person's susceptibility to heart disease, stroke, and cancer.

Stress has also been implicated in psychological disorders such as anxiety reactions, depressions and phobias, as well as poor work performance, drug and alcohol abuse, insomnia, and unexplained violence. If you are experiencing any of the above, it is extremely important that you learn and use various techniques for stress reduction or come to the decision, both for your well-being and that of your care-receiver that It is time to stop caregiving.

Below are some tell-tale signs of caregiver burnout which can help you assess when you have reached this fork in the road; seek help professional help, utilize more stress reduction methods, or stop caregiving:

- snapping at the care-receiver constantly even over little things,
- being constantly irritated,
- seldom laughing anymore,
- feeling constantly tired or pressured,
- losing sleep, failing to fall asleep for hours, sleeping restlessly all night long,
- yelling or screaming, or having crying fits, or rages frequently,
- withholding affection, feelings of goodwill from the care-recipient,
- withholding food, baths, dressing changes, etc.,
- constantly blaming the care-receiver for your being in this situation (his/her isolated caregiver),
- refusing to go out anymore, even for a walk because he/she needs me,
- withholding expenditures for goods or services he/she needs because he/she is going to die soon and it is wasted money

**Exercise 21** Think about the list above and record any of these signs that you have experienced.

**Signs of caregiver burn out**

While these are not exclusive, they indicate a classic picture of caregiver burnout. The treatment for caregiver burnout is simple -- get help and get away for extended periods, either through stress management respite help or through a complete change in caregiving.

No one can remain a full-time caregiver forever; the job is much too strenuous and stressful. The point we wish to set forth is: When should I say this is my limit; I am not able to do any more. Be honest with yourself,

and when that limit has been reached, STOP! Research alternatives, request help from qualified professionals, and rest easy, because you did the right thing!

**Exercise 22** Think about what would be your limit in your caregiving role. Write down your initial feelings- it may be the care recipient becoming incontinent, you becoming ill, the arrival of a grandchild. Try to consider plans that you would put in place at that time

### Knowing your limit

### Choosing a Residential Care Facility

In making the decision to seek an alternate living arrangement for your care-receiver you will first need to consult with your Doctor. The Doctor can be your best ally since most facilities require a current complete physical exam and the Doctor can assess the level of care your care-receiver needs. The law requires that care facilities be licensed. So when you select a care facility, check for the license to assure the protection provided by law and quality care for your loved one.

**What Should I Look for When I Visit a Care Facility** It is ideal if both you and your care-receiver could preview a care facility prior to deciding. Both prior to and during the preview process you have the opportunity to further discuss your feelings in making the decision. Since you have many things to do during your visit, you will find the outing less stressful and easier afterward to evaluate if you organize your thoughts beforehand, write down the questions you wish to ask, carry this checklist during your visit and make notes while looking around and talking to different people.

## Chapter 9 - What have I learnt for me as a Caregiver?

Caregiving presents considerable challenges—physical, emotional and economic. There is no reason to suffer in silence. If you take away one thing from this booklet, remember, it's always OK to seek and ask for help. Getting help can enable you to become a better caregiver.

**Remember**

As a caregiver, try to remember to:

- Strike a balance each day.
- Focus on your needs, too.
- Care for yourself while caring for your loved one.
- Make time for resting and relaxing.

Life-changing events often give people the chance to grow. They may help people see what's most important to them. Many say that caring for someone with cancer changed them forever. They used their strengths to support their loved one. And they learned more about themselves along the way.

Throughout our lives, many of us are asked to care for another person—to become family informal caregivers. Perhaps you were called to the task after a loved one's illness slowly progressed to the point where he or she needed help at home. Maybe someone needed your help suddenly, after a tragic accident.

Your caregiving responsibility may be short-term, long-term or indefinite. Whatever the circumstances, the road ahead on your caregiving journey may seem long and uncertain. Know that you are not alone. Although you may feel isolated, together family informal caregivers are part of a larger community. If you look around, you might discover:

- Your co-worker cares for an elderly parent at home.
- A family friend might be a caregiver to a spouse or life partner with a serious illness, such as cancer, and is dealing with end-of-life issues.
- Your pastor/spiritual advisor might be serving as a caregiver to his developmentally disabled daughter in addition to his responsibilities to his congregation.
- Each caregiver situation is unique, yet all share universal experiences that encompass physical, emotional and spiritual—as well as economic and legal—concerns.