

# *Partners in Care*





## *This part of “My Guide for Living with Dementia” is written for Partners in Care.*

Partners in Care refers to you – the family member, the friend, the professional - all of you are involved in supporting the Person with dementia. Many of you will experience different emotions in your role as ‘caregivers’. Remember that you are not alone but part of a caregiving team. Work together to support the Person with dementia and each other.

As a caregiver, each of you understands the Person with dementia in your own unique way, for example:

- Family or friends who live with the Person will know a lot of detail about that Person’s life.
- Family or friends who see the Person infrequently may see changes over time that others miss.
- A Personal Support Worker will come to understand bathing preferences.
- A family doctor will know the medical history.

Sharing information with other Partners will be very useful and will contribute to better care.

This Partners in Care section includes:

- Tips to help you support the Person with dementia as well as what to expect near the end of the Person’s life.
- The words of a caregiver.
- Information about maintaining your own health.

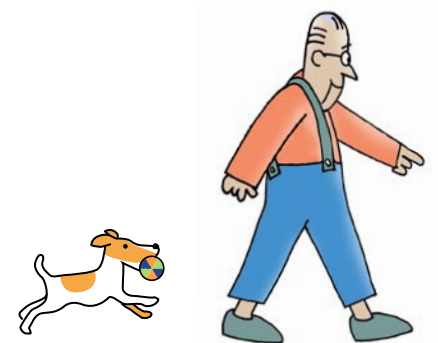
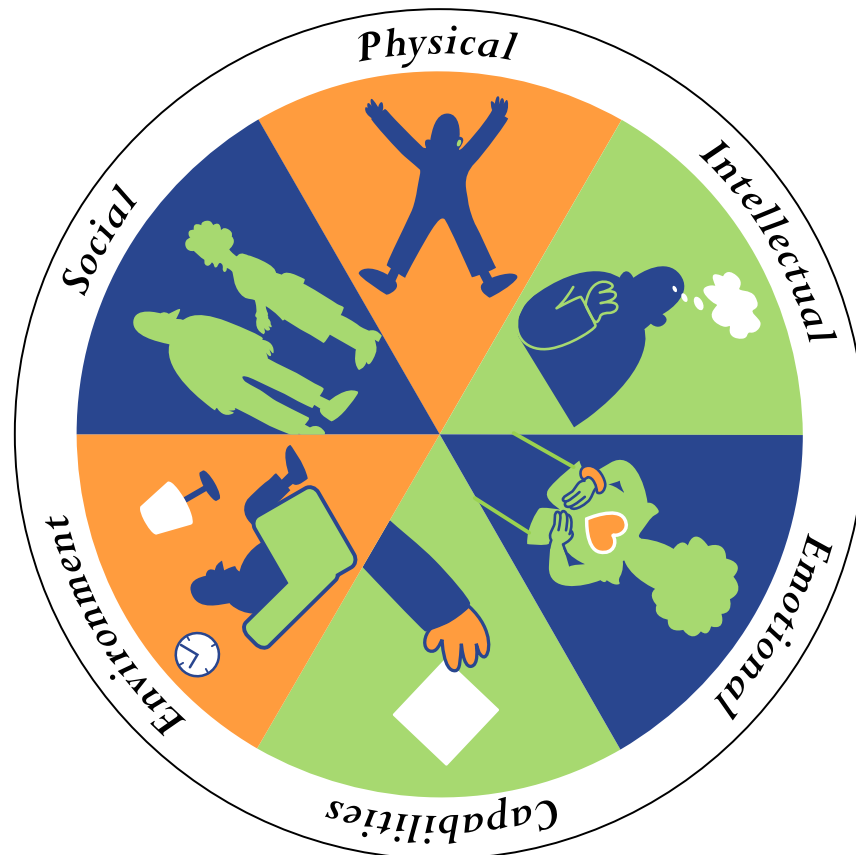
Other sections of this Guide will help you understand the many factors that can influence a Person with dementia:

- **Introductory Booklet**
- **‘Getting to Know Me’**, a place to record important information to help others better understand the Person with dementia
- **P.I.E.C.E.S.<sup>TM</sup>** section that describes many factors that can influence the well-being of a Person with dementia
- **Resources**

For the complete “My Guide for Living with Dementia” contact your local Alzheimer Society office or download it from [www.dementianetworksc.org/myguide](http://www.dementianetworksc.org/myguide).



The full “My Guide for Living with Dementia” is based on the P.I.E.C.E.S.<sup>TM</sup> model of care. There are more detailed subsections about Physical, Intellectual and Emotional well-being, Capabilities, and the effect of the Environment and Social history on the Person with dementia. This section was written for Partners in Care using the P.I.E.C.E.S.<sup>TM</sup> format.





## PHYSICAL WELL-BEING

The P.I.E.C.E.S.™ section of the Guide contains many tips about maintaining a Person's Physical well-being. Information is included about medication, pain and acute and chronic illnesses.

People with dementia are more likely to experience delirium, a serious condition that requires prompt medical attention.

Delirium occurs when a Person who has many health challenges experiences an additional stress that is too much for his or her body to manage. That stress is often a physical one; like an infection, a new medication or dehydration. However, other stressors may include a new environment or the loss of a close friend. As a Partner in Care, it is important for you to recognize the signs of delirium.

The most important sign of delirium is a **sudden change in abilities or behaviour**. The Person may also:

- Be less able to focus his or her attention.
- Appear very sleepy or become very fidgety and unable to rest.
- Become incoherent so that he or she no longer makes sense when speaking.

These symptoms may seem similar to those of dementia but they come on quickly and may indicate an underlying illness. It is, therefore, very important to have the Person assessed by a physician.





## *Work with the Person with dementia, the Substitute Decision Maker and other Partners to:*

- Implement the tips listed throughout the P.I.E.C.E.S.™ Physical section and keep the **'Getting to Know Me'** pages up to date.
- Monitor the storage, use or misuse of medications (prescription, over-the-counter drugs, herbal remedies) and alcohol.
- Watch for changes in daily routines such as fluid intake, bowel and bladder patterns and medication use to help avoid common causes of delirium.
- Review the signs of delirium, listed on the previous page, whenever you witness a change in the Person and seek medical attention if these symptoms persist.
- Monitor the Person's weight on a regular basis.
- Maintain a schedule for routine health care including oral care.





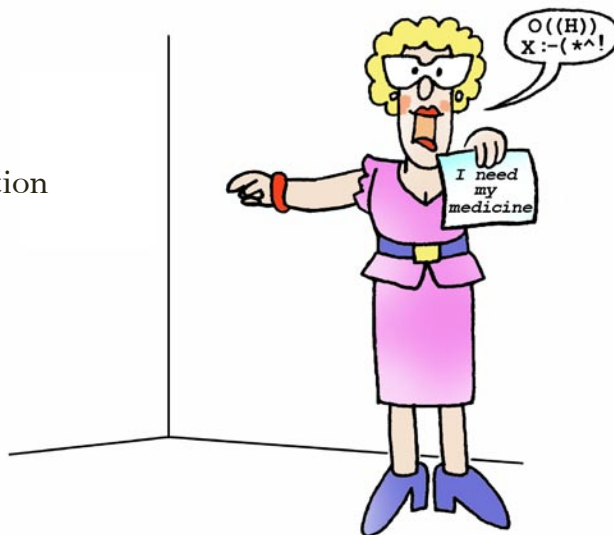
## INTELLECTUAL WELL-BEING

The P.I.E.C.E.S.™ section of the Guide contains information on Intellectual well-being and helpful strategies on managing the symptoms of dementia.

As dementia progresses, it is important to understand that the Person will see, hear and understand the world differently. Therefore, you will need to pay close attention to the Person's responses and adapt your interactions to suit his or her abilities. This may be hard to do at first, but will help the Person feel more at ease.

Most people with dementia experience ongoing memory loss. For example, a Person whose strongest memories are from thirty or more years ago may not recognize a spouse as they appear now. He or she may also mistake an adult child for a spouse or confuse grandchildren for children. While this can be very upsetting to you, correcting the Person may cause more confusion or upset for them.

As dementia progresses, communication becomes more difficult. The Person may know exactly what to say but is unable to express it. He or she may hear your message clearly yet not be able to make any sense of it. Either of these situations can cause the Person to withdraw from conversation or to feel frustrated or embarrassed. Over time, families develop their own way of interacting and communicating. The process of adapting old patterns may be very difficult but extremely helpful to the Person with dementia.





The Person with dementia will lose insight, or the ability to recognize changes in his or her own abilities. This can be a significant challenge for Partners in Care as the Person may not recognize the need for anyone's help. Someone who believes that they are well and managing their home and personal care successfully, may find it strange that others offer help.



### *Work with the Person with dementia, the Substitute Decision Maker and other Partners to:*

- Implement the tips listed throughout the P.I.E.C.E.S.™ Intellectual section and keep the **'Getting to Know Me'** pages up to date.
- Manage progressive memory loss.
  - Listen to understand what time frame the Person is speaking about and learn to share memories from that part of his or her life.
  - Avoid contradicting or correcting the Person. Speak respectfully and recognize this as an opportunity for you to connect with him or her in the moment.
- Manage the ongoing loss of communication.
  - Pay attention to tone of voice, facial expressions and gestures to help you understand the message. Repeat key words to provide reassurance and encouragement.
  - Try writing your message. Make sure the print is large and clear to account for any vision changes. Ask the Person to try writing a message.
  - Remember your non-verbal communication. Make sure that your facial expression, tone and body gestures match your verbal message.
- Manage the loss of insight.
  - Avoid contradicting or testing the Person. Correcting someone who feels that they are managing well may lead to embarrassment, anger or frustration.
  - Use what you know about the Person's strengths and interests during care activities. A connection through conversation can help the Person to feel safe.
- Share your successes and concerns with other Partners. See what works for them and ask if they have any suggestions for you.



## EMOTIONAL WELL-BEING

The P.I.E.C.E.S.™ section of the Guide provides many tips related to Emotional well-being, including information about coping strategies, the importance of Partners in Care, spirituality, and mental health.

Dementia is a progressive disease. Both you and the Person with dementia must continually make adjustments to adapt to new symptoms and ongoing losses.

As a Partner in Care, you cannot eliminate all stress, but you can support the Person to manage his or her situation.



### *Work with the Person with dementia, the Substitute Decision Maker and other Partners to:*

- Implement the tips listed throughout the P.I.E.C.E.S.™ Emotional section and keep the **‘Getting to Know Me’** pages up to date.
- Encourage the Person to describe how he or she feels. Let the Person know that you are interested and want to hear his or her thoughts.
- Contact your local Alzheimer Society office to see if there are support groups for Persons with dementia. This is an opportunity for the Person to talk with others in a similar situation.
- Help the Person to maintain contact with other sources of emotional support such as the church community, service and social groups or family members.
- Learn as much as you can about dementia. Talk to the Person’s other Partners in Care as appropriate and work together as a supportive team.





## CAPABILITIES

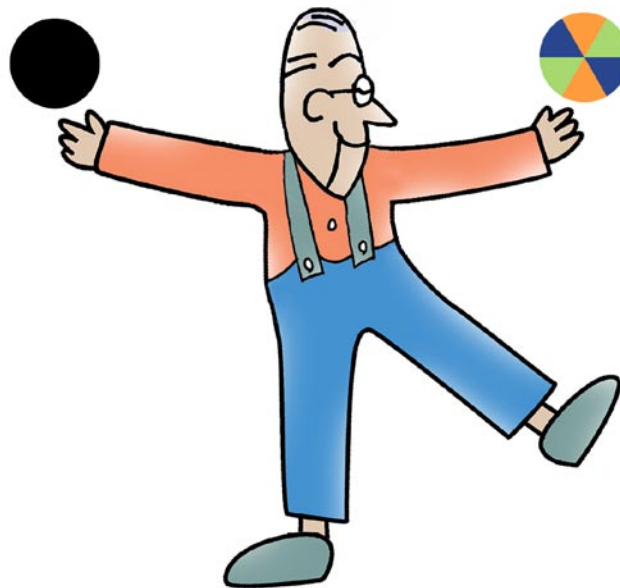
The P.I.E.C.E.S.<sup>TM</sup> section of the Guide on Capabilities provides information on how abilities may change with dementia as well as tips for maintaining independence. The activities addressed include: managing money, using the phone, preparing food, shopping, household chores, driving/getting around safely and managing medications.

As dementia progresses it may become harder for the Person to complete an activity independently. It is upsetting to see this change in someone we know. Consider that all activities are made up of several small steps. It is important to encourage, cue and allow the Person to carry out one or more steps as you help him or her complete the task.

Another important consideration in Capabilities is the Person's ability to maintain balance in life.

stress

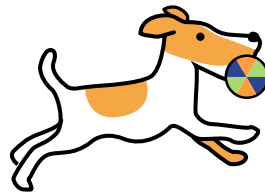
abilities/strengths



We all balance demands (placed on us by our health, caregivers or dementia) against our abilities (physical, intellectual or emotional strengths). As a Person with dementia loses abilities, he or she will manage fewer and fewer demands. When too many demands tip the scale, the Person may become angry or embarrassed and will behave accordingly.



Consider the Person's balance of demands and abilities. Watch for signs of frustration or withdrawal as these responses are a message that the Person needs something. Adjust your expectations of the Person.



*Work with the Person with dementia, the Substitute Decision Maker and other Partners to:*

- Implement the tips listed throughout the P.I.E.C.E.S.™ Capabilities section and keep the **'Getting to Know Me'** pages up to date.
- Divide activities into smaller steps. Regularly evaluate the Person's abilities to complete parts of activities and adjust tasks accordingly.





E

## ENVIRONMENT

Refer to the P.I.E.C.E.S.™ section of the Guide for information on how the Person's Environment may affect his or her experience with dementia.

Several **'Getting to Know Me'** pages are included.

As dementia progresses, the Person will depend more and more on the environment to decide how to act. The Person will look to you, or other Partners in Care, and the physical environment (objects, lighting, and actions of others) for cues.



It is important at this time to maintain a consistent routine so that the Person comes to understand what to expect at specific times of the day. It is also important to use the physical environment to give cues on what to do. For example, clothes laid out on the bed are a great cue to get dressed for the day.

Another key message about the environment is that a change in living situation often results in a temporary loss of abilities. The Person will need time to adjust to the new environment and the new routines so that he or she can function well.



*Work with the Person with dementia, the Substitute Decision Maker and other Partners to:*

- Implement the tips listed throughout the P.I.E.C.E.S.™ Environment section and keep the **'Getting to Know Me'** pages up to date.
- Consider the environment as a cause of changes in behaviour, such as agitation, confusion or withdrawal. Adjust the environment accordingly.



## SOCIAL

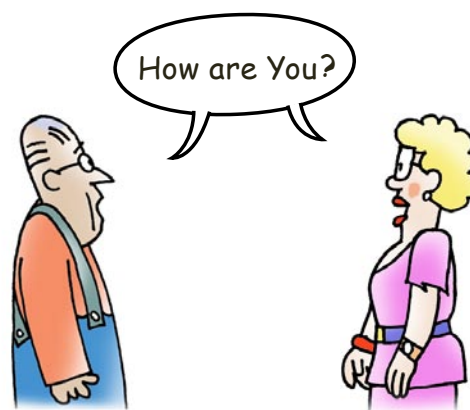
The P.I.E.C.E.S.™ section of the Guide contains many Social ‘**Getting to Know Me**’ pages to encourage the Person with dementia to share important information on his or her “life story”.

It is important to share significant information about the Person’s life with others, as appropriate. Pay attention to what you learn as you interact. You may be surprised what new information comes up!



### *Work with the Person with dementia, the Substitute Decision Maker and other Partners to:*

- Keep the ‘**Getting to Know Me**’ pages up to date.
- Incorporate the Person’s history in your interactions. Talk about important experiences or relationships in his or her life. Avoid topics that you know cause discomfort or distress.
- Maintain aspects of social, cultural, and spiritual connections that are important to the Person.
- Adapt activities and relationships to suit the Person’s changing abilities.





## END OF LIFE

Unfortunately, progressive dementias are life shortening. While various types of dementia may have different symptoms in the early stages, they become more similar towards the later stages.

Those who reach the end stage of their dementia may experience a range of symptoms such as weight loss, inability to communicate, poor mobility, and skin breakdown.

Each Person's experience is unique and will depend on his or her previous health and type of dementia.

Dementia may also weaken the body to the point that another illness, such as pneumonia or pressure ulcers, may cause death. Death may also occur from an unrelated cause.

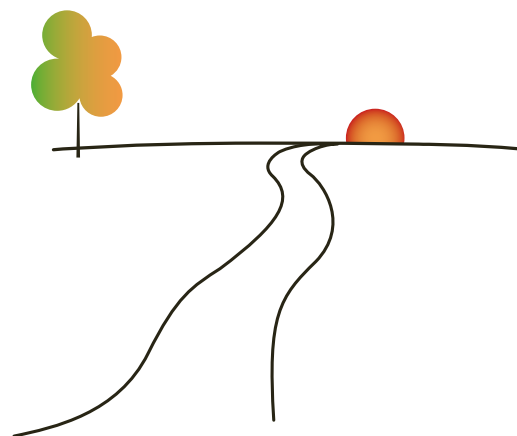
Reach out to other Partners who can help you with your specific questions about the Person's end stage experiences. Helpful Partners include the Alzheimer Society, the family physician, the Community Care Access Centre (CCAC) and Hospice services.

The Partner who acts as the Substitute Decision Maker faces many decisions near the end of life. Some examples are the use of treatments such as tube feeding, antibiotics or ongoing hydration and possibly a decision about where the Person will die. Decisions made on behalf of the Person are based on prior wishes and the best interest of the Person.

Substitute Decision Makers keep in mind such things as the expressed wishes for end of life, and the Person's cultural and spiritual values and beliefs.

If you are the Person's Substitute Decision Maker, you may wish to discuss the pros and cons of each decision with others so that you feel confident in the choices you make.

Additional resources on End of Life Care are available at your local Alzheimer Society and at [www.dementianetworksc.org/myguide](http://www.dementianetworksc.org/myguide).





*“As a caregiver to my wife, I am well aware of the overwhelming emotions that dementia can bring to both the Person with dementia and to the family caregivers. Especially the sense that we are alone to fight the ever-mounting problems that can occur along, what appears to be, a very lonely road. We get the idea that we can manage on our own, or that only we can take care of our loved one, that no one else is capable or willing to perform the task. ...with the help of this Guide you are not alone.”*

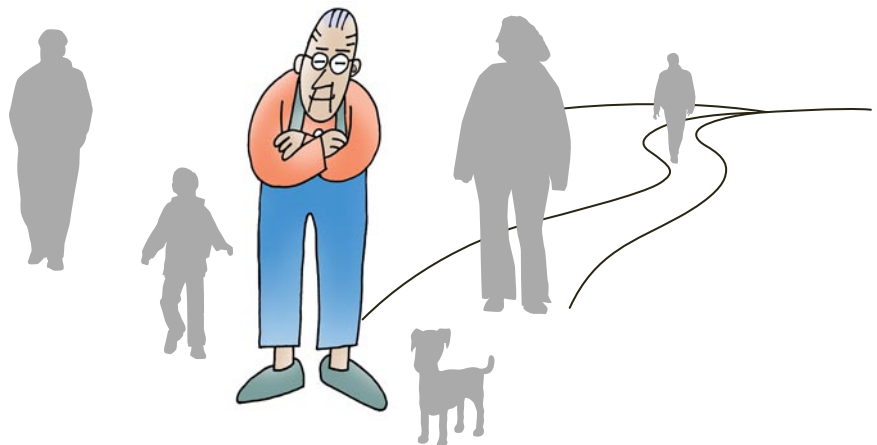
**By Mort Todd, Caregiver**

Mort’s full message is available on the website:

[www.dementianetworksc.org/myguide](http://www.dementianetworksc.org/myguide).

*“As a Partner in Care, I have seen how caregivers respond to the sentiments expressed in Mort’s poem – ‘The Lonely Road’. Those feelings of overwhelming loneliness and despair have been echoed by many family caregivers. No-one can truly put themselves in your shoes, understanding the emotional impact this disease is having on your family unit or the history that you share. What we can do, however, is offer encouragement and assistance to you in your role. You are not alone; there are people – other family, friends and professionals – who can support you and your family member as you go through this disease process. Together, we are Partners in Care.”*

Laura-Lynn Bourassa  
Public Education Coordinator  
Alzheimer Society of Greater Simcoe County





## LONELY ROAD

*Again I wake like yesterday,  
To walk this lonely road each day,  
Dreading what the dawn may bring,  
And clinging to each little thing,  
That gives me hope or lifts my heart,  
And so each day with doubt I start.*

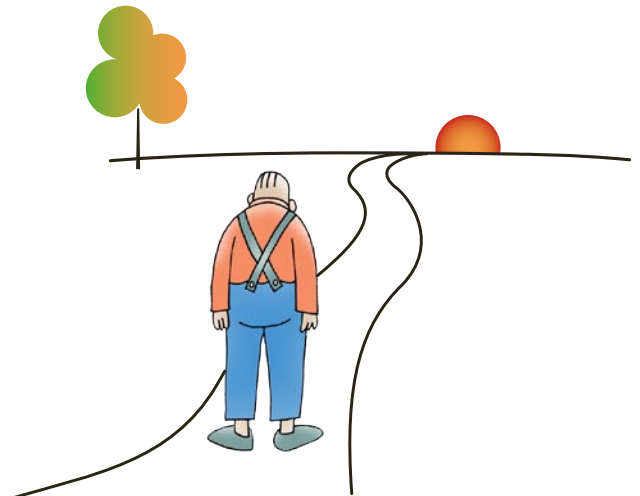
*By noon the day does then unfold,  
A lonely scene as I grow old,  
Searching for someone to care,  
Looking for some time to share,  
Searching in my solitude,  
Someone to share an interlude.*

*Thank God for loving friends who share,  
Their kindest thoughts as I despair,  
And take the time to sit and talk,  
For me to comfort as I walk,  
Along this lonely road so dire,  
Searching for my hearts desire.*

*But she is gone forever now,  
Her mind cannot remember how,  
We loved, we laughed, or how we played,  
As memories begin to fade,  
Of happy times we had together,  
Through tranquil days or stormy weather.*

*So now the sunset I do face,  
And I begin to slow my pace,  
To face the night alone again,  
And then in dreams perhaps attain,  
The love I once enjoyed back then,  
When she could still remember when.*

Mort Todd  
March 30, 2000





This section was written for Partners in Care using the P.I.E.C.E.S.™ format.

The P.I.E.C.E.S.™ model can help you to understand and recognize your strengths and challenges as a Partner in Care and is useful for anyone wanting to examine the factors that influence well-being. Consider reading the earlier sections of this Guide, using the tips and filling in the **‘Getting to Know Me’** pages, this time applying them to you.



**P**

### Physical Well-being

In your role as a caregiver, you may face situations that place excessive demands on your physical abilities, such as lifting a person or helping them to walk or bathe. Changes in your sleep pattern or diet will also affect your physical well-being. As physical demands gradually increase, you may not appreciate their impact on your health. In order to care for the Person with dementia, it is important to look after your physical health.

For example, eat well, get plenty of sleep, keep medical appointments and be willing to accept help and advice from others.



**I**

### Intellectual Well-being

Recognize your intellectual strengths and use them in your challenging role as a Partner in Care. Look back to the **‘Getting to Know Me’ – My Intellectual Strengths** pages and reflect on your strengths. Learn as much as you can about dementia and care giving. Ask questions of other Partners. Professional Partners can help you to understand the disease process and the health care system. Informal Partners, such as other family or friends, can help you by sharing their experiences and observations.



**E**

### Emotional Well-being

Be aware of your own emotional state. A wide variety of emotions are possible and normal. At times you may feel overwhelmed, anxious, angry or resentful about your role as a caregiver. At other times you may also feel satisfied, grateful or proud of your experience. Watch for signs of anxiety, guilt, grief, depression or burnout and take measures to keep yourself in a positive emotional state. Find someone you can talk to about your feelings and how you are coping. Make a list of activities that you enjoy and then plan to do one of these each day.



C

### Capabilities

The balance between your abilities and the demands placed on you (by your physical health, your care giving experience, and your family's needs) can be difficult to maintain. If you feel overwhelmed by demands, consider what your abilities are and how you might use them as strengths. And be realistic about your abilities. When possible, negotiate with other Partners to assist with tasks such as managing finances, shopping, baking and household maintenance. If you have always enjoyed an activity like hiking, schedule time for yourself to help you maintain balance in life.



E

### Environment

Just as the environment affects the well-being of the Person with dementia, it can also affect your well-being. Your home environment may change as adaptations are made for the safety of the Person. Professional Partners coming into the home may need to make additional changes to the environment so that they can work efficiently. As a family caregiver, you may feel that your home environment has been taken over by the needs of the Person with dementia. Take the time to organize your home for ease of care but also ensure that you maintain a favourite personal space just for you.



S

### Social

As dementia progresses, your relationship with the Person and with others will change. In your role as a caregiver, you may find it difficult to change old ways of communicating with the Person or to help with personal care. Take advantage of the support offered by friends, family and services such as the Alzheimer Society to help you adjust to the demands of caregiving and your changing relationship. As relationships change, interactions with the Person can still be positive and meaningful.

Think of yourself as part of a team of Partners in Care. Communicate with your team. Ask for help when you need it and watch out for the health and well-being of others.