



INTRODUCTORY
BOOKLET

*They say
I have
dementia...*

**My Guide
for Living
with Dementia**

www.dementianetworksc.org/myguide

*“They say
I have
dementia...”*

*...and some days
I believe it”*

Henry Stanfield



My Guide for Living with Dementia

www.dementianetworksc.org/myguide

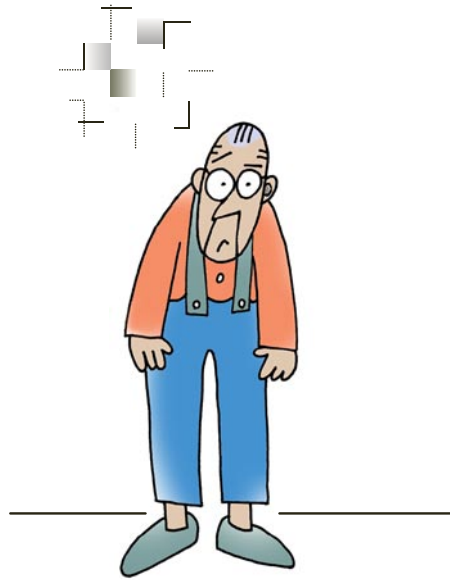
*Welcome to the
Introductory Booklet of
“My Guide for Living
with Dementia”,
a resource for Persons
with dementia
and their caregivers.*

*“My Guide” was created
by Persons with dementia,
their caregivers and
health care professionals.
The goal of “My Guide”
is to improve communication
between Persons with
dementia and their
Partners in Care to enhance
the quality of life
for all involved.*

*...and some days
I believe it”*

Henry Stanfield





Dementia is a term which refers to a set of symptoms. Those symptoms may include... the loss of memory, judgement and reasoning, or changes in mood and behaviour and are caused by damage to the nerve cells in your brain. They may affect your ability to function at work, in social situations or in day-to-day activities. Many diseases or conditions can cause dementia.

Alzheimer's Disease is the most common type of dementia. It is a progressive, degenerative disease. Brain cells shrink or disappear, and are replaced by dense, irregularly-shaped spots, or plaques. Thread-like tangles can also appear, eventually choking healthy brain cells.

Some other types of dementia are:

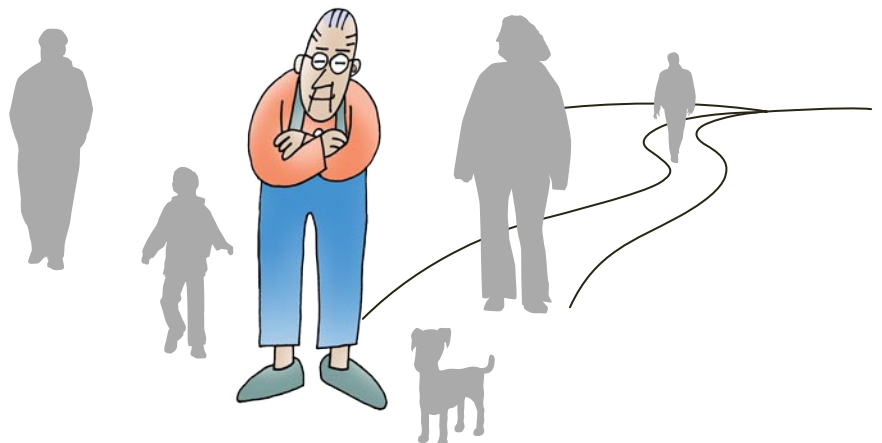
- Vascular dementia
- Lewy body dementia
- Frontotemporal dementia

Dementia affects each Person differently and the abilities that are affected will depend on what part of the brain is damaged.

For more information about Alzheimer's disease and other types of dementia, contact your local Alzheimer Society.

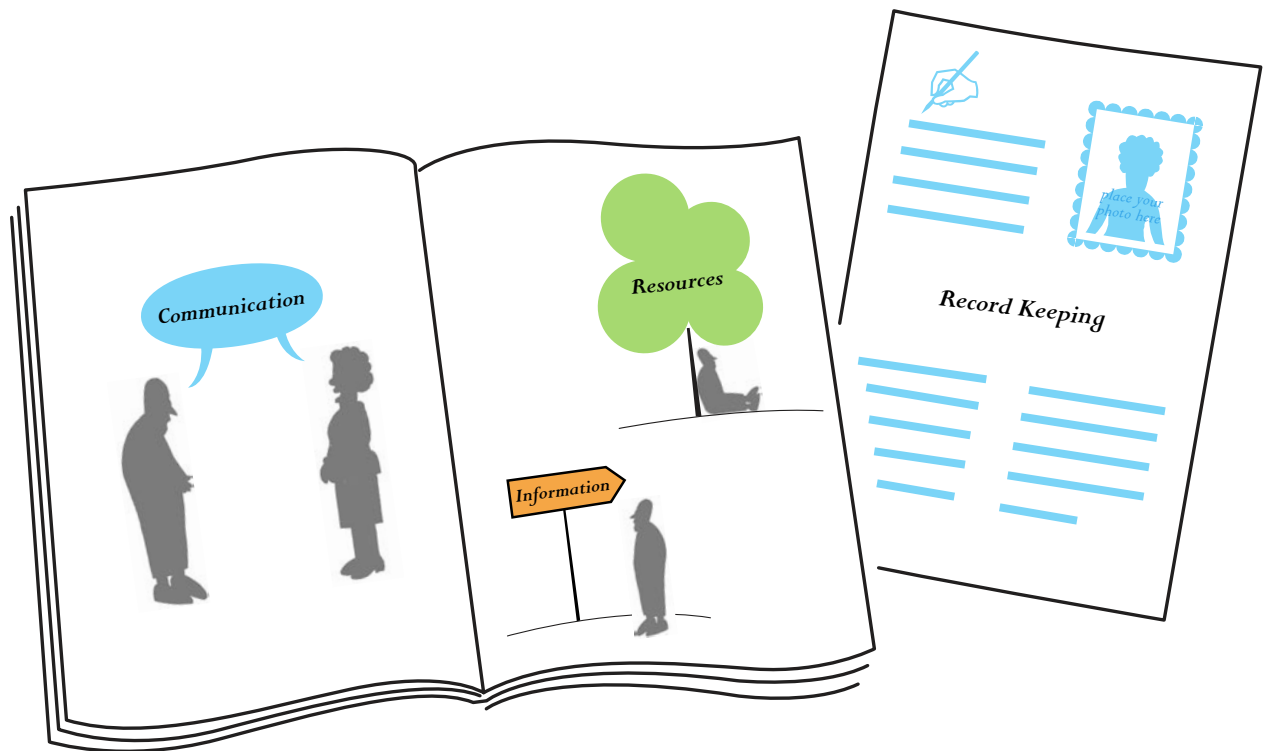
The symptoms of dementia can also be caused by other conditions, such as depression, thyroid disease, infections or drug interactions. Work with your Partners in Care to identify what is causing your symptoms.

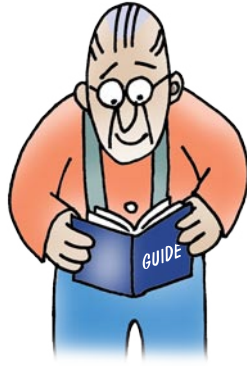
The term *Partners in Care* is used to describe the team of people who support you. Partners may include your family and friends or professional care providers such as nurses, therapists, doctors, pharmacists or Case Managers. You may have other Partners as well.



“My Guide for Living with Dementia” is a communication and care planning tool that will...

- Help with communication between you, your family, and others involved in supporting you
- Inform you about dementia and the many factors that can influence your dementia.
- Help you to record important information
- Provide you with valuable resources





You are now reading the Introductory Booklet to the full “My Guide for Living with Dementia”. Read the entire Guide or just the sections that you feel will be useful to you and your Partners in Care.

Here is an outline of what is in the Guide:

- Introductory Booklet provides basic information
- ‘Getting To Know Me’ section is a place for you to store important information to help your Partners in Care understand who you are!
- P.I.E.C.E.S.[™] section expands on the P.I.E.C.E.S.[™] model that you will read about later in this booklet. It includes useful tips and more ‘Getting To Know Me’ questions.
- Partners in Care section includes information to help your Partners to support you
- Resources section includes many types of resources for you and your Partners in Care.

All of these sections of “My Guide for Living with Dementia” can be obtained from your local Alzheimer Society or from the website
www.dementianetworksc.org/myguide

The next few pages will explain some of the content and concepts used in the full “My Guide for Living with Dementia”.

U-First!

U-First! is the name of a program developed by the Ministry of Health and Long-Term Care in Ontario. It uses a helpful wheel, pictured below, which describes the many factors that can influence the well-being of a Person with dementia.



The Simcoe County Dementia Network has used the wheel as the basis of this Guide.

More information about “U-First!” can be obtained from www.u-first.ca

U-First! Wheel

You may be familiar with the U-First! wheel. It contains a summary of the information presented in this Guide, and can be obtained from your local chapter of the Alzheimer Society.



Above is an image of the U-First! wheel.

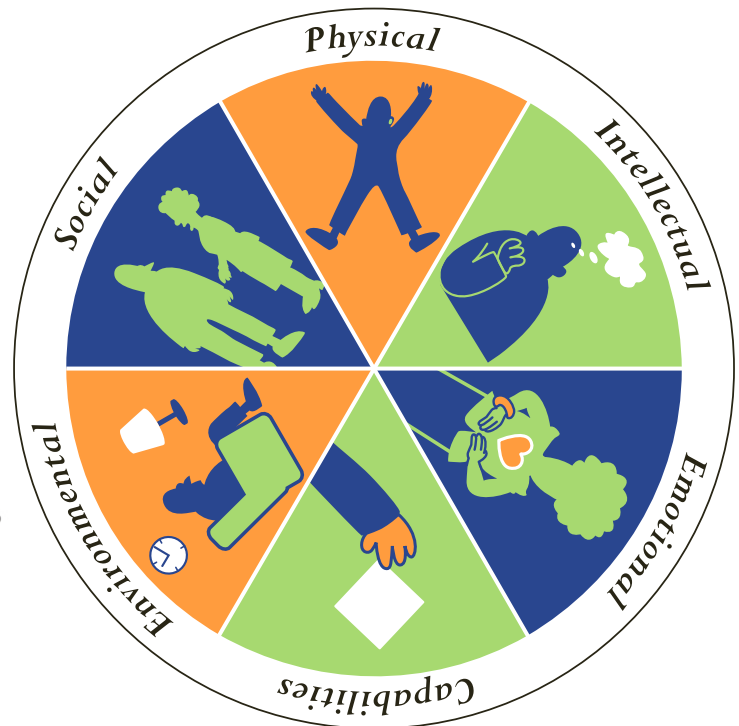
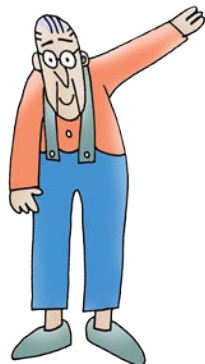
Each letter in the word P.I.E.C.E.S.[™] stands for an aspect of your well-being.

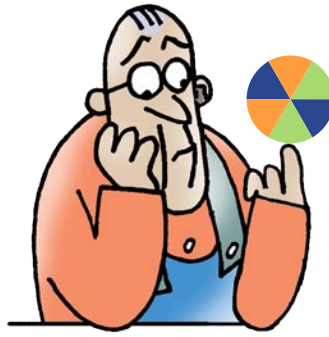
- P – physical well-being
- I – intellectual well-being
- E – emotional well-being
- C – capabilities
- E – environmental factors
- S – social history

Understanding P.I.E.C.E.S.[™] allows you and your Partners in Care to identify:

- your strengths
- areas where you may need support and
- ideas to help you plan for the future

This is our version of the U-First! wheel, that you will see throughout the Guide. Each symbol represents a different aspect of P.I.E.C.E.S.[™]





Understanding ‘You’ using the P.I.E.C.E.S.[™] model:

Note! There is a lot more detail in the P.I.E.C.E.S.[™] section of the Guide!



P

Physical Well-being

Maintaining good physical health will help you manage symptoms of dementia successfully. Physical factors, such as a cold or flu, changes in medications or pain can influence your abilities. Therefore, it is important that you and your Partners in Care understand your physical health.



I

Intellectual Well-being

It is important to understand how dementia has affected your abilities to remember, use language, plan and organize, and think through problems. Your Partners in Care need to understand the changes that are taking place as well as your remaining strengths.



E

Emotional Well-being

Your emotional well-being impacts on how you cope with dementia and other life stressors. It is important that you and your Partners in Care understand your personality and coping style as well as any past or present concerns about your mental health.



Capabilities

Dementia will impact your capabilities. However, it is important for you and your Partners in Care to recognize and use your remaining strengths and abilities. Frustration can arise when you or others expect too much or too little.



Environment

Your immediate surroundings can significantly impact your well-being. You might notice that some environmental factors such as lighting, temperature, and noise can change the way you feel and function. For example, having the television on during a conversation may make it hard for you to concentrate. Awareness of the environment and how it affects you will help you and your Partners in Care adapt.



Social

Your social history will influence your experience with dementia. It is important for your Partners in Care to understand your life experiences. This could include your values, cultural background, significant life events, and important relationships.

The third section of the complete Guide includes an expanded description of the P.I.E.C.E.S.[™] model. Get your copy by visiting www.dementianetworksc.org/myguide or your local Alzheimer Society office.

Getting To Know Me

On the next page, you will find the Introductory Page of the 'Getting to Know Me' section of the Guide. Use this page to start keeping track of your important information. You may want to ask your family or another Partner in Care to assist you.



If you download the complete Guide, you will see the Introductory Page again as Page 1 of the 'Getting to Know Me' section.

You can :

- Leave the Introductory Page in this booklet

OR

- Tear out the page and move it to the Guide

OR

- Fill it in again in the Guide

'Getting To Know Me' Introductory Page

Share information about your life so that your Partners in Care will get to know you better.



place your photo here

My name is: _____

Preferred names: _____

I was born: (when / where) _____

People who are close to me: _____

My pet(s) past / present: _____

My hearing is: _____ Hearing aids? Yes No

My eyesight is: _____ Glasses? Yes No

My health problems you should know about are: (conditions/pain/allergies) _____

I take these medications: _____

I need help with: _____

I have safety concerns about: (use of stove, smoking, driving, taking medications) _____

Things I like: (foods, activities) _____

Things I don't like: _____

Groups I belong(ed) to: _____

I am interested in: _____

In the past, I was interested in: _____

I worked as: _____

I lived in these places: _____

Important events in my life include: _____

If I need help or in case of an EMERGENCY, contact: _____

Name: _____ Phone number: _____

Date: _____

U-First! credits

The concept of the U-First! wheel was developed by the 1998/99 Hastings Prince Edward County Psychogeriatric Training Workgroup.

The U-First! concept framework including acronym was developed by Dr. J.K. LeClair and Pam Hamilton.

The U-First! curriculum and resource guide was developed by the U-First! Project Committee (Cathy Conway, Pam Hamilton, Diane Harris, Dr. J.K. LeClair, Maureen O’Connell, Debbie Warren).

For more information about U-First!, visit www.u-first.ca

P.I.E.C.E.S.[™] credits

The P.I.E.C.E.S.[™] model is being used within “My Guide for Living with Dementia” with the consent of the P.I.E.C.E.S.[™] Consult Group. This model is part of the larger, more comprehensive, educational initiative: P.I.E.C.E.S.[™], A Model For Collaborative Care and Changing Practice: A Learning Program for Professionals Providing Long-Term Care to Older Adults with Cognitive/Mental Health Needs. For information about P.I.E.C.E.S.[™], visit www.piecescanada.com





Produced by the Simcoe County Dementia Network with the assistance of the following Partners:

Community Care Access Centre Simcoe County
Alzheimer Society of Greater Simcoe County
Alzheimer Society of Orillia and District
Psychogeriatric Resource Consultant Program of Simcoe County
Advisory Committee of Community Service Agencies

“My Guide for Living with Dementia” was funded by a sustainability grant from the Ministry of Health and Long-Term Care through the Post-Alzheimer Strategy Staff Education Committee.

Cover image: “Walking Alone” was painted by ©Ted Harrison, husband and the closest caregiver to his wife Nicky who developed Alzheimer’s disease. Image of the road represents a journey of the person living with dementia and/or their caregiver.

Permission for the quote

“They say I have dementia.....and some days I believe it” was given by Henry Stanfield, a focus group member who assisted with the creation of the “Guide for Living with Dementia”.

For more information on “My Guide for Living with Dementia” contact your local Alzheimer Society:



Or visit: www.dementianetworksc.org/myguide