Determine to live life
with flair and laughter.

—Maya Angelou

7

7 CONTACT INFORMATION & HELPFUL WEBSITES

Facilitator Contact

If you have questions or concerns between **Shaping the Journey: living with dementia** sessions, please write them down and bring them up at our next session. If you are going to be late or have to miss a session, please call us to let us know. If we do not answer, please leave a message.

Name:_____

Organization: _____

Phone number: _____

Alzheimer Society of Nova Scotia

The Alzheimer Society of Nova Scotia exists to alleviate the personal and social consequences of Alzheimer's disease and other dementia in addition to promoting the search for the causes, treatments and cures. The Society provides information, education, support and referral. Contact us to learn more about programs and

services in your community.

PROVINCIAL OFFICE

112-2719 Gladstone St.
Halifax, NS B3K 0A4
Telephone: (902) 422-7961

THE INFOLINE (902) 422-7961 or
Toll-free 1-800-611-6345

Fax: 902-422-7971
Email: alzheimer@asns.ca
Website: www.alzheimer.ca/ns

Société Alzheimer Society
NOVA SCOTIA

Resources for Persons with Early Stage Dementia (2019)

While there are many good books and other resources available that discuss memory problems and dementia, many of these are directed at someone other than you- the person who is living with memory loss or dementia.

Thankfully, we are now seeing more and more resources written by and for, or at least inclusive of, persons with dementia. The Alzheimer Society of Nova Scotia has gathered together this list of resources. The list is not exhaustive, and it will be expanded as we become aware of new resources. We hope there will be something here for everyone.

You can call the Alzheimer InfoLine (1-800-611-6345) at any time to inquire about additions to this list, to ask about accessing any of the items listed, to discuss anything you've read in any of these resources, or to ask any additional questions you may have. We look forward to hearing from you.

Pamphlets and Brochures from Alzheimer Society of Canada/Alzheimer Society of Nova Scotia

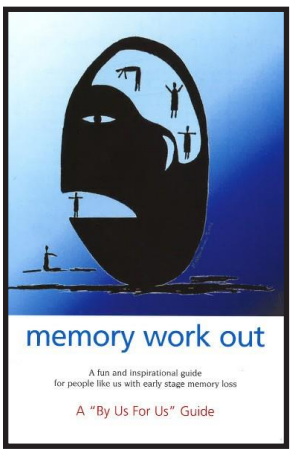
The Alzheimer Society of Canada produces a wide variety of brochures and pamphlets. All are available through the Alzheimer Society of Nova Scotia and online: https://alzheimer.ca/en/ns

All about me
Dispelling the Myths
First Steps: For Those Recently Diagnosed with Alzheimer's disease.
Getting a Diagnosis.
Heads Up for Healthier Living – For people with Alzheimer's disease and their families.
Treatment Options – Information for People with Alzheimer's Disease and their Families.
What is Alzheimer's disease?
Shared Experiences – Suggestions for those living well with Alzheimer's disease.
The Progression of Alzheimer's disease – Overview
The Progression of Alzheimer's disease – Early Stage
Decision Making: Respecting Individual Choice Participation in Research
Preparing for your doctor's visit
Mild Cognitive Impairment
10 Warning Signs (Poster)
Shaping the Journey® Workbook (Available for download on our website)
Be Ready for an Emergency Department Visit
Communication challenges and helpful strategies for the person with dementia (new)
Memory tips & tricks (new)
Resources available in French (new): https://alzheimer.ca/fr/Home

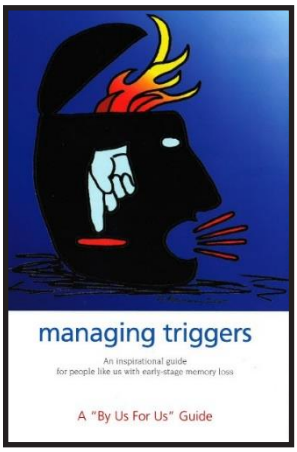
By Us for Us© Guides

The By Us for Us© Guides are a series of guides created by a group of talented and passionate persons with dementia and/or family partners in care. The guides are designed to equip persons with dementia with the necessary tools to enhance their well-being and manage daily challenges. What makes these guides particularly useful is that they are created by persons with dementia for persons with dementia. These guides are Canadian resources.

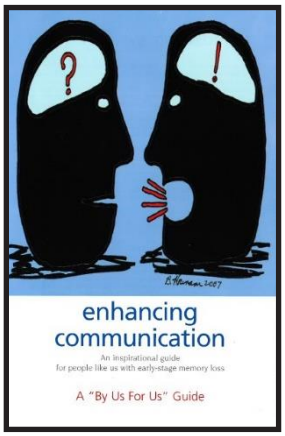
All MAREP guides are available free online, or can be ordered for $3.50. Go to the MAREP website at: https://the-ria.ca/programs/murray-alzheimer-research-education-program-marep/
You can also call the Alzheimer InfoLine 1-800-611-6345.



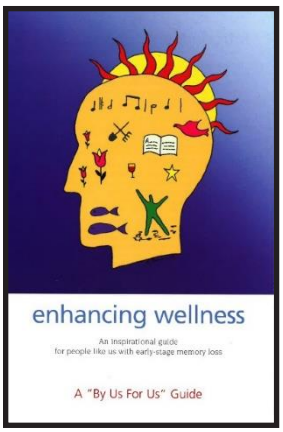
The Memory Workout Guide, the first guide in the Person with Dementia series, provides examples of cognitive exercises and it encourages persons with dementia to develop and maintain regular "workouts" for the brain so as to function better while engaging in enjoyable activities.



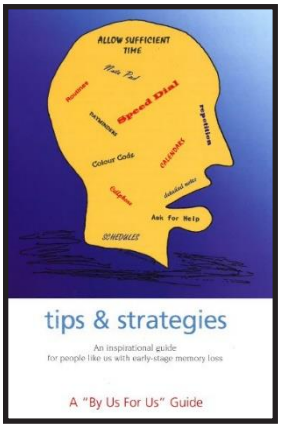
The Managing Triggers Guide, the second guide in the Person with Dementia series, is a practical resource that outlines the main triggers experienced by persons living with dementia, and offers solutions for how persons with dementia and their partners in care can manage and alleviate these triggers. The guide focuses on managing triggers associated with social situations, verbal communication, changes of abilities and memory, and managing your environment and negative emotions.



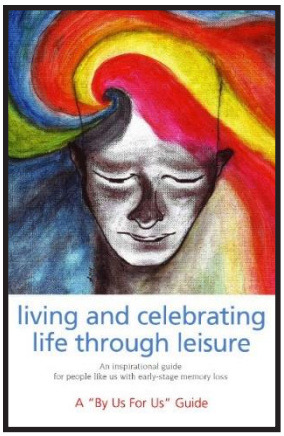
The Enhancing Communication Guide, the third guide in the Person with Dementia series, is a comprehensive resource that outlines the main challenges associated with communication as experienced by persons with dementia. It explores communication challenges that can occur with family and friends, in social situations, and when communicating with health care professionals. The guide provides practical solutions for persons with dementia and emphasizes the importance of using a wide range of communication strategies in order to make opinions, feelings and experiences known. It also suggests ways that family partners in care and professionals can enhance communication with persons with dementia.



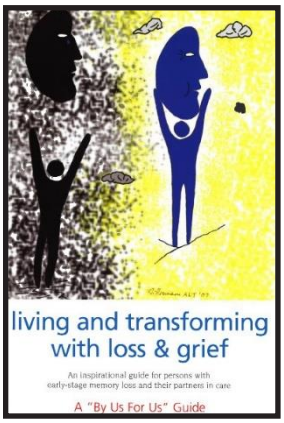
The Enhancing Wellness Guide, the fourth guide in the Person with Dementia series, focuses on how enhancing physical, psychological and emotional, social and spiritual well-being can help us live our lives to the fullest extent, even after diagnosis of dementia. The guide provides helpful tips for eating well, taking care of your body, being physically active, staying centered with yourself, staying connected with others, and living in peace, all of which are important in enhancing wellness.



The Tips & Strategies Guide, the fifth guide in the Person with Dementia series, is a helpful resource that contains ideas and suggestions for living daily with an illness causing dementia. The guide provides additional memory "workout" ideas, tips for those in the workforce, and general tips and strategies for daily living.



Living and Celebrating Life Through Leisure. The purpose of this sixth guide in the Person with Dementia series is to share with you some thoughts on living and celebrating life through leisure. Meaningful leisure can be a wide range of activities from enjoying coffee on your deck first thing in the morning to being involved with other people in a more structured and challenging venue. Activities that leave us feeling good are so important in contributing to a quality of life that everyone strives for.



The Living and Transforming with Loss & Grief Guide, is the first guide in the Partnership series, which incorporates the experiences of family partners in care as well as persons with dementia. The guide is a practical resource that recognizes the experiences of loss and grief that come with the journey of dementia, and provides useful tips and strategies for acknowledging, experiencing and transforming with loss and grief. This booklet aims to guide readers through the ebbs and flows of loss and grief to a place of acceptance, peace and hope.

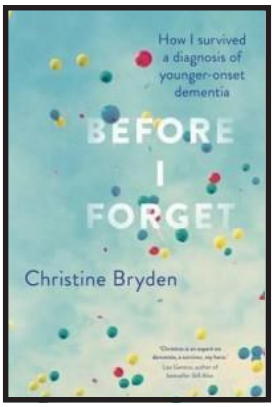
The Food & Mealtime Guide is the second guide in the Partnership Series, which incorporates the experiences of persons with dementia and family partners in care. Food is an essential part of living - it allows the body to function well. Whether shopping or preparing meals, or going to a restaurant to eat, it is important to acknowledge and accept changes around food and mealtimes for both persons with dementia and partners in care. This guide will present many strategies for adapting to the many changes associated with living with dementia.

Living Safely is the third guide in the Partnership series - a series of helpful resources written BY and FOR persons living with dementia and their partners in care. This guide offers many tips and strategies to understand safety concerns related to driving, safety at home and in the community, personal identification and use of technology, health and medication, physical safety, safety of persons with dementia when home alone, and financial safety. In addition, the guide presents information related to safety and dignity and offers a number of additional resources.

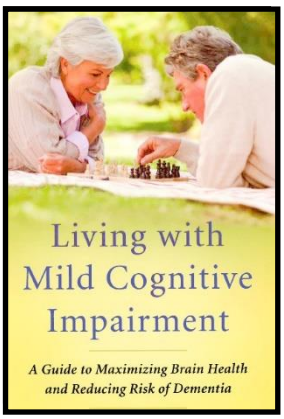
Safety When Out and About is the fourth guide in the Partnership Series - a series of helpful resources written BY and FOR persons living with dementia and their partners in care. Memory loss or reduced ability to solve problems can increase the risk of getting lost, or make finding your way more difficult for people living with dementia. This guide offers tips and strategies for staying safe in the community, including com- munication strategies and planning ahead. The guide was developed in partnership with the Alzheimer Society of Ontario and Finding Your Way™.

Books

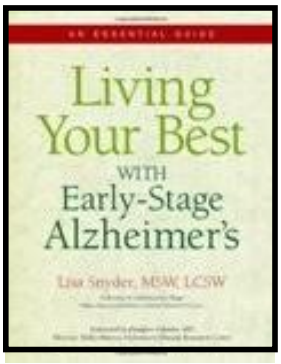
While there are many books on the market that discuss dementia, the following are books we have found that are either written by persons with dementia or speak primarily to the person with dementia.



Before I Forget: How I Survived a Diagnosis of Younger-Onset Dementia (2015)
by Christine Bryden
Christine Bryden was a top civil servant and single mother of three children when she was diagnosed with dementia at the age of 46 in 1995. Since then she has gone on to chal- lenge almost every stereotype of people with dementia by campaigning for self-advocacy, publishing four books, and speaking at national conferences. This book is her memoir of her experiences and strategies to live well. Her other books include: **Nothing About us Without us! (2015), Dancing with Dementia (2005), and Who Will I be When I Die? (1998, republished 2012).** You can order her books and read more about Christine at her website: http://www.christinebryden.com/



Living with Mild Cognitive Impairment (2012) by Nicole D. Anderson, Kelly J. Murphy, and Angela K. Troyer. Approximately one in ten adults over 65 has some form of mild cognitive impairment (MCI). MCI is classified as thinking problems that go beyond those associated with normal aging, but that fall short of the impairments experienced by people with dementia due to Alzheimer's disease or other disorders. This is the first book written specifically for individuals with MCI, for their family members, and for health care professionals.



Living Your Best with Early-Stage Alzheimer's (2010) by Lisa Snyder
Recent advances have made it possible to diagnose Alzheimer's disease when symptoms are mild. Today, when a person is diagnosed, they may have many, many years ahead with only mild symptoms. The result is that a growing number of people with early-stage Alzheimer's are seeking information about how to take charge of their lives, manage symptoms, and cope effectively with the disease. This book is a working guide to help the person with Alzheimer's feel empowered to move forward in life in light of this challenging diagnosis. This book is available for loan from Regional Branches of the Nova Scotia Public Library.

Newsletters and Blogs

Insight: This is a quarterly educational bulletin from the Alzheimer Society of British Columbia created for and by people with dementia. It offers helpful strategies including tips from Early Stage Support Group members, and personal stories from people who are living with dementia.
https://alzheimer.ca/en/bc/News-and-Events/Newsletters-and-updates/Insight

Perspectives: This is a quarterly free email newsletter for people with dementia. Individuals with Alzheimer's disease or other dementias contribute their perspectives to this newsletter in the form of articles, poetry, or letters. Back issues can be found at: adrc.ucsd.edu/news.html

Blogs: Dementia Alliance International has compiled a list of blogs written by people with dementia:
https://www.dementiaallianceinternational.org/services/blogs/

Online Communities for People with Dementia

ASANT CAFE: An online forum with discussion boards, videos, and access to education. The site has sections geared for people with dementia, and also has separate sections for family members and caregivers. It was created by the Alzheimer Society of Alberta and Northwest Territories. https://www.asantcafe.ca/

Alzheimer's Association Message Board and Chat Rooms: The Alzheimer's Association (USA) offers an online forum for people affected by dementia. Read what others have to say by browsing the page, or register to share your thoughts and experiences and to ask questions. https://www.alzconnected.org/

Frontal Temporal Dementia (FTD) Support Forum: The purpose of this forum is to provide a place for safe and secure communications for people who have been diagnosed with FTD, as well as for family members. http://ftdsupportforum.com/

Lewy Body Dementia Association (LBDA) Virtual Communities: The LBDA has discussion forums and online support groups available for people living with Lewy Body dementia, as well as for family members. https://www.lbda.org/content/virtual-groups

Healtheo360: This is an online community for persons with chronic conditions (including many dementias such as Alzheimer's disease and Lewy Body dementia) to share their stories and join online support groups. http://www.healtheo360.com/

Talking Point: This is an online support and discussion forum hosted by the Alzheimer Society of the UK. It is for anyone affected by dementia. It is a place to ask for advice, share information, join in discussions and feel supported. http://forum.alzheimers.org.uk

DASN International (Dementia Advocacy and Support Network): A worldwide organization by and for those diagnosed with dementia, working together to improve quality of life. http://www.dasninternational.org/

French Language Forum - Forum Agevillage: Vivre avec la maladie d'Alzheimer- www.agevillage.com

Nova Scotia Positive Aging Directory: The Positive Aging Directory is a comprehensive information directory published each year by the Department of Seniors to give Nova Scotia's seniors quick and easy access to the many programs and services for seniors in our province. View or order a directory online: https://novascotia.ca/seniors/directory/

211: Call 211 from anywhere in Nova Scotia or visit the website for access to human, social and community-related information and referral services. http://www.ns.211.ca/

811: Call 811 from anywhere in Nova Scotia to speak with a registered nurse about a medical concern. This service is available 24 hours a day https://811.novascotia.ca/

In Halifax, Seniors 65 and older ride free at certain times:
https://www.halifax.ca/transportation/halifax-transit

Accessabus: https://www.halifax.ca/transportation/halifax-transit/access-a-bus

Clinical Trials: This site is a registry and results database of publicly and privately supported clinical studies of human participants conducted around the world: https://clinicaltrials.gov/

Canadian Charter of Rights for People with Dementia: https://alzheimer.ca/en/Home/Get-involved/The-Charter

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