



Halton Dementia Guide



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Halton Dementia Guide

This guide is for you if you are caring for someone living with dementia in Halton Region, and would like to learn more about the services available.

Most people know very little about living with dementia in the family until it happens to them. Initially it is important to learn as much as you can about dementia: see section on *Learning About Dementia* for more information.

As the dementia progresses, you and the person living with dementia will likely need assistance from various agencies and programs. We are here to help, the more support you have, the easier this will be for everyone. This booklet is intended to introduce you to the many supports and services available in Halton.

Caring for yourself is one of the most important, and often one of the most forgotten, things you can do as a caregiver. When your needs are taken care of, the person you are caring for will benefit also. See the section on Self Care for some helpful tips.

Please note that the information in this guide is current as of April 2023.

We welcome feedback on this guide.

Please contact us toll free at 1-800-387-7127

Sincerely,

Acclaim Health

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About Dementia

Dementia is a general term for a decline in mental ability severe enough to interfere with daily life. It is a group of symptoms that may include memory loss and changes in thinking and language. It can also include changes in mood, perception, emotions, and behaviour causing confusion or difficulty in making sense of what a person can see or hear.

Alzheimer's disease is the most common type of dementia. There are many other kinds of dementia. For more information, please refer to the websites listed at the bottom of this page.

Dementia is not a normal part of aging. It occurs when the brain is affected by a disease causing physical changes that lead to the death of nerve cells. Every person experiences the effects of dementia differently, and how quickly dementia progresses is individual.

Dementia is progressive; this means that symptoms will get worse over time. However, many people living with dementia lead active and fulfilling lives for many years.

To learn more about dementia, you can also access the following websites:

- **Alzheimer Society of Canada:**
www.alzheimer.ca
- **Murray Alzheimer Research and Education Program:**
www.livingwithdementia.uwaterloo.ca
- **Association for Lewy Body Dementia:**
www.lbda.org
- **Association for Frontal Temporal Dementia:**
www.theaftd.org

Learning About Dementia

One of the most helpful things you can do for yourself is to learn as much as you can about dementia as early as possible, and to start preparing for the future. Halton has excellent resources for education. Listed below are two agencies that provide free education.

Acclaim Health Adult Day and Caregiver Support

Oakville

Patty's Place

2250 Speers Road, Oakville, ON L6L 2X8

Caregiver Educator

Phone: 905-847-9559 Ext. 2411

Burlington

2180 Itabashi Way, Burlington, ON L7M 5A5

Caregiver Educator

Phone: 905-632-8168 Ext. 2417

www.acclaimhealth.ca/programs/dementia-care/caregiver-education/

Services for: Family

Cost: Free

Location: In-person and virtual. Various locations in Halton.

- **Dementia Information Series**

This eight week series will teach you how to care for a person with dementia, what to expect as the disease progresses and how to access community resources.

- **Mid to Late Stages of Dementia Discussion Series**

For family caregivers who have been caring for a person living with dementia for some time, and wish to be prepared for the later stages of the disease. (5 sessions)

- **Individual or Family Education**

Provided by the Acclaim Health Caregiver Educators

Alzheimer Society of Hamilton and Halton

4391 Harvester Road, Burlington, ON L7L 4X1

Phone: 1-888-343-1017

www.alzda.ca

Services for: Persons living with dementia, caregivers, and public

Cost: Free

Location: Alzheimer Society of Hamilton and Halton (Virtual and various locations throughout Halton.)

- **First Steps** – Introduction to Alzheimer’s disease and other dementias to understand the diagnosis and learn about tips and strategies that might help you day to day. (4 sessions)
- **Dementia Education Series** – Planning for the future and helping the person living with dementia to remain as independent for as long as possible. (4 sessions)
- **Middle Stage Education Series** - Understanding the unique needs of the middle stage of dementia. How to support responsive behaviours, safety and security of the home environment. (4 sessions)
- **Care in the Later Stages** - Understand what to expect in the late and end stages of dementia. (5 sessions)
- **Positive Approach to Care** - Helps participants better understand the experience of dementia and provides practical tools to help support persons living with dementia. 3 workshops, 3 hours each. Fee applied to professional care partners.
- **The Reitman Centre CARERS Program** - Focuses on practical skills and emotional supports needed to care for people living with dementia and provides strategies for keeping a meaningful relationship through the care journey. (8 Sessions)

Self-Care Isn't Selfish, It's Necessary!

Caring for yourself is one of the most important, and often one of the most forgotten, things you can do as a caregiver. When your needs are taken care of, the person you are caring for will benefit also. The physical and emotional demands of looking after someone with dementia can be quite high. As the amount of care needed increases, more time and energy is required from you. It becomes even more important at this stage that you take care of yourself or these demands will wear you down.

Telling someone to "take care of yourself" can be said in such a way as to make it simply another failed task. Instead, recognize the absence of self-care as a symptom of increased stress and decreased coping.

"Carving out some time and space for yourself is not just something you should do, it's something you HAVE to do." (Emma Dickson, owner of Home Helpers).

Recognize that your needs come before another person's wants. For example, your need for respite, and to have the person you care for go into day or overnight respite, takes priority over that person's want to stay at home and not go into respite.

1. Every caregiver needs their OWN caregiver. Who is your caregiver?
2. Build a support network, ask for help from family, friends and professionals. Learn to accept help when offered!
3. Connect with other caregivers.
4. Schedule "me" time, write it in your calendar. You don't want to lose yourself in the caregiving. What activities give you pleasure?
5. Give yourself permission to take time off and enjoy life.
6. Take regular breaks, just like when you used to work outside the home. Caregivers who take regular breaks make better caregivers.

7. Pace yourself. Dementia caregiving is a marathon, not a sprint.
8. Be realistic about the disease, acknowledge that the person living with dementia is NOT going to get better, and is gradually going to get worse.
9. Be realistic about yourself and your own limitations. How is your health? How is your energy?
10. Be realistic about how much you can get done in a day – set a goal of a maximum of three things to do each day.
11. Do all you can and then let the rest go.
12. Learn to separate what you can and can't control. Many things are simply out of your hands.
13. Be three steps ahead of a crisis, instead of responding to one. Learn as much as you can about dementia, and take care of legal and financial matters.
14. There are no right or wrong answers in dementia care. Make a decision and don't second guess yourself, knowing that it was the best decision you could have made at the time.
15. Allow yourself time and space to grieve the many losses during the dementia journey.
16. Celebrate life events!
17. Look for the humour in life, and in your day to day situations. LAUGH OUT LOUD.
18. Have H.O.P.E. – Have One Positive Experience everyday! (Thanks to the Alzheimer Society of Hamilton and Halton, Friday morning coffee group for that).
19. Learn to say no.
20. Remember, we feel guilty because we love.
21. Add your own....

Five Quick Pick-Me-Ups for Caregiver Stress

(From Caring.com)

1. **Read or watch** something funny. Laughter has been shown to trigger the relaxation response, lower heart rate and blood pressure, and even boost the immune system and ease pain. (The same thing happens when we pet our animals, dogs, cats, etc!) **LAUGH OUT LOUD!**
2. **Crank the volume on a good tune!** Music therapy is known to boost good mood. Dance around the house.
3. **Take a power nap.** 10 minutes of shut-eye can help you feel restored, especially if you have had a disrupted night's sleep.
4. **Pump a little iron or get a quick breath of fresh air,** watch the sunset or sunrise.
5. **Write down what's upsetting you** – simmering resentment, anger or frustration can sap energy. When you are done, rip it up and let it go!

Create a space for calm within yourself.

Acclaim Health wellness supports can help you improve your overall well-being while reducing pain, stress and anxiety. Trained volunteers provide these supports to people with life-limiting illnesses, dementia or caregivers experiencing high stress.

Wellness Support, Acclaim Health:
www.acclaimhealth.ca/programs/social-supports/wellness-support/

Wellness Care Manager
Phone: 905-827-8800 ext. 2330

Getting Help in Your Home

As the dementia progresses and thinking and memory problems increase, you will see a decline in the ability of the person living with dementia to do daily activities. The family/caregiver need for involvement increases and more support is needed. Both in-home and out-of-home supports should be explored.

Acclaim Health offers a free, online session called "Understanding the Home Care System" on a regular basis.

www.acclaimhealth.ca/understanding-the-home-care-system/

Home and Community Care Support Services (HCCSS), formerly known as "The LHIN"

Home and Community Care Support Services provide in-home and community based health care services for eligible clients. Care Coordinators connect you with the personal care you need at home and in your community. They can coordinate access to in-home services such as personal support, nursing, and home safety assessments. They can also refer you to community supports such as Adult Day Programs and Supports for Daily Living. The services of Personal Support Workers may be arranged to assist the person with dementia with bathing, and Occupational or Physiotherapists can do in-home safety assessments.

Call your local HCCSS office to request an assessment. There is no charge for these services. Be prepared that setting up initial services takes time, so plan ahead.

Mississauga-Halton Home and Community Care Support Services

For Halton residents, *excluding* Burlington.

Phone: 905-855-9090 or 1-877-336-9090

www.healthcareathome.ca/mh/en/

Burlington Home and Community Care Support Services

For residents of Burlington.

Phone: 905-639-5228 or 1-800-810-0000

www.healthcareathome.ca/hnhb/en/

In-Home Caregiver Relief

In-home caregiver relief, or respite provides a vital role in allowing the caregiver time to take a break or to get out of the home.

Discuss your respite needs with your HCCSS Care Coordinator (note: limited respite may be provided). You may also choose to hire private caregivers from one of the many home care agencies in Halton.

When you contact the private agencies, ask to ensure that:

- They are an accredited home care agency.
- The staff have specific skills in dementia care.
- The supervisors oversee the quality of care and you have their contact information in case there is a problem.
- They provide clear information on fees, sliding payment and if there are payment options or contracts.
- There are Criminal Reference Checks on all employees.
- The agency is insured or bonded and the staff are bonded.

Acclaim Health now offers Private Care in the home, for more information call 1-800-387-7127.

www.acclaimhealth.ca/programs/home-care/private-care

Caregiver ReCharge

For residents of Oakville, Milton, Georgetown, and Halton Hills *excluding* Burlington.

This program provides temporary relief for caregivers who “experience a high level of stress”. There is often a long waiting list for service

Cost: Free

Referral: Caregivers may call directly or HCCSS Care Coordinator can make the referral.

Phone: 905-281-4443

www.centralregistry.ca

Volunteer Visitors

Acclaim Health Memory Visiting

A free walking and visiting program that provides companionship and physical activity for those experiencing the early stages of memory loss. Specially trained volunteers visit the client in their own home for 1-2 hours per week, and may take the client on outings.

Contact the Memory Visiting Coordinator in your area for more information:

Oakville

Phone: 905-827-8800 ext. 2317

Burlington

Phone: 905-827-8800 ext. 2314

North Halton, including Milton, Georgetown, Acton and Halton Hills

Phone: 905-827-8800 ext. 2318

www.acclaimhealth.ca/programs/social-supports/memory-visiting/



Getting Help in the Community

Adult Day Programs

Adult Day Programs provide engaging activities in the community for persons with dementia. Some programs are dementia specific, others will offer services to both persons with dementia as well as adults with other health concerns. Programs charge nominal fees for their services.

Access to all programs is through assessment by your local HCCSS Care Coordinator, but you may call the day program directly for information and tours.

Mississauga Halton Day Programs:

www.healthcareathome.ca/mh/en/Getting-Care/Getting-Supported-Living/Adult-Day-Programs

Burlington Day Programs:

For Burlington Programs visit www.adp-hnhb.ca, HNHB Adult Day Programs.

Specialized Day Programs for Persons Living with Dementia

Acclaim Health, Adult Day Programs

Burlington Adult Day Program

2180 Itabashi Way
Burlington, ON L7M 5A5
Phone: 905-632-8168

Soper Club Adult Day Program

Patty's Place
2250 Speers Road
Oakville, ON L6L 2X8
Phone: 905-847-9559

www.acclaimhealth.ca/programs/dementia-care/adult-day-programs

Halton Region Adult Day Services - Friends Landing

185 Ontario Street

Milton, ON L9T 2M4

Phone: 905-825-6000

www.halton.ca/For-Residents/Older-Adults/Community-Programs-Older-Adults

Seniors Life Enhancement Centres - Circle of Friends

2030 Bristol Circle #120

Oakville ON L6H 0H2

Phone: 905-279-9061

www.slec.ca

Integrated Adult Day Programs

Suitable for persons with mild to moderate dementia and/or other chronic health conditions:

Acclaim Health Adult Day Programs

Mississauga Club

2695 North Sheridan Way

Mississauga, ON L5K 2N6

Phone: 905-823-9264

Walmley Club

Patty's Place

2250 Speers Road

Oakville, ON L6L 2X8

Phone: 905-337-8937

www.acclaimhealth.ca/adult-day-program/

Halton Region Day Services (Milton & Georgetown)

Milton Place

185 Ontario Street

Milton ON L9T 2M4

Phone: 905-825-6000

Silver Creek Place

235 Guelph Street - Unit 5A

Georgetown, ON L7G 4A8

Phone: 905-825-6000

www.halton.ca/For-Residents/Older-Adults/Community-Programs-Older-Adults

Seniors Life Enhancement Centre - The Gathering Place

2030 Bristol Circle #120

Oakville ON L6H 0H2

Phone: 905-279-9061

www.slec.ca

Wellness House, Joseph Brant (Burlington)

2160 Itabashi Way
Burlington ON L7M 5B3

Phone: 905-632-5358

www.josephbranthospital.ca/en/programs-and-services/wellness-house.asp

Community Programs

Acclaim Health

Phone: 905-827-8800

www.acclaimhealth.ca/programs/

Caregiver Consultations - Individual consultations to provide you with strategies and connections to community resources.

Home Support Exercise Program - Improve balance, mobility during this 12-week program in your home.

Wellness Support - Reduce stress, pain and anxiety for people living with dementia and caregivers alike.

Alzheimer Society of Hamilton and Halton

4391 Harvester Road, Burlington, ON L7L 4X1

Phone: 1-888-343-1017

www.alzda.ca

Services for: Persons with dementia, Caregivers, and Public
Cost: Free

Location: Alzheimer Society of Hamilton and Halton (Virtual and various locations throughout Halton.)

Minds in Motion - To promote both physical and cognitive health in a dementia safe environment. (8 sessions)

Creative Expressions - Creative arts provide opportunities for stimulation and expression of feelings and thoughts. (8 sessions)

Sit to be Fit - Work out all major muscle groups with a focus on strength, endurance, flexibility and balance. (1 hour weekly sessions)

Getting Help for Overnight Relief

Persons living with dementia may experience changes in their wake/sleep patterns, and when this happens, the caregiver's sleep is often disrupted. Overnight relief for the caregiver means having the person living with dementia spend nights elsewhere occasionally or on a regular schedule.

Overnight Respite

Acclaim Health: JIM's Suites – Patty's Place

JIM's suites offers warm, friendly round the clock care while you get a break from caregiving. There are 8 private bedrooms, and during the day, the person living with dementia will attend the Soper Club onsite, a dementia specific day program.

Cost: \$100.00 for 24 hours, includes \$24 for day program

Eligibility: Clients living with dementia in Halton or Mississauga.

Process: Must go for a tour, assessment, and trial stay.

Guest Services Coordinator

2250 Speers Road, Oakville, ON L6L 2X8

Phone: 905-827-8800 ext. 2420

www.acclaimhealth.ca/programs/dementia-care/jims-suites/

Nora's House, Respite Care Alzheimer Society of Peel (Mississauga)

Nora's House provides a safe and secure home-like environment and cares for a maximum of 8 people at any one time. Programs are custom designed for the support and enjoyment of all who stay. Use and enjoyment of a therapeutic garden during spring, summer and fall.

Cost: \$100.00 per overnight

Eligibility: Clients with dementia. Not suitable for those with complex medical needs or those needing lifting. No residential requirement.

Process: Must have an assessment and trial stay.

Service Access Team

Phone: 905-278-3667 Ext.307

Email: direct.support@alzheimerpeel.com

www.alzheimer.ca/peel/en/help-support/programs-services/noras-house-respite-care

VON Hamilton

VON Overnight Respite Service provides an overnight break for caregiving families who are caring for persons living with progressive memory loss such as Alzheimer's disease. Assistance with social and recreational activities are provided by involvement in the day program, and personal care is provided during the 24 hour stay (4 PM to 4 PM), Monday to Sunday.

Cost: \$41.00 per overnight

Eligibility: Clients with dementia. Not suitable for those with complex medical needs or individuals requiring lifts, or 2 person transfers.

Process: Must go for tour, assessment and trial stay.

VON Hamilton

400 Victoria Ave N, Hamilton, ON L8L 5G8

Phone: 905-523-1055

Private Retirement Homes

Some of the private retirement homes in Halton offer short term stays. Contact local retirement homes for more information, including whether the home can accommodate the needs of persons living with dementia.



Safety and Security

MedicAlert Safely Home

Personal information and a hotline number are engraved on the unique MedicAlert bracelet that's worn full-time by a person with dementia. Should they ever go missing, police can quickly identify them by calling the MedicAlert 24-hour Emergency Hotline.

Cost: Fee for yearly membership **Phone:** 1-800-668-1507
www.medicalert.ca/safely-home

Connect Care Medical Alert

A personal emergency response service. Stay safe at home and on the go. Hospital owned and operated.

Cost: Fees **Phone:** 1-800-665-7853
www.connectcaremedicalalert.ca

Halton Region Police Services for Vulnerable Persons

Both of the services listed below are available through the Halton Police Services Victim Services Unit. **Phone:** 905-825-4747 ext. 5239

1. Halton Region Police Project Lifesaver

Combines radio technology with a coordinated police response to assist in locating wandering and disorientated persons living with dementia. Adults living alone, without a caregiver, are not eligible.

Cost: Start up fee is \$400.00. Annual maintenance fee is \$60.00.

www.haltonpolice.ca/en/services-and-reporting/project-lifesaver.aspx

2. Vulnerable Persons Registry

An online service that allows a family member or caregiver to provide information to police about a person, which can help during an emergency. Details such as physical description, habits, or specific needs can help police in locating or interacting with the person.

www.haltonpolice.ca/en/services-and-reporting/vulnerable-person-registry.aspx?_mid_=1508#

What is Behavioural Support?

Some persons living with dementia experience “responsive behaviours” which may include: wandering, verbal or physical behavioural responses, resistance, or many other types of behaviours. This is in response to real or perceived trigger(s), and could result in risk for the individual or others and/or provide challenges for caregivers.

The following is a list of resources that can be accessed to help caregivers whose care recipients experience these responsive behaviours.

Halton Seniors Mental Health Outreach Program St. Joseph’s Healthcare Hamilton

This service is for clients living with dementia and complex behaviour issues who cannot or are unable to seek services in traditional locations such as clinics and offices.

Cost: None

Referral: Must be approved by client’s physician, but can be requested by family.

Process: Following referral a clinical member of the Halton Seniors Mental Health Outreach Program, will do a home visit to initiate the assessment. A geriatric psychiatrist may also do a home visit, if needed.

Seniors Mental Health Outreach Program

Phone: 905-681-8233

Behavioural Supports Ontario

Behavioural Supports Ontario (BSO) is a provincial initiative that aims to improve the lives of seniors with complex behaviours due to dementia or mental health issues. Each health region in Ontario received funding to set up their own Behaviour Supports services. Burlington services differ from Oakville and North Halton services, as they are in different health regions, also known as Home and Community Care Support Services.

www.behaviouralsupportsontario.ca

Burlington

The Behavioural Supports Ontario Community Team helps older persons who have a cognitive impairment and responsive behaviours continue to live in their community. The team will provide behavioural management strategies and care plans.

Referral: Alzheimer Society of Hamilton/Halton

Phone: 289-837-2310

Oakville / Milton / Georgetown / Halton Hills

Behavioural Supports Ontario Services provided through the Alzheimer Society of Peel:

The target population for the BSO team is the older adult with complex responsive behaviours associated with Alzheimer's, dementia, mental health, substance use, and other neurological conditions. BSO provides support to the families and both formal and informal caregivers of the older adult, experiencing the complex responsive behaviours wherever they live (their private dwelling in the community, retirement home, long term care or elsewhere).

The goal is to reduce the strain and improve the outcomes for persons with challenging behaviours, their caregivers, health care providers and the health care system, ultimately improving the quality of life of individuals with responsive behaviours.

To access services **email** direct.support@alzheimersociety.ca or **call** 905-278-3667 ext 307

Cost: None

www.alzheimer.ca/en/peel

Residential Behavioural Units

InPatient Units

When all possible community services for behaviour stabilization have been accessed in the community, and behaviour concerns have not been resolved, a referral may be considered to an inpatient unit. Referrals may come from a physician, Seniors Mental Health Outreach, or other community agencies.

Sheridan Villa, Special Behaviour Support Unit

2460 Truscott Drive
Mississauga, ON L5J 3Z8

Cooksville Care Centre

55 Queensway W, Mississauga, ON L5B 1B5
Phone: 905-270-0170

Both of these units are for clients who have a primary diagnosis of dementia with significant behaviours that cannot be managed in the client's current environment. They are transitional treatment units and not intended to be a resource for emergency treatment.

Cost: Daily Fee

Application: Through the Mississauga/Halton HCCSS.

Hamilton Health Sciences

Specialized service for individuals who have behaviours related to a diagnosis of dementia, which present a risk to themselves or others.

St. Joseph's Healthcare Hamilton

Harbour North 1 - Seniors Mental Health Behavioural Program
100 West 5th St - West 5th Campus
Hamilton, ON L8N 3K7

Central Access Coordinator: 905-388-2511 ext. 36649

Hamilton Health Sciences

Lincoln Terrace / Yvonne Terrace
St. Peter's Hospital
88 Maplewood Ave.
Hamilton, ON L8M 1W9

Behavioural Health Social Worker: 905-521-2100 ext. 12327

Crisis Services

Crisis Outreach and Support Team (COAST)

You can call anytime, 24 hours per day, 7 days per week to speak to a professional, get support, and make a plan to stay safe. The mobile team may visit you wherever you are to provide support.

Please note: COAST is NOT an emergency response unit, you must call 911 in case of a life-threatening emergency.

Cost: Free

Phone: 1-877-825-9011, 24 hours/day, 7 days/week

Distress Centres of Halton

Confidential free telephone support, 24 hours/day, 7 days/week.

Oakville

Phone: 905-849-4541

Burlington

Phone: 905-681-1488

Milton/Halton Hills

Phone: 905-877-1211

Telehealth Ontario

A free, confidential service you can call to get health advice or general health information.

Cost: Free

Phone: 1-866-797-0000, 24 hours/day, 7 days/week

Financial and Legal Considerations

*Courtesy of Murray Alzheimer and Research Education Program, MAREP, at the University of Waterloo**

Legal and financial issues are important to consider early on in the journey. Seek professional advice from a lawyer, banker or financial advisor, and get answers to your questions related to planning for the future.

Things to note and consider:

1. It is wise to establish a Power of Attorney (POA) for Personal Care and Continuing Power of Attorney for Property before a diagnosis of dementia or as soon as possible after the diagnosis. POA's can only be established when the person has capacity to decide and make choices for themselves. Later in the illness, when the person becomes unable to make decisions, it becomes a difficult and long process for the family to go through the courts to establish a substitute decision maker.
2. Recognize the POA is the substitute decision maker when the individual no longer has the capacity to do so. Persons living with dementia should continue to be included in decision making as much as possible.
3. If the person living with dementia is your Power of Attorney or your will Executor, make the appropriate arrangements to have them removed and replaced from your will or POA.
4. Avoid the do-it-yourself approach when it comes to establishing wills and POAs.
5. Keep passports updated as they can be used for identification. Alternatively, you can request an Ontario Photo Card from Service Ontario if the person no longer has a driver's license.
6. Have a conversation with key personnel at your financial institution about the person living with dementia's diagnosis.
7. Investigate insurance responsibilities related to driving, and out of country travel.

8. Discuss with your insurance company what they cover with respect to medication and home care, such as the services of a personal support worker and purchase of assistive devices.
9. Consider placing a dollar limit on the credit and debit cards for persons living with dementia, or eliminate them altogether as remembering PIN numbers becomes a problem.
10. Be aware of changing legislation for support of partners in care, refer to the Ontario Caregiver Organization for information.
www.ontariocaregiver.ca/resources-education/caregiver-resources/financial-support
11. Persons with a confirmed diagnosis of dementia are eligible for the Disability Tax Credit. The disability amount is a non-refundable tax credit used to reduce income tax payable. A family physician or medical specialist will need to fill out the necessary form for the Disability Tax Credit, called Form T2201. Ask about your physician's policy on charging fees to complete medical forms such as the T2201. This form can be found on the Revenue Canada website at www.cra-arc.gc.ca.
12. Once the Disability Tax Credit has been accepted by Revenue Canada, medical expenses relating to the dementia may be claimed, such as Day Program costs and incontinence supplies. For more information, go to www.cra-arc.gc.ca and enter "Medical Expenses Disability" into the search engine.

**(Permission granted from Murray Alzheimer Research and Education Program, University of Waterloo, to reprint "Financial/Legal Issues" from Before/Early Diagnosis By Us For Us booklet. www.the-ria.ca/resources/by-us-for-us-guides/*

When is it Time for Long Term Care?

One of the questions we get asked a lot is: "When is it time to move someone into long term care?"

The answer is: *there is no right answer*. Everyone's circumstances are different.

In the Halton region, the average waiting time for a bed in a long term care facility may be several years. The challenge with this system of wait listing, of course, is how do you know when your care recipient will need placement? Will you be physically and emotionally able to cope with being the primary caregiver for a few years?

So here are some of the issues to look at when making the decision to wait list someone for long term care in a care facility:

1. Is the care recipient eligible for long term care? This is determined by an assessment by a HCCSS Care Coordinator.
2. What level of assistance does the person living with dementia need? Can this assistance be provided in the community by you, with assistance from other agencies including HCCSS? Is there family support?
3. Have you been using every possible source of support available in the community (day programs, respite, volunteers) and it's not enough support?
4. Do you have the finances to pay for private home supports, or for the care recipient to live in a retirement home?
5. Some geographic regions have less availability of PSW's (Personal Support Workers) and day programs, so you may not be able to get the services you need to keep the person living with dementia at home for a longer time.
6. How are you feeling emotionally? Are you showing signs of caregiver stress or burnout?
7. How is your physical health? Are you able to physically manage the caregiving?

8. How much time do you have to make this decision? Is it urgent, or can it wait?
9. How is your quality of life? How is the person living with dementia's quality of life?
10. Have you and the person living with dementia discussed what they would like when the time comes? A promise made years or even decades ago may no longer be relevant due to both your and the person's unanticipated health changes.
11. What messages about moving your care recipient into long term care are you getting from your relatives, your children, your siblings, and friends?

Making the decision to apply for long term care and subsequently to move the person living with dementia into long term care will most likely be one of the hardest decisions you will ever make. At a support group for spouses who have moved their relative into Long Term Care, many of the participants said that they had felt invincible while caregiving, and believed that there would never come a time when they would not be able to cope as a caregiver.

What it took for each of them was an outsider, be it their doctor, son/daughter or good friend, gently pointing out how the many stressors of caregiving was affecting their health, and that it was time to consider a move into long term care. When you are a caregiver day in, day out for years, if not decades, it is hard for you to be objective and to see how the caregiving has affected your health. **Listen to other people when they tell you what they see.** And don't be afraid to ask for their opinion or advice, if you are prepared to hear what they have to say.

Sometimes, despite all your good intentions and planning ahead, there may come a crisis in your lives. This crisis could precipitate an urgent move into long term care. The most common crises are:

1. Change in health condition of primary caregiver: hospitalization, stroke, pneumonia, mental health/exhaustion collapse, or even death. **(Do you have any provisions in place for what would happen to the person living with dementia if you are unable to provide care anymore?)**

2. Change in abilities of the person living with dementia: as they become more dependent on you for all their activities of daily living, you become less able to cope with the physical assistance required for toileting/showering etc.
3. Safety of the person living with dementia or yourself is at risk: if they suddenly start wandering outdoors unpredictably, or if you feel at risk due to a change in their behaviours (e.g. they threaten you in some way).
4. Dramatic change in health status of person living with dementia, often following a fall that necessitates hospitalization.

The largest obstacle to making the decision to move someone into long term care is GUILT. "Guilt is like a little voice in our heads. It tells us how we SHOULD act and behave, and criticizes what we have done. It is the voice of standards that we have set for ourselves, or sometimes it is the standard that our parents have set. Sometimes it is our fears about what other people will think of us. Guilt is your inner voice criticizing you for putting a family member in a home. " (Source: *Nursing Homes and Assisted Living*)

Common guilt concerns for caregivers contemplating moving someone into Long Term Care:

1. I should be able to handle this, I am her husband/his wife/son daughter.
2. I am a strong person and to move him/her into Long Term Care means I am weak.
3. If I move him/her into Long Term Care, I am abandoning him/her and my responsibilities.
4. If only my kids/sisters/brothers were around to help more often, we could look after him/her.
5. If only the doctor would order more supports for us, then we could cope.

Many of the above arguments are masking the true concerns, which are your **feelings of helplessness, loss, grief and failure** in the face of advancing dementia. Dementia is a progressive and palliative disease, with no cure at this time. It is important to have good support persons in your life with whom you are able to talk openly.

If you are ready to place the person living with dementia on a long term care wait list, you may call the long term care facilities yourself to arrange a tour. Your HCCSS Care Coordinator can provide further information, and will need to do an assessment of the person living with dementia to determine eligibility.

For a list of your local facilities, please refer to the HCCSS website for your area:

Mississauga-Halton Home and Community Care Support Services

For Halton residents, *excluding* Burlington.

Phone: 905-855-9090 or Toll-free: 1-877-336-9090

www.healthcareathome.ca/mh/en/

Burlington Home and Community Care Support Services

For residents of Burlington.

Phone: 905-639-5228 or Toll-free: 1-800-810-0000

www.healthcareathome.ca/hnhb/en/

There are many websites that provide more information on this topic, please see below.

- Alzheimer Society of Canada
www.alzheimer.ca
- Concerned Friends: A Voice for Quality in Long Term Care
www.concernedfriends.ca
- Ontario Long Term Care Association
www.oltca.com
- Ontario Ministry of Health and Long Term Care
www.health.gov.on.ca/en/public/programs/ltc

Caregiver Support

By joining a support group, you can meet others with similar experiences, learn about the disease and learn strategies for care. You can also share laughter, tears and your feelings.

Acclaim Health, Adult Day and Caregiver Support

We offer in-person and virtual support groups in Halton for all family caregivers, including exclusive groups for caregivers of Early Onset and Long Term Care.

These groups run 12 months a year.

Cost: Free

Phone: 905-847-9559 ext. 2411

www.acclaimhealth.ca/programs/dementia-care/caregiver-support-groups/

Alzheimer Society of Hamilton and Halton

Offers various virtual and social groups throughout Halton, such as: Adult Child Support Group, Fronto Temporal Caregiver Support Group, Lewy Body Dementia Caregiver Support Group, Men's Breakfast, Long Term Care Caregiver Support Group, Grief and Loss Caregivers Support Group.

Cost: Free

Phone: 289-837-2310 or 1-888-343-1017

www.alzda.ca

The Ontario Caregiver Organization:

Peer Support, education and helpline.

www.ontariocaregiver.ca



Acronyms

ADP: Adult Day Program

BSO: Behaviour Supports Ontario

COAST: Crisis Outreach and Support Team

HCCSS: Home and Community Care Support Services (formerly known as "LHIN")

HNHB HCCSS Hamilton Niagara Haldimand Brant Home and Community Care Support Services (includes Burlington)

LTC: Long Term Care

MH HCCSS: Mississauga Halton Home and Community Care Support Services

POA: Power of Attorney

PSW: Personal Support Worker

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HSMHOP

BSO

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HSMHOP: Halton Seniors Mental Health Outreach Program, BSO: Behaviour Supports of Ontario

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www.acclaimhealth.ca



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