



# Halton Dementia Guide

## for Caregivers



Acclaim Health, Adult Day and Caregiver Support

**LIFE CHANGING CARE**

Phone: 905-827-8800 Toll Free: 1-800-387-7127

[www.acclaimhealth.ca](http://www.acclaimhealth.ca)



*Acclaim Health is grateful for the funding received through  
The Halton Region Community Investment Fund  
to revise and design this guide.*

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# Halton Dementia Guide for Caregivers

Providing care for a person with dementia can be challenging. 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 your relative will likely need assistance from various agencies and programs. This is not a journey you can handle by yourself. 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 *Looking After Yourself* for some helpful tips.

Please note that the information in this guide is current as of January 2020.

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, 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 you can see or hear. Alzheimer's disease is the most common type of dementia.

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. As more nerve cells die, the brain becomes damaged. 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.

This Dementia Guide will outline the many community supports available in the Halton Region.

# 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.

[www.acclaimhealth.ca](http://www.acclaimhealth.ca)

## **Acclaim Health Adult Day and Caregiver Support,**

### **Oakville**

1430 Trafalgar Road, K Wing, Oakville, ON L6H 2L1

Caregiver Education Coordinator

Phone: 905-847-9559 Ext. 2411

### **Burlington**

2180 Itabashi Way, Burlington, ON L7M 5A5

Caregiver Education Coordinator

Phone: 905-632-8168 Ext. 2417

Services for: Family Caregivers

Cost: Free

Location: Various locations throughout 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.  
  
(Sessions: Spring and Fall)
- **Mid to Late Stages of Dementia Discussion Series**  
For family caregivers who have been caring for a person with Alzheimer disease or related dementia for some time, and wish to be prepared for the later stages of the disease. (Sessions: Spring and Fall)
- **Individual or Family Education**  
Provided by the Acclaim Health Caregiver Education Coordinator year-round.

## **Alzheimer Society of Hamilton and Halton**

4391 Harvester Road, Burlington, ON L7L 4X1

Phone: 1-888-343-1017

[www.alzhn.ca/alzheimer-hamilton-halton](http://www.alzhn.ca/alzheimer-hamilton-halton)

Services for: Persons with dementia, Caregivers, and Public

Cost: Free

Location: Alzheimer Society of Hamilton and Halton (Halton site 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. Sessions: 4 weeks.
- Dementia Education Series – Planning for the future and helping your family member or friend to remain as independent for as long as possible. Sessions: 4 weeks.
- 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. Sessions: 3 weeks.
- Care in the Later Stages - Understand what to expect in the late and end stages of dementia. Sessions: 3 weeks.
- Positive Approach to Care - Helps participants better understand the experience of dementia and provides practical tools to help support persons living with dementia. Sessions: 3 weeks. Fee applied to professional carepartners.
- 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. Sessions: 8 weeks.

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

- Alzheimer Society Canada: [www.alzheimer.ca](http://www.alzheimer.ca)
- Murray Alzheimer Research and Education Program: [www.livingwithdementia.uwaterloo.ca](http://www.livingwithdementia.uwaterloo.ca)
- Association for Lewy Body Dementia: [www.lbda.org](http://www.lbda.org)
- Association for Frontal Temporal Dementia: [www.theaftd.org](http://www.theaftd.org)

# 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.  
For more information on POA's see Advocacy Centre for the Elderly website at [www.advocacycentreelderly.org](http://www.advocacycentreelderly.org)
2. Recognize the POA is the substitute decision maker when the individual no longer has the capacity to do so. Persons with dementia should continue to be included in decision making.
3. If your partner with a 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. Obtain an Ontario Photo Card from Service Ontario, once the driver's license is no longer valid, to use for photo identification. Alternatively, keep passport updated.
6. Have a conversation with key personnel at your financial institution about your partner'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 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 in your province/country.
11. Persons with a definite 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. This form can be found on the Revenue Canada website at [www.cra-arc.gc.ca](http://www.cra-arc.gc.ca).
12. Once the Disability Tax Credit has been accepted by Revenue Canada, expenses relating to the dementia may be claimed, such as Day Program costs and incontinence supplies. Ask about your physician's policy on charging fees to complete medical forms such as the T2201.

*\*(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.uwaterloo.ca/murray-alzheimer-research-and-education-program](http://www.uwaterloo.ca/murray-alzheimer-research-and-education-program).*

# 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](http://www.medicalert.ca/safely-home)

## **Halton Region Police Project Lifesaver**

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

Cost: Start up fee is \$400.00.

Annual maintenance fee is \$60.00.

Phone: 905-825-4810

[www.haltonpolice.ca/projectlifesaver/](http://www.haltonpolice.ca/projectlifesaver/)

# 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 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.

## **The Local Health Integration Network (LHIN), Home and Community Care**

The LHIN's provide in-home and community based health care services for eligible clients. LHIN 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 LHIN office to request an assessment. There is no charge for these services. Be prepared that setting up initial services with LHIN takes time, so plan ahead.

### **Mississauga-Halton LHIN, also known as MH LHIN**

For Halton residents, *excluding* Burlington.

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

[www.mississaugahaltonlhlin.on.ca](http://www.mississaugahaltonlhlin.on.ca)

### **Burlington LHIN, also known as HNHB LHIN**

For residents of Burlington.

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

[www.hnhblhlin.on.ca](http://www.hnhblhlin.on.ca)

## **In-Home Caregiver Respite**

In-home caregiver relief 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 LHIN Care Coordinator (note: limited respite may be provided by the LHIN). 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.

## **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 LHIN Care Coordinator can make the referral.

Phone: 905-281-4443

Email: [respitereferrals@centralregistry.ca](mailto:respitereferrals@centralregistry.ca)

[www.centralregistry.ca](http://www.centralregistry.ca)

# Volunteer Visitors

## Acclaim Health Memory Visiting

A free walking and visiting program that provides companionship and physical activity for those experiencing memory loss. Specially trained volunteers visit the client in his or her 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 x2317

Burlington

Phone: 905-827-8800 x2314

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

Phone: 905-827-8800 x2318

<http://www.acclaimhealth.ca/menu-services/volunteer-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 LHIN Care Coordinator, but you may call the day program directly for information and tours.

Video tours of all adult day programs in Mississauga Halton (*excluding Burlington*) may be found here:

[www.healthcareathome.ca/mh/en/Getting-Care/Getting-Supported-Living/Adult-Day-Programs](http://www.healthcareathome.ca/mh/en/Getting-Care/Getting-Supported-Living/Adult-Day-Programs)

For Burlington Programs visit [www.adp-hnhb.ca](http://www.adp-hnhb.ca), HNHB Adult Day Programs.

## Specialized Alzheimer Disease or Related Dementias Day Programs

### Acclaim Health, Adult Day Programs

#### **Burlington Adult Day Program**

2180 Itabashi Way

Burlington, ON L7M 5A5

Phone: 905-632-8168

Hours: Monday to Friday, 8:00am-5:00pm

Open every Saturday, 8:30am-5:00pm

#### **Oakville Adult Day Program**

1430 Trafalgar Road, K-Wing

Oakville, ON L6H 2L1

Phone: 905-847-9559

Hours: Monday to Friday, 8:00am-5:00pm

Open every Saturday, 8:30am-5:00pm

Tuesday evenings to 8:30pm

Note: we will be relocating in 2021 (approximate date)

## **Seniors Life Enhancement Centres - The Circle of Friends Program**

2030 Bristol Circle #120

Oakville ON L6H 0H2

Phone: 905-279-9061

[www.slec.ca](http://www.slec.ca)

## **Halton Region Adult Day Services - Friends Landing**

185 Ontario Street

Milton, ON L9T 2M4

Phone: 905-825-6000

[www.halton.ca](http://www.halton.ca)

## **Integrated Adult Day Programs**

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

### **Acclaim Health Adult Day Programs (Oakville)**

Central

53 Bond Street

Oakville ON L6K 1L8

Phone: 905-337-8937

Palermo

2521 Dundas Street West

Oakville ON L6M 4J4

Phone: 905-847-3394

<https://acclaimhealth.ca/adult-day-program/>

### **Seniors Life Enhancement Centre - The Gathering Place**

2030 Bristol Circle #120

Oakville ON L6H 0H2

Phone: 905-279-9061

[www.slec.ca](http://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](http://www.josephbranthospital.ca/en/programs-and-services/wellness-house.asp)

**Halton Region Day Services (Milton & Georgetown)**

Milton Place

185 Ontario Street

Milton ON L9T 2M4

Phone: 905-825-6000

Silver Creek

235 Guelph Street - Unit 5A

Georgetown, ON L7G 4A8

Phone: 905-825-6000

[www.halton.ca](http://www.halton.ca)

**Community Programs:****Alzheimer Society of Hamilton and Halton**

4391 Harvester Road, Burlington, ON L7L 4X1

Phone: 1-888-343-1017

[www.alzhn.ca/alzheimer-hamilton-halton](http://www.alzhn.ca/alzheimer-hamilton-halton)

Services for: Persons with dementia, Caregivers, and Public

Cost: Free

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

**Minds in Motion** - To promote both physical and cognitive health in a dementia safe environment. Sessions: 8 weeks.

**Creative Expressions** - The benefits of the creative arts are well documented as they bypass parts of the brain affected by dementia and provide new opportunities for stimulation and expression of feelings and thoughts. Sessions: 8 weeks

**Sit to be Fit** - The class involves a work out of all major muscle groups with a focus on strength, endurance, flexibility and balance. Sessions: 1 hour, weekly.



# Getting Help for Overnight Relief

Persons 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 with dementia spend nights elsewhere occasionally or on a regular schedule.

## Overnight Respite

### **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, can live anywhere in Halton.

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

#### **Service Access Team**

Phone: 905-232-6016 Ext.307

Email: [direct.support@alzheimerpeel.com](mailto:direct.support@alzheimerpeel.com)

### **VON Hamilton**

VON Overnight Respite Service provides an overnight break for caregiving families who are caring for persons 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:** \$40.00 per overnight

**Eligibility:** Clients with dementia

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

#### **VON Hamilton**

400 Victoria Ave N, Hamilton, ON L8L 5G8

Phone: 905-523-1055

[www.von.ca/en/hamilton/service/overnight-respite-services](http://www.von.ca/en/hamilton/service/overnight-respite-services)

**Acclaim Health Overnight Respite Care Services:**

Acclaim Health is building a new Adult Day Program with 8 overnight respite care beds at 2250 Speers Road, Oakville. This new centre is scheduled to be open in 2021.

**Eligibility:** Clients with dementia. Not suitable for those with complex medical needs.

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

**Contact:** 905-827-8800, ext 2400

**Private Retirement Homes**

Some of the private retirement homes in Halton offer short term stays for rates from about \$80.00 per overnight and up. Contact local retirement homes for more information, including whether the home can accommodate the needs of persons with dementia.

**Long Term Care Homes**

A very limited number of Long Term Care homes provide overnight respite for approximately \$40.00 per overnight. The respite must be booked through your LHIN Care Coordinator. Respite dates are often booked months in advance.

The Advocacy Centre for the Elderly has additional information on both retirement homes and Long Term Care homes, visit:

[www.advocacycentreelderly.org](http://www.advocacycentreelderly.org)



# What is Behavioural Support?

Some persons 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 relatives experience these responsive behaviours.

## **Halton Seniors Mental Health Outreach Services St. Joseph’s Healthcare Hamilton**

This service is for clients with dementia and complex behaviour issues who cannot or will not 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 member of the Halton Seniors Mental Health Outreach Services (SMHOS), clinical team will do home visit to initiate assessment. A geriatric psychiatrist may also do a home visit, if needed.

### **Seniors Mental Health Outreach Services**

Toll Free: 1-866-429-7677

Email: [info@hgmhop.ca](mailto:info@hgmhop.ca)

[www.hgmhop.ca](http://www.hgmhop.ca)

## **Behavioural Supports Ontario**

The 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 “LHIN”s, or Local Health Integration Networks.

## **Burlington**

The Behavioural Supports Ontario Community Outreach Team (BSO-COT), helps older persons who have a cognitive impairment and responsive behaviours continue to live in their community. The team will provide short-term support and assistance for clients and their families in crisis or at risk of a crisis and help them connect with appropriate longer-term services and community resources.

Cost: None

Referral: Families may call COAST or professionals may refer them to COAST

### **Halton Crisis Outreach and Support Team (COAST)**

Accessible 24 hours per day / 7 days per week

Phone: 1-877-825-9011

## **Oakville / Milton / Georgetown / Halton Hills**

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

**Outreach Counsellors:** The role of a BSO Outreach Counsellor is to provide education, support, counselling and guidance to caregivers and family members who are caring for a relative with Alzheimer's disease and related dementias. BSO counsellors also help families and caregivers navigate the health care system to link them with available community resources.

**Community Support Workers (CSW):** The primary role of the Community Support Worker is to address responsive behaviours of members within the community. Community Support Workers also provide assistance with the transition of individuals with Alzheimer's and related dementias from home into day programs and from the day program into long term care.

**Psychogeriatric Resource Consultants (PRC):** The primary role of the PRC's is to work with staff providing care to persons with dementia, helping them to provide care for seniors with responsive behaviours related to complex physical, cognitive and mental health needs.

Cost: None

Referral: Self-referral, or through an agency

### **Alzheimer Society of Peel**

Phone: 905-278-3667

[www.alzheimer.ca/en/peel](http://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

The Special Behaviour Support Unit (SBSU) is a 19-bed unit within Sheridan Villa Long Term Care Home for clients who have a primary diagnosis of dementia with significant behaviours that cannot be managed in the client's current environment. It is a transitional treatment unit and not intended to be a resource for emergency treatment. It is anticipated that residents will stay for a maximum of 120 days, after which time they will be discharged to long term care or to the community.

### **Cooksville Care Centre**

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

The Responsive Behaviour Program delivers a holistic approach with professionally trained Behavioural Support staff to minimize behaviours.

Cost: Daily Fee

Application: Through your local LHIN.

### **Hamilton Health Sciences**

Specialized service and treatment in a safe, compassionate, caring environment for individuals who have behaviours related to a diagnosis of dementia.

#### **St. Joseph's Healthcare Hamilton**

Harbour North 1 - Seniors Mental Health Behavioural Program  
100 West 5th St - West 5th Campus  
Hamilton, ON L8N 3K7  
Phone: 905-522-1155

## **Hamilton Health Sciences**

Lincoln Terrace / Yvonne Terrace

St. Peter's Hospital

88 Maplewood Ave.

Hamilton, ON L8M 1W9

Phone: 905-777-3837

# 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 Lines**

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

Cost: Free

### **Oakville Distress Centre**

Phone: 905-849-4541

### **TeleCare Burlington**

Phone: 905-681-1488

### **TeleCare Distress Centre North Halton**

Phone: 905-877-1211

## **Telehealth Ontario**

A confidential telephone service you can call to get health advice or general health information from a Registered Nurse. Telehealth Ontario will connect family caregivers of people with dementia to support, advice, and referral, particularly after hours when other services are closed. Telehealth Ontario resources have been reviewed and updated specifically to support family caregivers of persons with dementia.

Cost: Free

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

# When is it Time for Long Term Care?

One of the questions we get asked a lot is: “When is it time to move Mom/Dad/my husband/wife 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 relative 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 your relative eligible for long term care? This is determined by an assessment by a LHIN, Home and Community Care Coordinator.
2. What level of assistance does your relative need? Can this assistance be provided in the community by you, with assistance from other agencies including LHIN? Is there family support?
3. Have you been using every possible source of support available in the community (day programs, respite and the LHIN assistance) and it’s not enough support?
4. Do you have the finances to pay for private home supports, or for your relative 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 your relative 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 your relative with dementia's quality of life?
10. Have you and your relative discussed what your relative would like when the time comes? A promise made years or even decades ago may no longer be relevant due to both your and your relative's unanticipated health changes.
11. What messages about moving your relative into long term care are you getting from your other relatives, your children, your siblings, and friends?

Making the decision to apply for long term care and subsequently to move your relative 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 your relative with dementia if you are unable to provide care anymore?)**
2. Change in abilities of relative 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 your relative 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 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 placement:

1. I should be able to handle this, I am her husband/his wife/son daughter.
2. I am a strong person and to place him/her means I am weak.
3. If I place him/her, 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 your relative on a long term care wait list, you may call the long term care facilities yourself to arrange a tour. Your LHIN Care Coordinator can provide further information, and will need to do an assessment of your relative to determine eligibility.

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

**Mississauga-Halton LHIN, also known as MH LHIN**

For Halton residents, *excluding* Burlington.

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

[www.mississaugahaltonlhin.on.ca](http://www.mississaugahaltonlhin.on.ca)

**Burlington LHIN, also known as HNHB LHIN**

For residents of Burlington.

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

[www.hnhblhin.on.ca](http://www.hnhblhin.on.ca)

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

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

# Connecting with Other Caregivers

Attending a support group can offer you opportunities to be with other caregivers who are having similar experiences and feelings, to share laughter and tears, to learn strategies for caregiving and problem solving, and to learn about community resources.

## **Acclaim Health, Adult Day and Caregiver Support**

We offer support groups throughout Halton for family caregivers. These groups run 12 months a year.

Cost: Free

Burlington Spousal Group

Burlington Dementia Discussion Group

Oakville Spousal Group

Oakville Family Group

Oak Park Support Group

Milton Family Group

Halton Hills Family Group

## **Alzheimer Society of Hamilton and Halton**

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

Cost: Free (\*materials fee may apply)

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

[www.alzhn.ca](http://www.alzhn.ca)



# 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. Be realistic about the disease, acknowledge that the person with dementia is NOT going to get better, and is gradually going to get worse.
8. Be realistic about yourself and your own limitations. How is your health? How is your energy?
9. 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.
10. Do all you can and then let it go.
11. Learn to separate what you can and can't control. Many things are simply out of your hands.
12. 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.
13. 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.
14. Allow yourself time and space to grieve the many losses during the dementia journey.
15. Celebrate life events!
16. Look for the humour in life, and in your day to day situations.  
LAUGH OUT LOUD.
17. 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).
18. Learn to say no.
19. Remember, we feel guilty because we love.
20. 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!

# Acronyms

ADP: Adult Day Program

BSO: Behaviour Supports Ontario

BSO-COT: BSO Community Outreach Team (Burlington)

LHIN: Local Health Integrated Network

COAST: Crisis Outreach and Support Team

CSW: Community Support Worker with BSO

HNHB LHIN: Hamilton Niagara Haldimand Brant LHIN  
(includes Burlington)

LTC: Long Term Care

MH LHIN: Mississauga Halton LHIN

POA: Power of Attorney

PRC: Psychogeriatric Resource Consultant

PSW: Personal Support Worker

RH: Retirement Home

SDP: Seniors Day Program

SMHOS: Seniors Mental Health Outreach Services, formerly known  
as Halton Geriatric Outreach Program



[www.acclaimhealth.ca](http://www.acclaimhealth.ca)



This guide was completed with:

*Société Alzheimer Society*  
HAMILTON AND HALTON  
HAMILTON ET HALTON

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2370 Speers Rd.

Oakville ON L6L 5M2

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Toll Free: 1-800-387-7127

Fax: 905-827-3390

### **Burlington Adult Day Program**

2180 Itabashi Way

Burlington, ON L7M 5A5

Phone: 905-632-8168

### **Oakville Adult Day Program**

1430 Trafalgar Road, K-Wing

Oakville, ON L6H 2L1

Phone: 905-847-9559

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Funded in part by



**United Way**  
Halton & Hamilton



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Mississauga Halton Local  
Health Integration Network

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CHARITABLE REGISTRATION NUMBER: 11928 4602 RR0001.