ENGLISH · REVIEW DRAFT

Living With Dementia: A Family Companion Guide

A practical, plain-language reference for people experiencing changes in memory, communication or behaviour, and for the families who support them.

Communication | Responsive behaviours | Shared decisions | Local support

This is an independent, unofficial adaptation of six English-language source documents supplied by a family. It is prepared for family use and Alzheimer Society review; it is not an Alzheimer Society publication and should not be distributed as one without review and permission. Program information was published in October 2025 and may have changed.

Read what you need

- Start here: four essentials
- Understanding communication changes
- Ten communication habits
- For the person experiencing changes
- Understanding agitation, pacing and hallucinations
- Shared decisions and planning ahead
- Daily checks and missing-person safety
- Programs, support and contact details
- Sources, editorial method and disclaimer

QUICK START

Remember these four things

Return here whenever you are unsure what to do next.

1

Communication remains possible

Even when speech changes, eye contact, expression, movement, touch, music and presence can still carry meaning.

2

Behaviour communicates

Agitation, pacing, refusal or withdrawal may mean: I hurt, I am afraid, I am tired, I am thirsty, or I do not understand.

3

Connect; do not correct

Respond to the feeling before solving the task. Arguing about facts often increases distress.

"They are not trying to be difficult. They may be telling me something in the best way still available to them."

Fourth: take a sudden change seriously. A rapid increase in confusion, hallucinations, agitation, withdrawal or mobility problems warrants assessment for treatable causes such as pain, infection, constipation, depression, delirium, sensory problems or medication effects. Contact local emergency services if anyone is in immediate danger.

When you do not know what to do

1. **Slow down.** Lower your voice, allow space and make the situation safe.
2. **Name the feeling.** Try: "You look worried. I am here with you."
3. **Check physical needs.** Pain, toilet, hunger, thirst, temperature and fatigue.
4. **Reduce stimulation.** Turn off the television, say less and do one thing at a time.
5. **Offer two simple choices.** "Tea now, or in ten minutes?"
6. **Pause if it is not working.** Change the person, time or approach, then observe again.

Sources: Communication pocket card p. 1; Day to Day: Communication pp. 3-6; Dementia and Responsive Behaviours pp. 2-5.

CHAPTER 1

Why communication becomes harder

Abilities change, but the person's dignity, feelings and need for connection remain.

Dementia is an overall term for symptoms caused by disorders affecting the brain. It may affect memory, thinking, problem-solving, language, mood and behaviour. Alzheimer's disease is one cause; vascular dementia, Lewy body disease and frontotemporal dementia can have similar or overlapping features.

Changes you may notice

Expressing thoughts
Word-finding trouble, unfinished sentences, new words, or getting stuck on a word or topic.

Understanding speech
Multi-step directions, fast speech, jokes, figurative language and abstract ideas may become difficult.

Following conversation
The person may lose their train of thought, move off topic or struggle when several people speak.

Reading and writing
Reading, writing and organizing words into complete sentences may change.

Language use
Some people return to their first language or speak less than before.

Sensory factors
Hearing, vision and sensitivity to noise or tone can intensify confusion and distress.

These changes are not laziness, stubbornness or deliberate non-cooperation. As language decreases, expression, posture, movement, vocalization, behaviour and touch become more important.

Support remaining abilities

- [ ] Arrange regular hearing and vision checks. Keep glasses clean and hearing aids working.
- [ ] Begin with what the person can and likes to do: setting a table, familiar music, gardening, art or folding towels.

- [ ] Remember the continuing need for companionship, purpose, belonging and respect.
- [ ] Watch non-verbal signs. A grimace, guarding part of the body, withdrawal or pacing may indicate discomfort.

Sources: Day to Day: Communication pp. 1-5; Communication Challenges and Helpful Strategies pp. 1, 3-4.

CHAPTER 2

Make conversation easier to follow

A little shorter, slower and gentler; understanding comes before correction.

1. **Approach from the front and introduce yourself.** “Hi Mom, it is Lina. I am here to have lunch with you.” A gentle reminder of identity and purpose can help even with familiar people.

2. **Gain attention first.** Face the person, make natural eye contact, move slowly and avoid a sudden touch from behind.

3. **Use the preferred name.** Speak slowly and clearly in a calm tone. Avoid baby talk, “elderspeak” and patronizing language.

4. **Offer one idea at a time.** Short sentences are easier than long explanations. Finish one step before presenting the next.

5. **Turn open questions into simple choices.** “Tea or coffee?” is easier than “What would you like?” Yes-or-no questions can also help.

6. **Allow time to answer.** Wait quietly. Do not rush to answer for the person or show impatience.

7. **Listen, then check.** “Are you saying your shoulder hurts?” Offer a missing word only if help seems welcome.

8. **Show as well as tell.** Point to the door, bring the coat, use a photo or gesture, and let actions support words.

9. **Acknowledge emotion first.** “That sounds frightening.” “You want to go home, don't you?” Feeling understood can make the next step easier.

10 **Use touch gently and watch the response.** Holding a hand may comfort one person; sudden, rough or unwanted touch may increase stress.

Replace correction with connection

Avoid: "I told you three times. How can you forget again?"

Try: "That is okay. We can look at it together again."

Avoid: "You are wrong. This is your home."

Try: "You want to be somewhere that feels safe. Tell me about that home."

Avoid: "Why won't you take a bath?"

Try: "Would you like a bath now or after dinner?"

Avoid: "Hurry up. We have no time."

Try: "Take your time. I am here. This sleeve first."

Avoid: Talking only to others about the person while they are present.

Try: Speak directly to the person and include them as much as possible.

Make the setting part of the solution

- Turn off the television or radio and reduce competing conversations.
- One-to-one or small-group conversations are often easier than large groups.
- Avoid figurative phrases, sarcasm and humour that depends on fast interpretation.
- If either person is becoming distressed, pause and try later at a calmer, more alert time.

Sources: Communication pocket card p. 1; Day to Day: Communication p. 6; Communication Challenges and Helpful Strategies pp. 2-3.

CHAPTER 3

Help other people understand you

You remain an important expert on your own health, feelings and preferences.

- [ ] Tell people, “I need more time to find the word. Please wait before finishing for me.” If you prefer help finding words, say that too.
- [ ] Ask the other person to slow down, use short sentences or repeat. Move somewhere quiet if noise is getting in the way.
- [ ] Choose one-to-one conversation when a group feels tiring. It is okay to let a lost thought go; it may return later.
- [ ] Use notes, calendars, phone recordings, pictures, drawing, gestures and body language.
- [ ] Rest before an important conversation. Treat yourself with the same patience you would offer a good friend.
- [ ] Stay socially connected where possible. A support group can connect you with people who understand.

Prepare one page for a health appointment

- Write down changes since the last visit, symptoms, medications and the three most important questions.
- Ask for a longer appointment when possible and bring someone you trust to help take notes.
- Ask the provider to speak directly to you, explain in plain language and write down instructions.
- Describe changes honestly and use specific examples.

When more communication support is needed

Ask a physician about referral to a speech-language pathologist. They can assess language concerns and teach alternative communication strategies. Their support is particularly important in primary progressive aphasia.

> **State future wishes early.** While communication is clearer, talk with trusted people about preferences for healthcare, daily life and finances. Record and revisit them. Chapter 5 provides a fuller checklist.

Sources: Communication Challenges and Helpful Strategies pp. 2-4; Day to Day: Communication p. 5.

CHAPTER 4

There may be a message behind the behaviour

Look for causes before choosing a response. A behaviour that creates no distress or risk may not need to be changed.

Responsive behaviours include aggression, agitation, wandering, restlessness, hallucinations, paranoia, unexpected noises and withdrawal. These actions, words or gestures often respond to something uncomfortable, frustrating or confusing in the body or environment.

Ask: what might the person be telling me?

Body

Pain, hunger, thirst, toilet needs, constipation, fatigue, infection or a medication effect.

Senses and setting

Poor vision or hearing; too much noise, light, darkness, crowding, unfamiliarity, stimulation or boredom.

Emotion and connection

Fear, loneliness, grief, frustration, being rushed, or a need for reassurance and company.

The task

The person may not understand the request, the steps may be too numerous, or the task may exceed current ability.

Life history

An old routine or memory may be active. Pacing at the same time each day may reflect a past school-pickup or work routine.

Brain changes

The disease itself can affect mood, sleep, appetite, judgment and the interpretation of surroundings.

A six-step problem-solving loop

1. **Describe the behaviour objectively.** Is it dangerous or distressing, or simply different from our preference?
2. **Look for what came before.** Which people, sounds, tasks, times or physical symptoms were present? Are there patterns?
3. **List possible causes.** Include pain, illness, basic needs, senses, surroundings, emotions and life story.
4. **Consider gentle strategies.** Choose options that fit the person's routine, preferences and current abilities.

5 **Try one at a time.** This makes it easier to know what helped.

6 **Record the result.** If it did not help, blame no one. Try another approach and seek input from healthcare, care teams or the local Society.

Common situations and first options

What you see	Check first	Options to try
Agitation or restlessness	Pain, infection, medication, fatigue; too much noise or light; not enough engagement	Reduce stimulation; offer something familiar to hold; try music, photos, a simple game or a short walk.
Pacing or trying to leave	Toilet, thirst, constipation; looking for someone; an old routine	Provide daytime activity and exercise; ask about needs; if leaving alone is unsafe, reduce departure cues such as a visible coat and maintain a missing-person plan.
Hallucinations	New physical illness, medication, vision or hearing changes, shadows	Say, “That sounds frightening”; do not argue; improve lighting; redirect with music, exercise or photos; arrange medical assessment.
Belief that items were stolen or someone means harm	Misplaced items; real abuse or financial risk; infection or medication	Validate feelings; help search; investigate plausible risks; seek medical assessment for new or worsening symptoms.
Sexual expression that does not fit the setting	Past patterns of intimacy, privacy needs and environmental cues	Do not shame; redirect toward activity; offer privacy where appropriate while protecting everyone's boundaries.

About restraints: Physical restraints, medications used to restrict behaviour, and locked or otherwise restrictive environments can cause injury, weakness, confusion, boredom and loss of independence. No restraint is the preferred care approach. Assessment, appropriate care and safe design should address the need first. Any restraint decision requires qualified professional assessment and monitoring and must not be used merely for convenience.

Sources: Dementia and Responsive Behaviours pp. 1-7; Day to Day: Communication pp. 3-4.

CHAPTER 5

Keep the person involved in their own decisions

A dementia diagnosis does not remove all decision-making ability. Support should preserve choice and dignity.

Decision-making capacity generally means being able to understand information relevant to a decision and the possible consequences of the options. It is not the same as making a choice that family members consider "good." Memory difficulty does not automatically mean incapacity.

Difficulty deciding where to live does not mean a person cannot choose what to wear, what to eat or whether to join an activity. Capacity is specific to the decision and can be affected by time of day, fatigue, pain and medication.

Support the person's own decision

- [ ] Choose the person's most alert and comfortable time. Address pain and make sure glasses and hearing aids are in place.
- [ ] Turn off the television and reduce distraction. Use plain language, pictures or objects.
- [ ] Guide one step at a time and reduce choices. "Now or later?" is easier than "When?"
- [ ] Allow time. Important decisions can be discussed across several conversations.
- [ ] Use notes or recordings to support memory and document the person's choice.
- [ ] Only move to decision-making on the person's behalf after different supports have been tried without success. A professional capacity assessment may be needed; laws vary by province and territory.

Plan three things early

1. **Choose a substitute decision-maker.** Consider availability, respect for the person's values, ability to collaborate under stress, and conflict-resolution skills.

2. **Keep talking.** Discuss healthcare, living arrangements, finances, personal care and end-of-life preferences more than once.

3. **Record wishes through locally valid documents.** Advance directives and substitute decision-making laws vary. Seek local Alzheimer Society information and legal advice.

Questions families can answer together

Healthcare

Which treatments would or would not be wanted for another major illness? What about CPR or feeding tubes? How would treatment affect physical health, cognition and quality of life?

End of life

If possible, would the person prefer home, hospice or hospital? Who should be present? Which music, faith or cultural rituals matter?

Finances and legal documents

Who will manage financial interests? Are wills, insurance and banking records together in a safe place? What spending priorities matter most?

Personal care

Preferred language, food, grooming, clothing, sleep routine, tea, news or other daily habits.

Interests and comfort

Music, television, crafts and activities that create calm, meaning and belonging.

Safety and housing

Allergies and fears; preferred type of long-term care setting if home is no longer safe.

For the substitute decision-maker

Follow the person's expressed wishes whenever possible rather than substituting your own. If wishes are unknown, unclear or impossible to follow, return to the person's values, the risks and benefits, physical and emotional wellbeing, and quality of life. A neutral, trusted third party may help with conflict.

Source: Conversations About Decision-Making pp. 1-6.

CHAPTER 6

A reference for every day and difficult moments

A checklist is not a demand for perfection. It helps families notice small, solvable problems.

A brief daily check

- [ ] Any new pain, fever, constipation, urinary symptoms, fall or marked mental change?
- [ ] Are glasses clean and hearing aids in place with working batteries?
- [ ] Has the person had fluids, food, toilet access and enough rest?
- [ ] Is the setting too loud, bright, dark, crowded, hot or cold?
- [ ] Was there one meaningful, familiar activity the person could complete successfully?
- [ ] Did we offer choice, time and direct participation?
- [ ] Was there a moment of laughter, touch, familiar music or quiet companionship?

A four-line behaviour note

1. Before
Time, place, people present, the preceding activity and physical state.

2. What happened
Record what was seen and heard, without labels such as “deliberate” or “unreasonable.”

3. What we tried
Record one approach at a time.

4. Result
How long until the situation eased? What may have helped? What will we adjust?

Patterns when a person is lost

The pocket card notes that a lost person with dementia may not know they are lost. They may continue in a straight line across fields, creeks or obstacles, then stop in brush, drainage areas, woods, or near roads and railways. They may be hidden, may not call for help and may not respond to their name.

If someone is missing: Contact local police or emergency services promptly and state that the person has dementia. Search quietly and listen for singing, crying or small sounds. The source reports that in urban areas, 75% are found within 3.2 km of the last-seen point. Keep reunions calm. Consider a locating device in advance.

Prepare an information card

- A recent photograph, commonly used name, familiar destinations, people they may seek and former addresses.
- Diagnosis, important medications, communication needs and emergency contacts.
- Locating-device information; keep a copy with family and on the phone.

Sources: Communication pocket card p. 2; Dementia and Responsive Behaviours pp. 3-6. The information card is a practical editorial suggestion.

CHAPTER 7

Support in Brant, Haldimand Norfolk, Hamilton and Halton

A 2025 overview of local services. Families do not need to wait for a crisis before calling.

The Alzheimer Society of Brant, Haldimand Norfolk, Hamilton Halton (ASBHNHH) provides education, counselling, support groups, system navigation and health activities. **First Link** connects people with dementia or mild cognitive impairment and their care partners with information and community services from diagnosis through the disease journey. A formal diagnosis is not required to become a registered client; some programs are also open to the public.

Phone
1-800-565-4614 (tel:+18005654614)

Email
help@alzda.ca (mailto:help@alzda.ca)

Website
www.alzda.ca (https://www.alzda.ca)

Language access: The program guide states that some services can use an external translation service. Ask for Mandarin or Cantonese interpretation during the first contact. French service: 1-800-565-4614 ext. 879.

Services families can ask about

Counselling and support
Coping strategies, system navigation, future planning, and online or in-person support groups.

Family education
Dementia Education Series, First Steps, Middle Stages, Options for Care, Care in the Later Stage, and Taking Control of Our Lives.

Public online education
Getting Started, Toolbox Talks, Finding Your Way, and Focus on Communication. Topics vary monthly.

Health and connection
Minds in Motion, Creative Expressions, Teleconnect, Social Cafe, Online Social Club, and Sit to be Fit.

Specialized and complex support
Behavioural Supports Ontario, Responsive Behaviour Specialist, emergency-department DREAM Team, intensive case management, PRCs, and First Link Care Navigators.

Other activities
H.A.C. physical, cognitive, art and social programs; eligible families can receive a no-cost Music for Memory player, headphones and setup.

Support group range

Care partners can ask about general, spousal, adult-child, long-term care, young-onset, men's, women's and 2SLGBTQ+ groups; condition-specific frontotemporal and Lewy body groups; self-care, grief and bereavement groups. Groups for people living with dementia include early-stage, mild cognitive impairment and young-onset.

Main offices listed in the 2025 guide

Brantford & Brant County
1-515 Park Road North, Brantford, ON N3R 7K8
519-759-7692

Norfolk County
645 Norfolk St. N., Simcoe, ON N3Y 3R2
519-428-7771

Haldimand County
42 Main St. S., Hagersville, ON N0A 1H0
905-768-4488

Hamilton
205-550 Fennell Ave. E., Hamilton, ON L8V 4S9
905-529-7030

Halton
8-4391 Harvester Rd., Burlington, ON L7L 4X1
289-837-2310

By appointment
Dunnville: 201 Forest St. E.; Georgetown: 33-360 Guelph St.; Paris: 202-25 Curtis Ave.

Confirm before attending: Sit to be Fit and other schedules in the source are from 2025 and say times and locations may change. This adaptation does not present that timetable as current in 2026. Call or use the online calendar.

Source: 2025 Program Guide pp. 2, 4-20.

DOCUMENT NOTES

How this companion was prepared

It preserves the source themes, merges repetition and reorganizes content for family use.

This is not a line-by-line reproduction. Three communication publications overlap substantially, so their content is combined into chapters on understanding changes, communication habits and self-advocacy. Decision-making and responsive behaviours remain distinct. The local guide is summarized by service type and contact route; detailed 2025 schedules are not repeated as if current.

Supplied source file	Pages	Main use in this companion
Communication challenges and helpful strategies-Alzheimer Society-2024.pdf	4	Self-advocacy, healthcare visits and speech-language support
Communication-Tip-Pocket-Card-en-Alzheimer-Society.pdf	2	Ten communication tips and missing-person characteristics
day-to-day-series_communication.pdf	6	Person-centred communication, stage-related strategies and sensory connection
Conversation-About-Decision-Making-en-Alzheimer-Society.pdf	6	Capacity, supported decision-making, advance planning and substitute decisions

Supplied source file	Pages	Main use in this companion
conversations_dementia-and-responsive-behaviours.pdf	8	Meaning of behaviour, assessment, response options and restraint concerns
ALZProgramGyude-09.2025.v2web.pdf	20	ASBHNHH services, programs, support groups and offices

Editorial choices for Society review

- Uses “person” before diagnosis and avoids infantilizing language.
- Frames behaviour as communication and emphasizes medical assessment for sudden or new changes.
- Separates decision-making capacity from whether others agree with a decision.
- Adds a brief emergency-services instruction and an information-card suggestion for family usability; these are identified as editorial additions.
- Does not treat 2025 class times as current. Contact details are attributed to the supplied 2025 guide.

Important disclaimer

This companion is for information and family reference only. It is not clinical, treatment, legal or financial advice. Individual circumstances differ. Sudden changes in symptoms or behaviour warrant healthcare assessment. Rules concerning capacity, advance directives, powers and substitute decision-making vary by province and territory.

Copyright in the source publications remains with the respective publishers. This unofficial adaptation should be reviewed and permission obtained before public distribution, publication or representation as an Alzheimer Society resource.

Prepared July 2026 from six PDFs supplied by a family. The 2025 program timetable was not treated as a current 2026 schedule.

May every conversation begin with dignity, patience and connection.