HÔTEL-DIEU GRACE
ESTD HEALTHCARE 1888

Geriatric Assessment Program (GAP)

Education and Resource Package

Specialized Geriatric Outpatient Services

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Introduction

Noticing changes in your memory and thinking skills can be frightening and overwhelming. This package is here to help you navigate the commonly asked questions when experiencing memory loss. Please take the time to review the Table of Contents and browse the information that is most applicable to you and your family.

We hope this will act as a guide to ease some of the unknowns as you navigate this journey through memory changes. If you have further questions that cannot be answered with the information provided, please reach out to the GAP Clerical Team; they will direct you to the appropriate discipline.

Geriatric Assessment Program (GAP) Clerical Team:
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Is it normal for memory to change with age? Doesn't it happen to everyone?

Yes, some changes in working memory are commonly seen with normal aging. This includes things like:

- Walking into a room and forgetting what you wanted to do there
- Losing things from time to time, such as your glasses
- Forgetting the name of an acquaintance
- Forgetting to take a medication occasionally
- Having a more difficult time learning new things
- Making a minor bad decision
- Forgetting which word to use when speaking or writing

However, as part of normal aging:

- These lapses occur once in a while and are not frequent enough to be a matter of concern to family or friends.
- There should be no significant increase in the frequency of forgetfulness over a short period (weeks to months)
    - Stress, poor sleep, poor nutrition, medications, or medical problems may explain a sudden/rapid decline in memory or clear thinking.
- Commonly, the forgotten information will come back with a few minutes of concentration or will be spontaneously recalled later.
- Your memory testing scores will be normal (for your education level)

When might we be concerned about changes in memory or thinking?

- When changes in memory and thinking become frequent enough to concern loved ones
- When memory testing shows greater than expected changes
- When there are big changes in problem solving, judgment, or personality compared to one's previous norm
- When changes in thinking make it difficult to function in the household or community, or with tasks such as driving or financial management
- When language abilities such as speaking or writing change very quickly compared to one's previous level (large decline in 1-2 years)
- When someone develops hallucinations or delusions as an older adult, outside of other possible explanations, such as a psychiatric condition, medication side effects, infection, or other medical problem

I note memory/thinking changes in myself, and perhaps my loved ones have noted a slight change, but my memory testing is normal. What does this mean?

- Testing is not 100% sensitive in picking up memory changes, which is why telling your physician/provider about your observations in day-to-day life is important. The key is to mention things that have changed noticeably over a relatively short period (months to 1 year).
- Mildly concerning memory changes with normal testing is called **Subjective Cognitive Impairment (SCI)**. Research is ongoing to study what it might mean for memory changes later in life. There is no specific treatment for this – the recommendation is to stay as fit and active as possible, manage stress, and eat a healthy diet.

How do you classify memory/thinking changes of concern? Does any abnormal memory loss mean I have dementia?

No. Not all memory/thinking changes are a sign of dementia. They can be normal for aging as mentioned previously. Even if your memory changes are greater than expected for normal aging, it does not automatically mean you have dementia.

Many older people with memory loss are in a gray area called **Mild Cognitive Impairment (MCI).** This is diagnosed when:

- You/your loved ones have noted changes in memory and thinking
- We note that your memory testing scores are lower than expected (keeping your education level in mind) in at least one area of thinking
- Importantly, although you have some changes in your memory/thinking, you are generally able to compensate for them. You have not had to give up an area of functioning in your day-to-day life, although you may need reminders or supervision.

We diagnose many people with Mild Cognitive Impairment, and many other older adults live with it in the community without a formal diagnosis.

There are more people living with mild cognitive impairment than with dementia.

MCI is more common the older you get. Approximately 10% of people 60-69 years old may have it, increasing to around 25% of adults aged over 80.

Around 10-15% of people with MCI progress to dementia each year. However, 50% are stable at around the 5-year mark, and in some people the MCI resolves entirely.

MCI can be caused or contributed to by many possible factors:

- Your medical conditions
- Your medications

- Your emotional state (e.g., the presence of untreated depression, anxiety, or ongoing emotional stress such as with grief or other loss/change)
- Your sleep (e.g., if you have untreated sleep apnea or if you have broken sleep because you urinate frequently at night)
- Alcohol, tobacco, and substance use
- Lack of activity – physical, mental, social
- A poor diet – lacking in fruits, vegetables, and healthy fats; containing lots of processed foods or unhealthy ingredients
- Hearing and vision loss

When investigating MCI, we look into these factors and offer advice about things that can be corrected or optimized. It is important to remain active in every way possible, eat a healthy diet, and reduce/eliminate alcohol and tobacco use.

When is memory loss classified as dementia?

To meet criteria for dementia, the changes in memory/thinking must be:

- Noticeable to others and on testing (in more than one area of thinking)
- Progressively worsening over time
- Not explained by any other condition
- Importantly, they result in a progressive loss of safe day-to-day functioning in at least one area (e.g., driving, financial management, medication management, job or volunteering, household management, personal care)

Some cases are trickier to diagnose than others as fluctuations occur – there will be good days and bad days. Generally, the passage of time makes the diagnosis more clear.

What is "reversible dementia"?

Certain conditions such as obstructive sleep apnea or normal pressure hydrocephalus present as dementia, but if diagnosed and treated early there can be reversal in memory loss/thinking changes. Most often, dementia is irreversible when diagnosed.

Is dementia and Alzheimer's the same thing?

Alzheimer's disease is the most common cause of dementia. Alzheimer's disease can be present in the brain without dementia. Research is working on how to detect the changes from the disease before the point where dementia develops.

There are other causes of dementia, such as vascular dementia (caused by damage to blood flow in the brain), Parkinson's dementia, Lewy Body dementia, mixed dementia from more than one cause, and others.

In conversation and even in the medical records, dementia can be used as a general term when the specific type of dementia is either not known, or as a shorthand term for any kind of dementia (usually Alzheimer's dementia).

What stage of dementia am I in?

To keep things simple, we break down dementia into the mild, moderate, and severe stage.

- Mild – loss of function with what we call Independent Activities of Daily Living (IADLs) – driving, shopping, medications, finances, housekeeping, electronics
- Moderate—loss of function with Basic Activities of Daily Living (BADLs or just ADLs) – knowing how to dress appropriately to go out/for the weather, bathing, dressing, grooming, toileting
- Severe – loss of function with the above, as well as more basic tasks such as speaking, swallowing, or walking. More significant difficulty with toileting.

Scores on testing do not always fit neatly into these categories, and we don't rely on them alone to determine the stage. Day-to-day function tends to be more useful, especially as the disease progresses.

Note: We don't usually continue to do memory testing once it is obvious the dementia is moderate or worse. It is frustrating for the patient and doesn't change management.

If you have access to the internet, you can find the Seven Stages of Dementia listed on the Alzheimer's Society website or elsewhere. The concept is similar, with more subcategories. There is also a Clinical Dementia Rating scale available online, which breaks up observations into several categories.

If you have been diagnosed as having dementia and a later time you/your family would like to know which stage you are in, you can approach the Alzheimer's Society for a review and repeat memory testing if needed.

The Global Deterioration Scale (GDS)

Stage	Typical Symptoms
Stage 1: No cognitive decline (normal function)	• No memory problems
Stage 2: Very mild cognitive decline (may be normal age related changes or earliest signs of Alzheimer's disease)	• Memory lapses • Forgetting familiar names and locations of objects • These lapses are not typically obvious to others
Stage 3: Mild cognitive decline (early stage Alzheimer's disease can be diagnosed in	• Mild forgetfulness • Difficulty learning new things

some, but not all individuals with these symptoms)	• Difficulty concentrating or limited attention span • Problems with orientation, such as getting lost • Communication difficulties such as finding the right word • Loss or misplacing of valuable objects • Difficulty handling problems at work • Issues are noticeable to family, friends, or co-workers
Stage 4: Moderate cognitive decline (mild or early stage Alzheimer's disease)	• Some memory loss of one's personal history • Difficulty with complex tasks e.g. managing finances, shopping, travel • Decreased knowledge of current events and recent events • Impaired ability to perform challenging mental arithmetic (e.g. counting backwards from 75 by 7)
Stage 5: Moderately severe cognitive decline (moderate to mid-stage Alzheimer's disease)	• Major gaps in memory e.g., phone numbers or names of close family members • Help is needed with day-to-day tasks
Stage 6: Severe cognitive decline (moderately severe or mid-stage Alzheimer's disease)	• Continued memory loss e.g., occasionally forgetting the name of a spouse or primary caregiver • Loss of awareness of recent events and experiences in their lives e.g. not remembering what they had for lunch or their child's graduation • Assistance is needed with activities of daily living e.g., getting dressed, bathing • Difficulties counting • Personality and emotional changes such as confusion, anxiety, suspiciousness, anger, sadness/depression, hostility, apprehension, delusions and agitation • Obsessions such as repetition of simple activities • Disruption of normal sleep/waking cycle • Increasing episodes of incontinence
Stage 7: Very severe cognitive decline (severe or late-stage Alzheimer's disease)	• Severe cognitive impairment • Vocabulary becomes limited and verbal abilities eventually disappear • Loss of ability to walk independently and sit without support • Help is needed with eating and using the toilet; usually incontinent

Modified from Global Deterioration Scale, Reisberg, 1982

Is there medication for dementia?

For certain types, yes. The medication we have available was developed for Alzheimer's dementia. Sometimes we use them in other forms of dementia. It can be used from the mild stage to the severe stage.

Cholinesterase Inhibitors for Dementia

Generic Name	Brand Name
Donepezil	Aricept
Galantamine	Reminyl
Rivastigmine	Exelon

How It Works

Cholinesterase inhibitors increase the level of a brain chemical called acetylcholine. People with **Alzheimer's disease** and related conditions have decreased brain levels of this neurotransmitter. Increasing the amount of acetylcholine appears to slow mental decline in people with Alzheimer's disease.

These medicines help the brain cells work better but do not stop or reverse the destruction of brain cells and loss of acetylcholine that occur in Alzheimer's disease. They do not prevent the disease from getting worse but may slow the progression of symptoms.

Why It Is Used

Cholinesterase inhibitors may be used to treat some symptoms of Alzheimer's disease. They also may be used in other types of **dementia**, such as **dementia with Lewy bodies** and **multi-infarct dementia**.

How Well It Works

Cholinesterase inhibitors may produce small improvements in memory and general ability to function. For example, the person may be able to remember friends' names better and be able to dress himself or herself with less difficulty. This may translate to being able to remain at home for a longer period of time.

Cholinesterase inhibitors do not help everyone who has dementia. It is believed that as the disease progresses, the medicine eventually may stop working.

The various cholinesterase inhibitors have similar effects on memory and cognitive function, so the choice between medicines may be based on side effects, dosing schedules and ease of use, individual response to a particular medicine, or other factors.

Side Effects

In general, most people seem to tolerate cholinesterase inhibitors very well. The most common side effects are:

- Nausea
- Diarrhea
- Vomiting
- Indigestion
- Abdominal pain
- Loss of appetite and weight loss
- 1-10% chance of dizziness/fainting
- 1% chance of low heart rate
- Less common side effects include insomnia, fatigue, and muscle cramps. Side effects tend to be mild and usually go away within a few weeks after treatment with the medicine is started.

What to Think About

Cholinesterase inhibitors do not work for everyone who has Alzheimer's disease or dementia, but they are helpful for some people. They may be a reasonable option for those who understand the risks and costs and feel the possible benefits are worth it.

Most studies of cholinesterase inhibitors for people with Alzheimer's disease found that the benefits of taking these medicines are small.[2, 3]

Side effects seem to be milder and occur less often with donepezil or galantamine than with rivastigmine.

Experts agree that reducing problems with memory loss may help people with dementia live better. In some cases, reducing these problems may help people live more independently for a longer period of time.

Rivastigmine (Exelon) can now be given through a skin patch. Skin patches release medicine into the blood at a steady level and may reduce side effects. When a person uses a skin patch, it's easier for caregivers to make sure the person is getting his or her medicine properly.

In addition to the above medications, there is a second-line medication called memantine (Ebixa™), which is used in moderate to severe Alzheimer's dementia. It is meant to be used in addition to the first-line medications. Benefit of the combination is modest. It costs around $200/month out of pocket unless secondary coverage is available.

Newer medications that specifically work against the abnormal amyloid protein complexes in Alzheimer's disease are now available in the United States and are being observed there to see how much benefit is noted in patients' day to day lives. They are not approved in Canada. They are very expensive and require monitoring due to a small risk of swelling and bleeding in areas of the brain.

Will the medications reverse the dementia?

Unfortunately, no. It may help to slow the rate at which your thinking worsens. The greatest benefit is noted in the first few months, but if there was some benefit it is continued afterwards. About a third of people don't experience benefit at all.

How long does it take for dementia to progress?

Alzheimer's dementia on average takes 7-10 years to progress to end-stage. Lewy Body dementia and frontotemporal dementias may progress faster, 5-7 years. However, there is a lot of variation. Your physician/provider will likely not give you an exact timeframe due to this.

Does having dementia mean I can't drive?

This can be a complicated question in the early stages of dementia, or in mild cognitive impairment. Some people with mild cognitive impairment can drive safely, others not. In the mild stage of dementia, some people may be able to drive safely for a while.

In the moderate or severe stages, driving is inadvisable.

We use information gathered about your general functioning and performance behind the wheel, in addition to office-based testing, to determine next steps.

If you are in a gray area or if there is a potential risk, you will likely be referred to undergo on-road testing via the Ministry of Transportation or at a Functional Driving Assessment Centre.

It is mandatory for certain healthcare providers to send a report to the Ministry of Transportation when a person has certain health conditions or if there may be a potential risk to their driving abilities. Once a report is sent, it is reviewed by the Ministry's medical review board and they will provide you with further instructions or ask for more information.

Changes to Expect

What kind of memory/thinking changes may I see going forward?

- As dementia starts and then progresses, it is common for people to become disoriented to time – first the date and eventually the year.
- One may forget biographical details such as address, telephone number, birthdate etc.

- Short term memory retention might become shorter and shorter.
- Remembering names becomes more difficult. In the later stages, recognizing family members may be difficult, or vary day to day.
- Following a sequence of steps to complete a task becomes more difficult.
- Misplacing things becomes more common.
- One may become disoriented to place in the moderate and severe stage. One may think one isn't at home and want to go home (which may be an earlier or childhood home).
- Problem solving is no longer possible as dementia progresses.

Insight into one's own condition may diminish or become absent, even in the mild stage. People may not be aware they cannot safely drive or use the stove. They may say they are doing things they are not, and vice versa.

What other changes may I see other than memory/thinking?

There are many features that people with dementia will demonstrate outside of the memory/thinking changes themselves. These include (but are not limited to):

- Mood changes
- Sleep changes
- Behaviour changes
- Balance problems, slowed walking, short steps, loss of strength
- A more limited vocabulary, with simpler speech – in the late stages the speech may not make sense or even have clear words (this happens in a subset of patients, not all)

What mood changes occur with dementia?

- For example, in the early stages of memory loss (even before dementia is noted), people will often have changes in their mood – they become more irritated, sad, or withdrawn. Sometimes, more so at the later stages, they may cry or laugh for little or no reason.
- Depression and dementia can go together, but dementia itself can cause lack of interest and drive in things one used to enjoy. This is called apathy or abulia. Sometimes people give up things they used to enjoy because it gets too frustrating to keep on.
- Monitor your/your loved one's mood and if there is a persistent down mood or lack of enjoyment in things that used to be enjoyable for 2 weeks or more, talk to your family doctor or care provider.
- Anti-depressants or stimulants may be considered to treat depression or apathy depending on your/your loved one's overall health condition.

- Depression and anxiety associated with dementia is harder to treat than depression and anxiety without dementia.

Which sleep changes may occur?

In older adults, sleep is lighter and more broken. This is more obvious in dementia. The sleep cycle can become reversed. This is difficult to treat. Medications can be considered – there is a risk of falls or daytime grogginess with sedating medications however. Going outside into sunlight during the day helps maintain the brain's own day-night cycle.

Maintain good sleep hygiene. This is important for good sleep.

If the sleep-wake cycle is reversed and medications are risky or not helping, you may have to adjust your routine around the new normal.

Sleep Hygiene

Are you having difficulty sleeping at night? If so, here are some helpful hints you may want to try in order to improve your chances of having a good night's sleep.

- Do not eat or drink for at least 2 hours before bedtime. Do not drink caffeinated beverages (coffee) after 4 pm. Do not smoke after 6 pm. Do not exercise (except for stretching) for at least 2 hours before bedtime.
- **Consciously relax** during the last couple of hours before bedtime. During this transition time participate in quiet calming activities such as reading a book, listening to quiet music, meditation, having a warm bath, sitting peacefully, or whatever else works for you. Avoid such things as heated discussions and disturbing TV in the last few hours before bed.
- Establish a **"get ready for bed routine"** that you carry out each night.
- Maintain a sleep-wake schedule. Try to keep the **same bedtime and wake time** every day.
- If possible, **avoid naps** during the day because they decrease the need for sleep at night. If you take naps, **keep them short** (less than an hour), perhaps in the mid afternoon to reduce stress and renew energy.
- If you have any fears connected to sleeping, **talk to a loved one** or therapist.
- When you go to bed, the room should be **quiet, dark** and at a **moderate to cool temperature**.
- Once in bed, find a really **comfortable position** and **breathe slowly and gently**. Lie still and feel the tension drain out of your muscles. Do not think about sleep. Enjoy the relaxation, and let your mind go clear. In this state, sleep should come automatically.

What about personality/behavior changes?

Hallucinations, delusions, paranoia, suspicion, wandering, pacing, repeatedly doing or saying the same thing are seen in some patients with dementia. They are called Behavioural and Psychological Symptoms of Dementia (BPSD). These are challenging for caregivers and medical care providers to manage and there may not be a good solution. If there is a risk to safety or if there is a lot of distress associated with some of these behaviours, we may consider medications called antipsychotics. They have their own risks. Most importantly

they can increase the risk of stroke and heart problems. We try to use the lowest dose possible for a limited time, but sometimes that is not realistic.

Repetitive behaviours, wandering, pacing, calling out do not typically respond to antipsychotics, although caregivers frequently ask for medications as these are distressing to caregivers.

Whenever possible, non-medication treatments are preferred. Understanding the nature of Alzheimer's disease is key to being able to learn how to cope with the caregiving challenges of dementia. Most often, behavioral issues are a form of communication. If the person with dementia cannot formulate the words or thoughts to tell the other person how they feel, that they feel scared, sad or angry, etc., the individual usually reacts with what we view as "negative behaviors", such as shouting, pacing, cursing, hitting, to name just a few. Learning to know what triggers these behaviors is important.

The following is a mnemonic to help figure out and respond to those triggers.

Please BREATHE

Please: The P is for PAIN
Pain should be the first source of a behavior to rule out. Pain is the more frequent cause of many behaviors. Even if the individual with Alzheimer's is not able to verbally acknowledge pain or discomfort, pay attention to their non-verbal facial and extremity cues. Using a visual pain level scale can be helpful too to help identify the level and location of the pain.

B: BORED
Do you have a daily structure? Does your loved one have a favorite activity or meaningful task they can still engage in? Is exercise a part of their day? Are you spending quality time interacting, and not just being in the same room with them? If no, then they are probably bored and expressing a desire to be engaged and purposeful.

R: RESTROOM
When is the last time he/she has gone to the toilet? Could he/she be discomforted? Constipated? Full bladder? Incontinent? This can be so upsetting to the person with dementia. Establishing a routine of specific times to go to the bathroom throughout the day will help reduce this source of behavior manifestations.

E: EXHAUSTED
Does your loved one need a break? While keeping your loved one occupied throughout the day is important, equally important is offering times of rest, wind down, or naps. Avoiding stimulants such as caffeine, candy, television, loud noise or high energy activities prior to rest or sleep are necessary.

A: ANXIOUS

The person with dementia is biologically experiencing a profound loss of their ability to negotiate new information and stimulus. They are experiencing so much loss in their life. How would you feel? Scared, anxious, fearful, needing support and reassurance? Be empathetic to the loss in their life, validate, and then offer ways to prevent or reduce the agitation caused by anxiety by creating a calm environment, removing stimuli, simplifying their world, to name a few tips.

T: THIRSTY

Persons with dementia should drink six to eight glasses of fluids each day – more if they have hard stools, just like the rest of us. If the individual refuses, or makes taking a drink difficult, try using visual cues to orient her to what you want out of her. She may have simply forgotten what to do next. If avoiding hydration is a behavior rooted in anxiety or paranoia, try simplifying the task. Instead of asking "Do you want a drink?" simply say, "It's time to drink."

H: HUNGRY

It seems that dementia patients always have eating issues, whether it's eating too much or too little. There usually isn't a happy medium. You must remember that appetite is controlled by the brain. Try leaving many healthy snacks around the house, so they can eat on the go. When setting the table, avoid plates that do not provide contrast. A person with Alzheimer's usually has visual/spatial problems which might translate into not being able to see the food on the plate, especially if the plate is white. Try using alternate, bold contrasting colors to distinguish the plate and cups from the table cloth or table. Additionally, check your loved one's mouth for sores and thrush, which can often go unnoticed or not vocalized as being painful or discomforting.

E: ENVIRONMENT

The environment is so often overlooked, and yet it plays a large role in behaviors. Is the area too hot, too cold, is it loud or too quiet, too much activity or not enough visitors, is the room cluttered or busy? Pay attention to the surroundings. Again, using picture cues to help identify possible environmental triggers can be a tremendous tool.

After you have identified and treated the source of the behavior, redirecting or changing the focus into a more calming and pleasing activity or conversation will be the next step. You, as the caregiver, should be able to identify what best calms your loved one.

The key is to put yourself in the shoes of your loved one with dementia. Their altered behavior or agitation could be their way of trying to understand their confusing world.

Sometimes, as the dementia progresses, the behaviours and distress seem to get better on their own. In a subset of patients, that does not occur. In frontotemporal dementia (a rarer form of dementia) or damage, personality changes can become more prominent over time.

My loved one has worsening dementia. When is it time to consider long term care?

Long term care is generally suggested at two points:

- Your loved one needs constant supervision – you cannot leave them alone
- Your loved one needs more hands-on care than you and other providers can give them at home/in a retirement home

Once you are considering placement, the patient must be properly assessed and deemed eligible for long term care. The Ontario Health at Home Coordinator carries out the long-term care assessment. They may use the medical record to give them information to help with their assessment.

If you are not connected to Ontario Health at Home, ask your doctor/provider for a referral. (ph: 1-888-447-4468; www. ontariohealthathome.ca)

Even if you're not at the point where you cannot care for your loved one, if you can foresee this occurring in the near future, it doesn't hurt to ask for an assessment. For guidance in this area please talk to our team Social Worker.

Power of Attorney (POA)

How do I know if I/my loved one can make decisions about finances, personal care, or power of attorney?

We do not determine the capacity for these decisions in our program. You can contact specially trained capacity assessors for this. (www.ontario.ca/page/list-capacity-assessors.ca) Also refer to the back of this resource package for local service providers.

We recommend speaking to your loved ones as soon as possible after your diagnosis to let your wishes be known and complete care planning paperwork (wills, advanced care directives, powers of attorney) if not completed already. (www.ontario.ca/page/make-power-attorney)

What is a Power of Attorney?

A Power of Attorney is a legal document that gives someone else the power to act on your behalf. This person is called your "attorney". In Canada the word "attorney" usually does not mean lawyer, as it does in the USA.

You can give someone a Power of Attorney for Personal Care if you want them to make personal care decisions on your behalf if you become mentally incapable of making them yourself. This is sometimes called a"personal power of attorney".

What is the difference between a Power of Attorney for Personal Care and a Power of Attorney for Property?

Continuing Power of Attorney for Property or a General Power of Attorney for Property gives your attorney the power to make decisions about your finances, home, and possessions. A Power of Attorney for Personal Care deals only with personal care decisions.

You can name the same person as your attorney for both property and personal care, or you can name different people.

Who decides that I am mentally incapable of making personal care decisions?

It depends on the situation. In most cases, your attorney would decide this unless you name someone else in your Power of Attorney to "confirm" that you are mentally incapable.

If you do name someone else, your attorney cannot start making personal care decisions for you until that other person confirms that you are incapable of making decisions. If your attorney thinks you might be mentally incapable, they must arrange for that person to assess you and confirm your incapacity.

Who can I name to confirm that I am mentally incapable?

You can name a certain individual, such as your family doctor, another health professional, or even a personal friend. Or you can say it must be a certain type of professional, such as a social worker, psychologist, or nurse.

You can also state that you would like your mental incapacity confirmed without naming an individual or profession. If you do this, it will be confirmed by a "capacity assessor". This is someone trained and approved to determine mental incapacity.

Please visit steps to justice for legal information:
https://stepstojustice.ca/

Please visit the consent and capacity board for more information:
http://www.ccboard.on.ca/scripts/english/index.asp

What can I/my loved ones expect at the late stages?

At the severe stage, help is needed for nearly every task. People become frailer and their immune system is not very good at fighting off infections. Pneumonia may occur more frequently due to difficulty swallowing (the food "goes down the wrong way" into the lungs, and there may be no sign of a problem until an infection occurs). Hip fractures may occur when frail people fall down, especially as they do not remember how to walk safely. Dementia also causes poor balance in the later stages. These conditions may lead to one's passing away.

It is common for people not to want to eat or drink much at the late stages. This can be difficult for loved ones to watch, but inserting tubes for artificial nutrition in advanced dementia is not recommended as it doesn't increase the length of life but does increase discomfort. It still carries a risk of pneumonia from reflux of food. The tube may also be pulled out by a confused patient. The Canadian and American Geriatrics Society advise against feeding tubes in advanced dementia. Careful hand feeding is recommended for quality of life.

Delirium

Delirium is a sudden change in the way a person thinks and acts. It causes confusion and changes in behavior. Delirium can last a few hours, days or over several weeks. Symptoms can come and go.

What causes delirium?

- Infection, such as UTI
- Medication side effects or not taking as prescribed
- Worsening of a chronic illness
- Dehydration
- Malnutrition
- Constipation or diarrhea
- Pain
- Alcohol intoxication or withdrawal
- Surgery
- Injury
- Recent move or hospital stay
- Grief and/or stress

What increases the risk of delirium?

- Advanced age
- Had delirium in the past
- Has dementia
- Problems with seeing or hearing

- Taking more than 5 medications

Signs of delirium

- Confusion, not making sense
- Restlessness, upset
- Slurring their speech
- Seem annoyed, bothered and/or worried
- Paranoid
- Seeing or hearing imaginary thing
- Having trouble staying awake
- Mixing up days and nights
- Forgetfulness
- Having trouble focusing
- Not knowing where they are

Treatment for delirium

The most effective way to treat delirium is to treat the underlying cause. This usually means ordering blood tests, x-rays, EKG's, brain imaging, like, CT, MRI and asking questions about medical history and health. There is no medication that can treat delirium itself. The healthcare provider can treat what is causing the delirium or certain symptoms.

How to help a person with delirium

- Promote regular day and night schedule. Help them to stay awake during the day by letting sunlight in. At night, reduce noise, close curtains and turn off lights.
- Reduce noise and distractions.
- Make sure they are comfortable.
- Encourage them to get out of bed and move around, when safe to do so.
- Help them to eat and drink.
- Encourage the use of glasses and hearing aids.
- Promote mental stimulation, like reading about current events, doing puzzles and games.
- Remind them date and time of day, using a calendar/clock.
- Keep conversations simple, one topic at a time. Avoid asking too many questions.
- Give them time to respond.
- Use a calm and soothing voice.
- Do not argue or try to correct them. Acknowledge their feelings and reassure them.

Recovering

Delirium can last from hours to sometimes months. When the underlying medical issue is found and treated, the delirium can go away. Some people still have delirium symptoms months after the cause was treated. Some people do much better when they go home. Continue to support the person at home with the same strategies listed and follow up with the persons' primary care physician.

Further information on delirium can be found:

https://www.mskcc.org/cancer-care/patient-education/delirium

https://ccsmh.ca/areas-of-focus/delirium

This is a lot to cope with. Where do I get help?

If you or your loved one require support in coping with life after diagnosis you can request a referral to our team Social Worker. The Social Worker will help you learn ways to manage behavior changes, get set up with community supports, and develop positive coping strategies to avoid/lessen caregiver burnout.

Due to our services being short term, you are also encouraged to contact the following for ongoing support:

- The *Alzheimer's Society* can help you and your family through the entire course. https://alzheimer.ca/windsoressex/ or (519) 974-2220
- Your family physician/provider should be able to assist you with some questions. They can start or adjust medications for dementia, mood, or behaviours.
- The *Erie St Clair Healthline* lists most health services available locally. https://www.eriestclairhealthline.ca/
- *Alz Live* is a website that provides caregivers with input on others experiences and articles providing information from health-care contributors and journalists. For more information visit: https://alzlive.com/
- *Trillium Health Partners* provides persons with dementia and their caregivers with activities to promote memory and thinking. More information is provided on: https://www.thp.ca/patientsupport/caregiver-resources/Practical-Skills/Pages/Activities-for-seniors-to-help-memory-cognition.aspx
- McMaster Optimal Aging Portal is a source for trustworthy, evidence-based healthy aging information. www.mcmasteroptimalaging.org

Local Community Resources

Government covered support for personal care (i.e., showering, toileting etc.)

The first step in implementing in home care for your loved one is getting a referral to *Ontario Health at Home* (also known as CCAC, LHIN, or HCC). This can be done by your family doctor, the GAP team, or another medical professional. You can also contact Ontario Health at Home directly for a self-referral.

Contact: http://healthcareathome.ca/eriestclair/en or 1-888-447-4468

Private Paid Supports for personal care and respite (i.e., showering, toileting, companionship, house cleaning etc.)

When your loved one requires more care than is offered by Ontario Health at Home, the following agencies are a great avenue to increase support and keep your loved one in their home.

Agency	Website	Contact #
Amy's Helping Hands	https://www.amyshelpinghands.ca/	519-915-4370
Bayshore	https://www.bayshore.ca/	519-973-5411
CarePartners	www.carepartners.ca	1-855-245-1154
Comfort Keepers	www.comfortkeepers.ca	519-946-1001
Home Instead	www.homeinstead.ca	519-739-1500
iAID	www.iaidcare.com	519-997-2728
Nurse Next Door	https://www.nursenextdoor.com/locations/windsor-on/	1-866-318-7932
ParaMed Home Health Care	www.paramed.com	519-972-7760
Saint Elizabeth Health Care	www.sehc.com	519-972-3895
Victorian Order of Nurses (VON)	www.voneriestclair.ca	519-254-4866
The Noble Oak	www.thenobleoak.care	226-250-1179

***Please speak to the team Social Worker for more information on local resources.**

Capacity Assessors Windsor-Essex

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- **Dementia**
- **Intellectual Disabilities**
- **Other Neurological Disorders**
- **Psychiatric Disabilities**
- **English**
- **French**

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- **English**

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- **English**
- **Hindi**
- **Punjabi**
- **Urdu**

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- **Dementia**
- **Intellectual Disabilities**
- **Other Neurological Disorders**
- **Psychiatric Disabilities**
- **English**

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