Neurocognitive disorders.

Brochure for a **person living with a cognitive impairment** and **their caregiver(s)**

PLAN ALZHEIMER
RÉGION OUTAOUAIS

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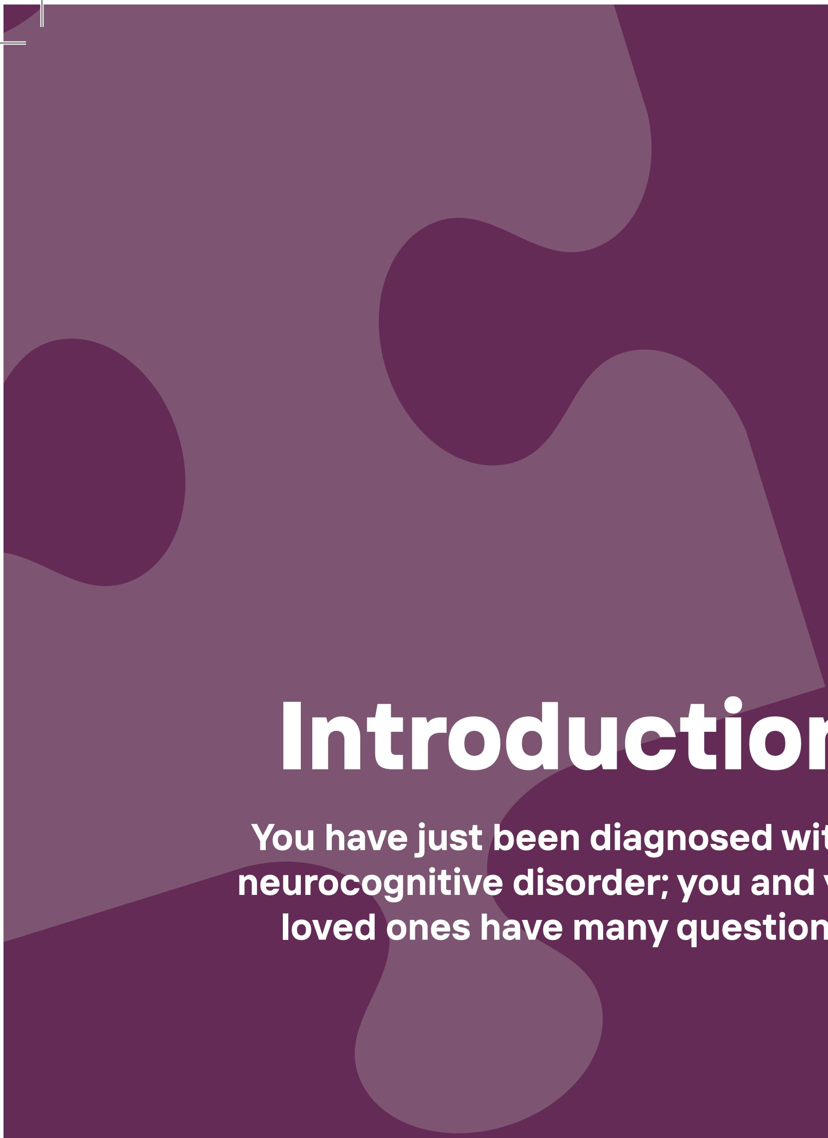

Introduction

You have just been diagnosed with a neurocognitive disorder; you and your loved ones have many questions.

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This brochure is designed to provide people with neurocognitive disorders and their loved ones with general information to navigate this challenging stage of life as easily as possible.

We have simplified the information as much as possible to make it accessible to all. Each person is unique and will react differently.

Your healthcare team—doctors, nurses, and social workers—are always available to answer your questions. Do not hesitate to ask them.

For the purposes of this document, we will call the individual caring for the person with a neurocognitive disorder the “**CAREGIVER**”

For more detailed information
« Devenir proche aidant. Maladie d’Alzheimer et autres troubles cognitifs » de Dre Marie-Jeanne Kergoat, M.D., Dre Judith Latour, M.D., Karine Thorn, inf., M. Sc.

CHAPTER 1

Neurocognitive Disorders

DEFINITION

Definition of mild neurocognitive disorders

Mild cognitive disorders are halfway between healthy cognitive aging and advanced neurocognitive disorders (formerly called dementia).

Mild neurocognitive disorders affect memory, language, orientation, planning and reasoning.

But, unlike advanced neurocognitive disorders (dementia), these changes do not affect the daily lives of people with the disorder, who can still go about their business independently.

It should be noted that depression can cause subjective memory problems that will disappear with appropriate treatment.

Neurocognitive disorders are sometimes the result of normal aging.

Here are some warning signs:

- Memory loss affecting common/routine skills;
- Difficulty performing familiar tasks;
- Verbal expression problems;
- Disorientation in time, space and recognizing people;
- Impaired judgement;
- Difficulties with abstract notions;
- Losing objects;
- Changes in mood or behaviour;
- Personality changes;
- Loss of interest.

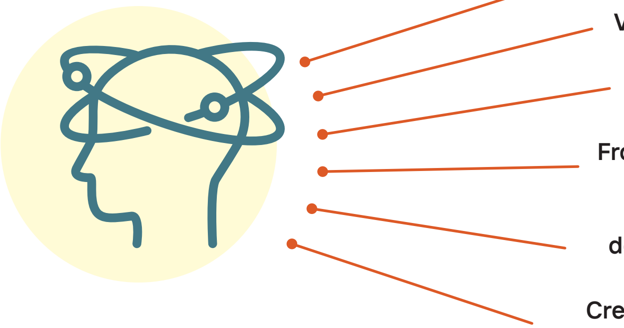
> *These changes do not affect the daily lives of people with the disorder*

DEFINITION

Advanced neurocognitive disorders

Advanced neurocognitive disorders (ANCD) are part of a large family that includes several diseases that affect cognitive functions, including memory, language, higher cognitive functions, perceptual processing (visual and auditory recognition), orientation and praxis (coordination of movements).

Here are the different types of advanced neurocognitive disorders:



- **Alzheimer** Type
- **Vascular** Type
- **Mixed** Type
- **Fronto-Temporal**
- **Lewy body dementia** Type
- **Creutzfeldt-Jakob**, **Parkinson**, **Pick & Korsakoff** Type

What happens in the brain when neurocognitive disorders take hold?

Normally, the brain sends messages and instructions to all parts of the body through an extraordinarily complex network.

Messages are transmitted from cell to cell by neurotransmitters. In the case of Alzheimer's disease, this neurotransmitter is called ACETYLCHOLINE.

DEFINITION

Alzheimer-type advanced neurocognitive disorders

Alzheimer's is the most well-known and most common (43% of ANCD) neurocognitive disorder. It is caused by a gradual loss of connections between neurons due to a decrease in acetylcholine and an abnormal accumulation of protein in the brain. Neurons die and disappear, bringing about a change in the structure of the brain. The latter shrinks, which causes damage to the surrounding regions, affecting memory, thinking and planning.

This shrinking that takes place in the hippocampus, which plays an essential role in memory, results in a gradual and irreversible deterioration of cognitive function.

The brain loses its ability to function normally, and the person becomes unable to go about their daily business as before.

Cognitive functions, other than memory, that are affected include language, higher cognitive functions, perceptual processing/ gnosis (visual and auditory recognition), orientation and praxis (coordination of movements).

Here are some symptoms:

- Change in mood, getting angry for no reason, crying;
- Repeating things often and asking the same question(s);
- Forgetting the names of relatives, even your spouse;
- Forgetting what you did that day;
- Forgetting where you put objects, finding them in strange places;
- Getting lost;
- Social withdrawal.

At the outset of the disease, the person can go about their daily activities with little supervision (depending on how fast the disease progresses). As the disease advances, supervision and assistance will be required during activities of daily living.

The more the disease progresses, the more constant help will be needed.

Functional impact is the most important criterion.

The person can no longer do what they did before.

Possibility of medication

After undergoing some laboratory and cognitive tests, as well as a review of their pharmacological record, the person will have a meeting with their doctor to be given the diagnosis. Following the discussion with the doctor, possible treatment may be suggested, depending on the person's condition:

Possible cholinesterase inhibitors (ChEIs):

- Aricept (donepezil);
- Exelon (rivastigmine);
- Reminyl (galantamine);
- Ebixa (memantine).

Of course, medication can cause unwanted side effects, but your nurse can help you manage these symptoms.

Always keep in mind that medication can delay the progression of the disease but will not cure it.

> *Always keep in mind that medication can delay the progression of the disease but will not cure it*

The response to treatment varies from person to person, and medication is effective when it results in:

- An improvement/stabilization in cognition (memory, language, orientation);
- An improvement/stabilization in functional capacity (ability to perform activities of daily living);
- A slowdown in the deterioration.

How long should the medication be taken?

For as long as the person is functional. Depending what stage the person is at, they could regress if they stop taking the medication. There may also be no change. The doctor will help you with this decision.

Who will take care of the follow-up

The case worker at your family medicine group (GMF), the nurse, or the social worker will be the person who administers the annual cognitive tests to monitor the progress of the disease and who makes sure your medication is covered by the RAMQ (if you do not have private insurance). You will meet with your doctor annually or as required. Your case worker is always there to help you or to refer you to the right place as needed.

Non-medication treatments

These treatments are complementary to medication.

They include: music therapy, animal therapy, light therapy, physiotherapy, walking, and group or individual stimulation therapy.

They aim to:

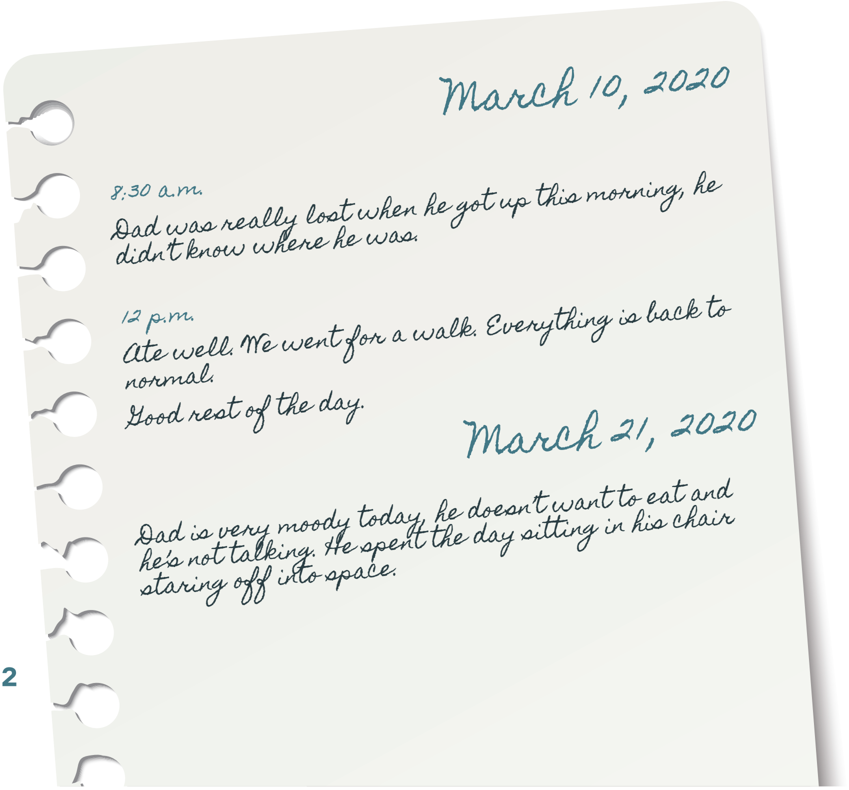
- Improve and/or maintain cognitive functions;
- Helping with mood and behavioral disorders;
- Reduce the stress related to the disease;
- Preserve functional autonomy for as long as possible (washing, dressing, eating, using the toilet).

Where to find places that offer non-medication treatments?

- Organizations such as the Alzheimer Society and community organizations in your area.
- Talk to your case worker at your family medicine group for information about available services in your area.

Why keep a journal

Writing down the things that happen every day or every week allows you to track the progress of the disease and helps the doctor monitor your response to treatment.



March 10, 2020

8:30 a.m.

Dad was really lost when he got up this morning, he didn't know where he was.

12 p.m.

Ate well. We went for a walk. Everything is back to normal.

Good rest of the day.

March 21, 2020

Dad is very moody today, he doesn't want to eat and he's not talking. He spent the day sitting in his chair staring off into space.

DEFINITION

Vascular advanced neurocognitive disorders

These are cognitive and functional losses related to damage to the cerebral vascular network, i.e., damage to the vessels that circulate blood in the brain.

- The cause is due to one or more stroke events.
- The severity is due to the extent of the damage.
- Risk factors: diabetes, high blood pressure.
- Sudden onset.
- Varies depending on the area of the brain affected.
- Can be reversible (the person can recover from the loss(es)).

Here are some symptoms :

- Emotional lability (laughing, crying for no reason);
- Personality changes;
- Unexplained abnormal gait;
- Difficulty retaining new information;
- Difficulty recalling information;
- Trouble recognizing familiar objects and people;
- Balance disorder (tingling, falls);
- Difficulty pronouncing words, slow speech.

> A vascular advanced neurocognitive disorders is rarely a solo condition; it's almost always accompanied by Alzheimer's disease

DEFINITION

Mixed advanced neurocognitive disorders

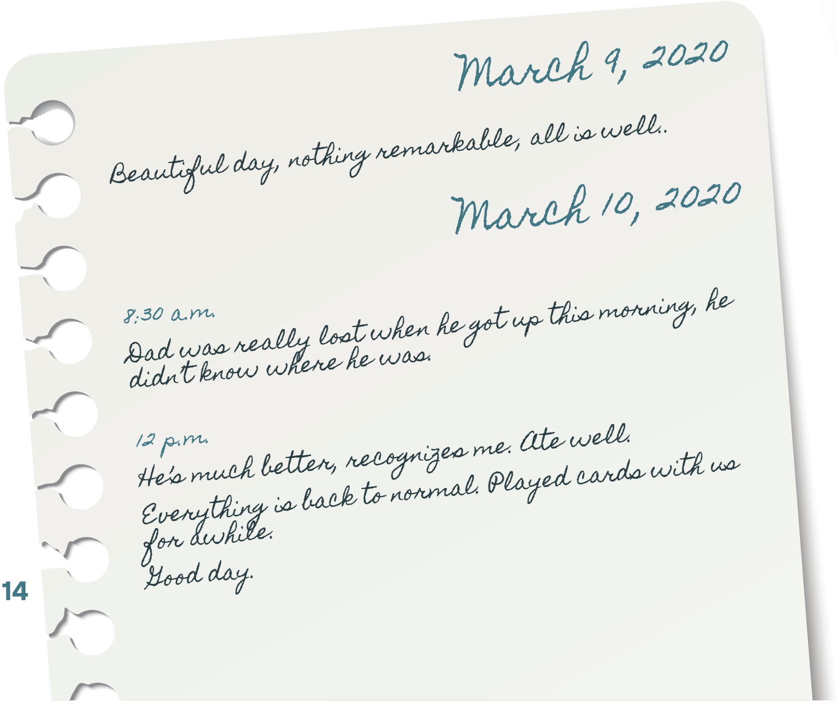
As its name suggests, a mixed advanced neurocognitive disorder is characterized by some symptoms resembling those of Alzheimer's disease and some resembling those of a vascular disorder.

Medication

Your doctor will talk to you about whether medication could be beneficial.

Why keep a journal?

Writing down the things that happen every day or every week allows you to track the progress of the disease and helps the doctor monitor your response to treatment.



March 9, 2020

Beautiful day, nothing remarkable, all is well.

March 10, 2020

8:30 a.m.
Dad was really lost when he got up this morning, he didn't know where he was.

12 p.m.
He's much better, recognizes me. Ate well.
Everything is back to normal. Played cards with us for awhile.
Good day.

Who will take care of the follow-up

As with all neurocognitive disorders, the case worker at your family medicine group (GMF), the nurse, or the social worker will be the person who administers the annual cognitive tests to monitor the progress of the disease and who makes sure your medication is covered by the RAMQ (if you do not have private insurance). You will meet with your doctor annually or as required. Your case worker is always there to help you or to refer you to the right place as needed.

DEFINITION

Frontotemporal advanced neurocognitive disorders

- A frontotemporal neurocognitive disorder is characterized by the gradual development of a change in behaviour and personality and/or a language deficit;
- Unlike Alzheimer’s disease, memory disorders only become apparent late in their development;
- It is an insidious disease that evolves progressively (approximately 10 years);
- It sets in at an early age (50 to 70 years old);
- It is characterized by a premature loss of social awareness, a loss of respect for oneself and others, and a change in personality.

Here are some symptoms :

- Mental rigidity (inability to adapt to change);
- Repetitive and stereotypic movements;
- Sadness, indifference, apathy;
- Change in social behaviour (no filter);
- Neglect for personal hygiene and appearance;
- Depression, anxiety;
- Impulsiveness;
- Mostly intact memory;
- Possible incontinence.

N.B. Symptoms will vary depending on the location of the brain damage.

Medication

Your doctor will talk to you about whether medication could be beneficial.

Who will take care of the follow-up

As with all neurocognitive disorders, the case worker at your family medicine group (GMF), the nurse, or the social worker will be the person who administers the annual cognitive tests to monitor the progress of the disease and who makes sure your medication is covered by the RAMQ (if you do not have private insurance). You will meet with your doctor annually or as required. Your case worker is always there to help you or to refer you to the right place as needed.

Why keep a Journal

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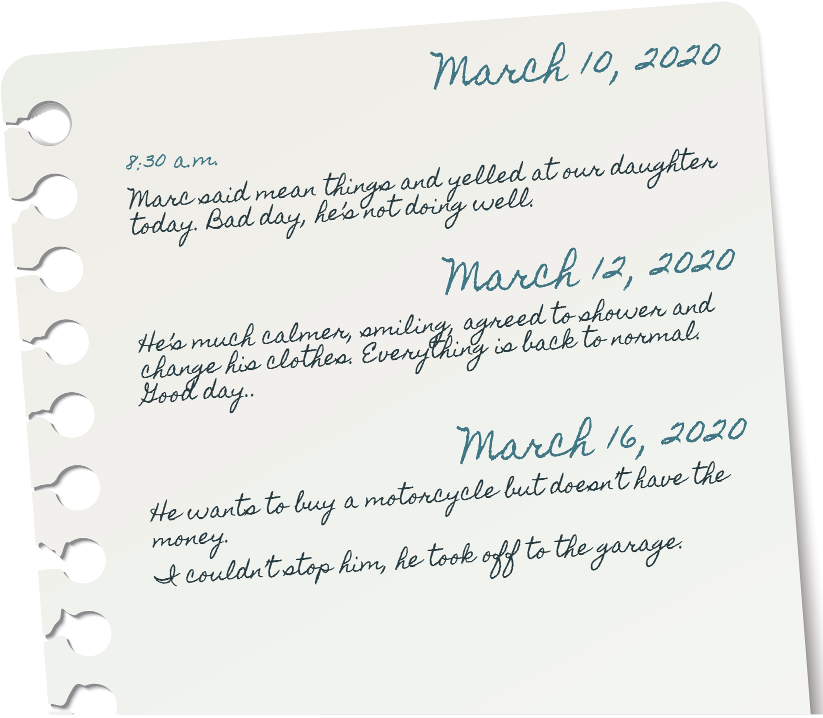

March 10, 2020

8:30 a.m.

Marc said mean things and yelled at our daughter today. Bad day, he's not doing well.

March 12, 2020

He's much calmer, smiling, agreed to shower and change his clothes. Everything is back to normal. Good day..

March 16, 2020

He wants to buy a motorcycle but doesn't have the money.
I couldn't stop him, he took off to the garage.

DEFINITION

Lewy body dementia

- Like Alzheimer's, Lewy body dementia is a degenerative disease. It is associated with abnormal deposits of a protein called alpha-synuclein in the brain cells, affecting the transmission of signals.
- The disease mainly affects the parts of the brain related to cognitive functions and movement.
- It is accompanied by a gradual cognitive decline serious enough to impact the person's activities of daily living and social life.
- It progresses in stages, with symptoms that fluctuate during the day.
- It is typically seen after age 55.
- It is also accompanied by early changes in attention, visuospatial abilities, and higher cognitive functions.

Here are some symptoms :

- REM sleep disorders (an important stage of sleep which allows you to recover mentally);
- Recurrent and highly detailed visual hallucinations;
- Ataxia (inability to sit still, need to move);
- Tremors;
- Involuntary muscle contractions;
- Memory loss that worsens as the disease progresses;
- Intense delusions (theft, jealousy, extramarital affairs);
- Risk of falls;
- Depression, mistrust, irritability;
- Difficulty thinking logically;
- Difficulty solving problems and completing multiple tasks simultaneously.

Medication

Your doctor will talk to you about whether medication could be beneficial. Symptomatic treatment is the preferred route.

Who will take care of the follow-up

As with all neurocognitive disorders, the case worker at your family medicine group (GMF), the nurse, or the social worker will be the person who administers the annual cognitive tests to monitor the progress of the disease and who makes sure your medication is covered by the RAMQ (if you do not have private insurance). You will meet with your doctor annually or as required. Your case worker is always there to help you or to refer you to the right place as needed.

Why keep a Journal

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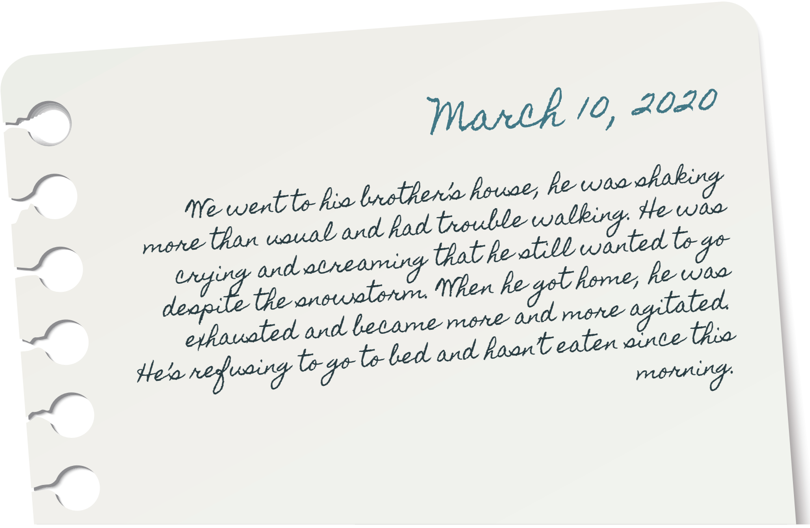


March 10, 2020

We went to his brother's house, he was shaking more than usual and had trouble walking. He was crying and screaming that he still wanted to go despite the snowstorm. When he got home, he was exhausted and became more and more agitated. He's refusing to go to bed and hasn't eaten since this morning.

DEFINITION

Creutzfeldt-Jacob disease, Huntington's disease, Parkinson's disease, Pick's disease, and Wernicke-Korsakoff syndrome

These neurocognitive disorders are seen more rarely. Your nurse is the best person to give you more information as needed.

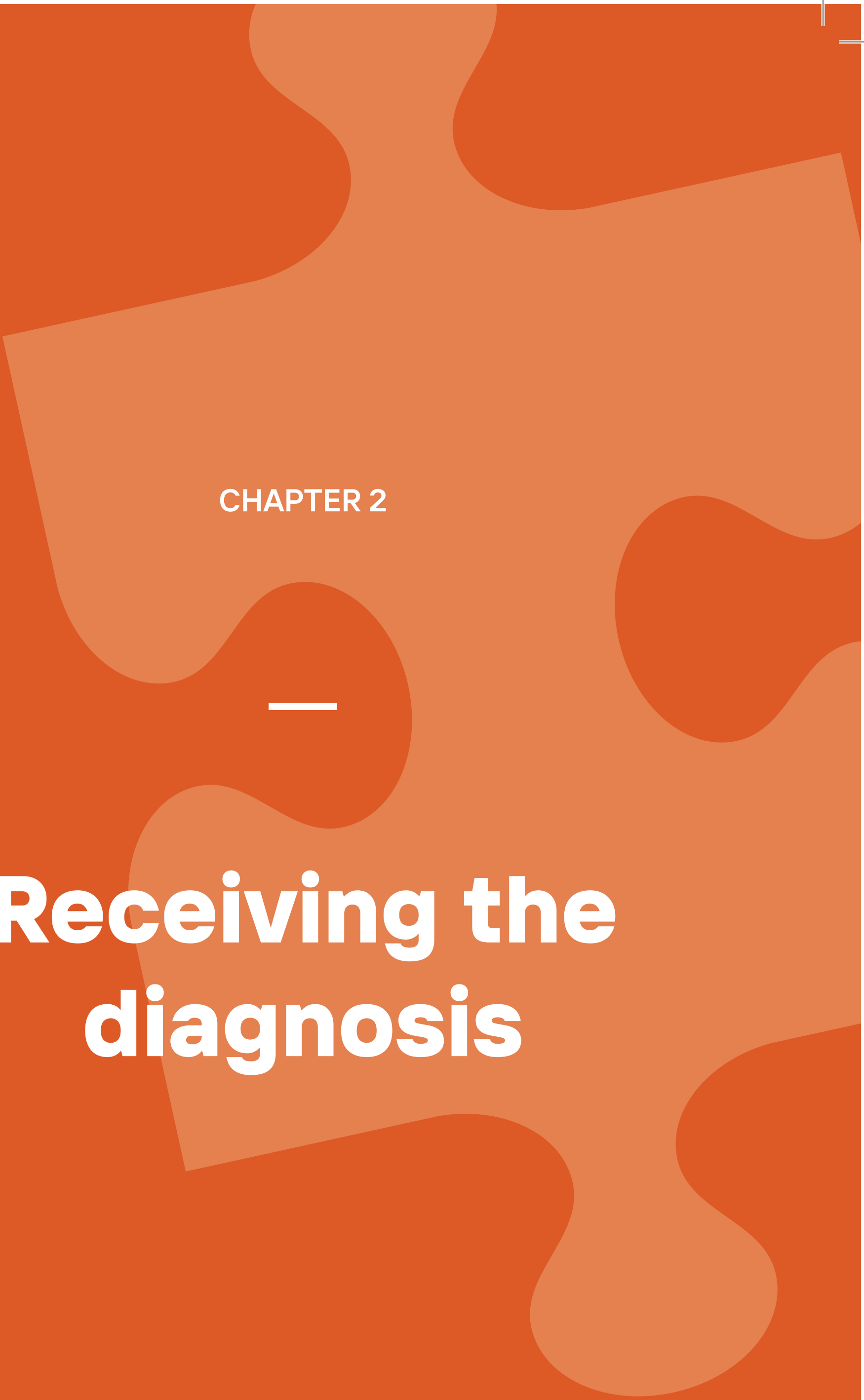
You will receive the same follow-up, no matter what type of neurocognitive disorder you may have.

The staff at your family medicine group are there to support you or to refer you to the right place, throughout your disease.

Do not hesitate to contact them.

CHAPTER 2

Receiving the diagnosis



Neurocognitive disorders most often affect people age 65 and over, although they are now starting to appear in people at increasingly younger ages. They do not discriminate in terms of gender, race, profession, or level of education.

You've recently noticed some signs and symptoms—changes in your memory and behaviour. Your doctor has you take some memory tests (MMSE, MoCA, GDS). You undergo a medical examination with lab tests and even brain scans.

Your suspicions are confirmed: You are diagnosed with a neurocognitive disorder.

Many people diagnosed with a neurocognitive disorder go on to lead active, fulfilling lives for many years. Healthy lifestyle choices and certain medications can help slow the progression of the disease, but cannot stop it.

As the disease progresses, it will be important for the person with the disease to adjust their activities. The caregiver will also have to adjust their expectations and ask for help as needed, to make sure they maintain a good quality of life for themselves and the person with the disease.

Many organizations can provide help and support during these times, whether for the person with the disease or their caregivers.

Community organizations in your area are listed at the end of this brochure.

It is essential to inform the person with the disease of the diagnosis, however painful this may be.

In the early stage, the person with the illness will understand the consequences of the disease.

The doctor will adjust the announcement of the diagnosis based on the patient's condition and the family's requests. Of course, reactions may vary.

It may also take a few months after the announcement for the diagnosis to sink in; give the person time to digest the news.

The announcement of the diagnosis allows the person with the disease to:

- Express their concerns;
- Decide what they want to do;
- Make plans for their future.

What to do when faced with denial

The person with the disease may not want to accept the illness. **There is no point in arguing**. There is no need to remind the person of their memory problems or to point out their mistakes.

It's often easier to help them with whatever they need at each stage without any confrontations.

At the end of the day, you'll arrive at the same results with fewer hassles:

- Offer your **support**;
- Seek help from the people who are **already involved**;
- Involve the support network, **become the caregiver**.

CHAPTER 3

Understanding the disease in order to better intervene

At the outset of the disease, memory problems can be isolated and can appear as difficulty finding objects in the house or forgetting new information.

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Subsequently, the oversights become increasingly important. The person will try to downplay their memory loss by inventing answers or giving vague responses. They may have trouble identifying objects. They may also have difficulty focusing their attention without becoming distracted. It will be hard for them to retain information or accomplish a routine task.

Learning difficulties even appear for simple acts such as learning how to work a new microwave or the TV, or how to manage their medication. However, old habits remain ingrained for a long time (signing their name, brushing their teeth, etc.). The person will have trouble finding their bearings outside their home, in unfamiliar places, and even in their own home.

Memory loss for older information occurs later on.

The person will want to talk less and less, and their sentences will become shorter and incomplete. They may ask the same questions repeatedly. They will have difficulty expressing their feelings or any pain they might experience, which often explains the aggression, anxiety, and agitation.

At the advanced stage, the person may stop talking and repeat the same word or words over and over.

Here are some tips that might help you:

How should I communicate with the person?

- Speak to them respectfully, say their name;
- Make sure they can see and hear well;
- Use short sentences, giving one instruction at a time;
- Offer two possible answers, e.g., do you prefer the pink dress or the yellow dress?
- Speak calmly to the person, make eye contact with them;
- Offer help, e.g., «Let me help you put on your coat»;
- Use non-verbal communication, e.g., pictures, your facial expression, gestures, touch, music;
- Reduce the stimuli around the person (noise, light, etc.)

How can I help the person get their bearings?

- Establish a routine;
- Indicate where objects are located, e.g., notes on the kitchen cabinets showing where the cups, pots and pans, etc., are kept;
- Place one or more calendars in view;
- Write down activities or appointments where the person can see them;
- Write down important phone numbers;
- Avoid rearranging things in the home;
- Avoid asking them what day/date it is; instead, repeat them often.

It is possible to communicate with a person living with a neuro-cognitive disorder at all stages of the disease.

Sometimes, you have to try several strategies before finding the one that works best.

Why does the person keep repeating themselves?

- Because a person with memory problems has trouble expressing their needs, they often struggle to find the right words. They will speak much less than before, even going so far as to isolate themselves;
- They may even invent new words to replace the ones they can't remember;
- They will have a hard time forming logical sentences;
- They may sometimes use profanity without realizing what it means.

What to do when they keep repeating the same words or questions?

Even though this can be very upsetting or irritating, there's no point in trying to reason, argue or get angry with the person.

- The best strategy is to create a diversion by focusing their attention on something else they like, e.g., a photo album, music, flowers, etc.;
- Moving to another room can also put a stop to the repetitive questions or words;
- Ask another caregiver to take over.

How should you react if they get angry or stubborn?

- A person living with a neurocognitive disorder needs to feel like they can trust you;
- It is important for you, and your physical and mental health, to adjust your expectations toward the person so as not to get frustrated;
- Since you are the person closest to them, you will be the target of their anger and frustration;
- Get the help you need (training is available from the Alzheimer Society) or speak to a social worker.

Always take the time to make sure their basic needs are met!

Activities of daily living

These are activities that are essential to meeting basic needs, such as eating, walking, dressing, and washing. During the course of the disease, the person will lose their ability to perform these activities on their own. You will need to adapt your support according to the stage of the illness; it will be important to respect the person's pace.

Tips and tricks for walking

- Encourage the person to walk regularly;
- Walk short distances, but often;
- Choose a pleasant spot that the person enjoys, if possible;
- Ensure there is good lighting;
- Remove obstacles (carpets, electrical wires, clutter, etc.);
- Offer your arm.

Tips and tricks for hygiene care

- At the outset of the disease, simply remind the person;
- The more the disease progresses, the more you will have to guide and help them;
- Encourage them to do as much as possible for themselves and finish up if necessary;
- If they refuse, postpone the task and reassure them;
- Give short explanations about what you want them to do;
- Give them as much privacy as possible;
- Adjust the room temperature to their preference;
- Give them a treat afterwards;
- Always encourage them;
- Go at their pace.

Tips and tricks with dressing

Starting at the moderate stage, the person will often have difficulty dressing themselves.

It is important to help them dress appropriately, as this is essential for their dignity.

- Take away all unnecessary clothing;
- Prefer clothes that are easy to put on;
- Encourage the person to choose their outfit;
- Help them if they can't do it alone, or do it for them;
- Lay the clothes out on the bed in the order they should be put on;
- Offer to help the person get dressed, as needed.

Stimulation

It is important to keep the person mentally and physically active for as long as possible.

Make sure they have activities they like in order to keep them interested: knitting, puzzles, word searches, music, painting, socializing, dance, etc.

Be creative and loving.

> *Always take the time to make sure their basic needs are met!*
>
> *In order to provide the best possible care, it's important to know what they were like before.*

CHAPTER 4

Behavioural and psychological symptoms of dementia (BPSD)

This represents an unmet need.

The person who is at an advanced stage of the disease cannot identify what is bothering them or causing pain/discomfort. Therefore, they may express it in a way that is sometimes disturbing to those around them, such as:

- Screaming, insults, cursing, repeating the same words;
- With or without aggression: wandering, accumulating objects, undressing, hitting, biting, throwing objects;
- Increased anxiety, depression that sets in;
- Delusions, hallucinations.

It's not always easy to find the cause. At the beginning of the disease, we ask the person with the disease and the family to fill out a short questionnaire that we call:

Biographical history

EMPLOYMENT:
nights at an aluminum factory

SLEEP:
with classical music and a nightlight.

HYGIENE:
showers every morning and likes the bathroom warm.

FOOD:
never eats breakfast, eats lunch and supper, hates fish, loves fruits and vegetables.

SOCIAL ACTIVITIES:
enjoys playing cards and having a beer with friends.

In order to provide the best possible care, it's important to know what they were like before.

The **"Biographical history"** provides details about the person's past life and habits.

Examples:

- Mr. X worked was a mailman. He liked to walk, so if this gentleman is sitting all day in an armchair, he'll probably try to get up and walk; that does not mean he's trying to run away;
- Mrs. X was a night nurse; she walks around the house at night—a clue as to how to structure our interventions;
- Mrs. X has always been afraid of the dark; the light in her room is turned off and she screams all night long.

The **"Biographical History"** is an indispensable tool for the professional or caregiver to have handy when the person or family cannot give us details about the person's previous life.

It helps us understand if a need is not being met.

This document is completed by the person and their family at the beginning of the illness, then added to the person's file as a reference in the event of BPSD. It can also be transferred if the person is placed in a residence, with the family's permission.

How can we help the person presenting with BPSD?

It is recommended to initially intervene with non-pharmacological approaches. If the BPSD do not represent a danger to the person themselves or to others, then we try to find the cause; we refer to the person's **"biographical history"** for clues about what's causing the problem, and we intervene accordingly.

It's not always easy to find a solution quickly, but it's important to take the time.

The case worker at your family medicine group is there to help. They know the person and their caregivers; a bond of trust has been established during the follow-up that allows them to intervene easier than a stranger. They will give the family advice on how to deal with the BPSD.

Once you have made use of the available resources, and if the BPSD are still present, your case worker has access to a specialized BPSD management team that can respond as required. The case worker will observe the person in their own environment to determine whether the approach is appropriate and will advise the caregiver. A non pharmacological approach is always preferred.

A pharmacological approach will be used in cases where there is a danger to the person or others, in an emergency or a case of severe psychological distress.

CHAPTER 5

Planning for the future

The stages of the disease

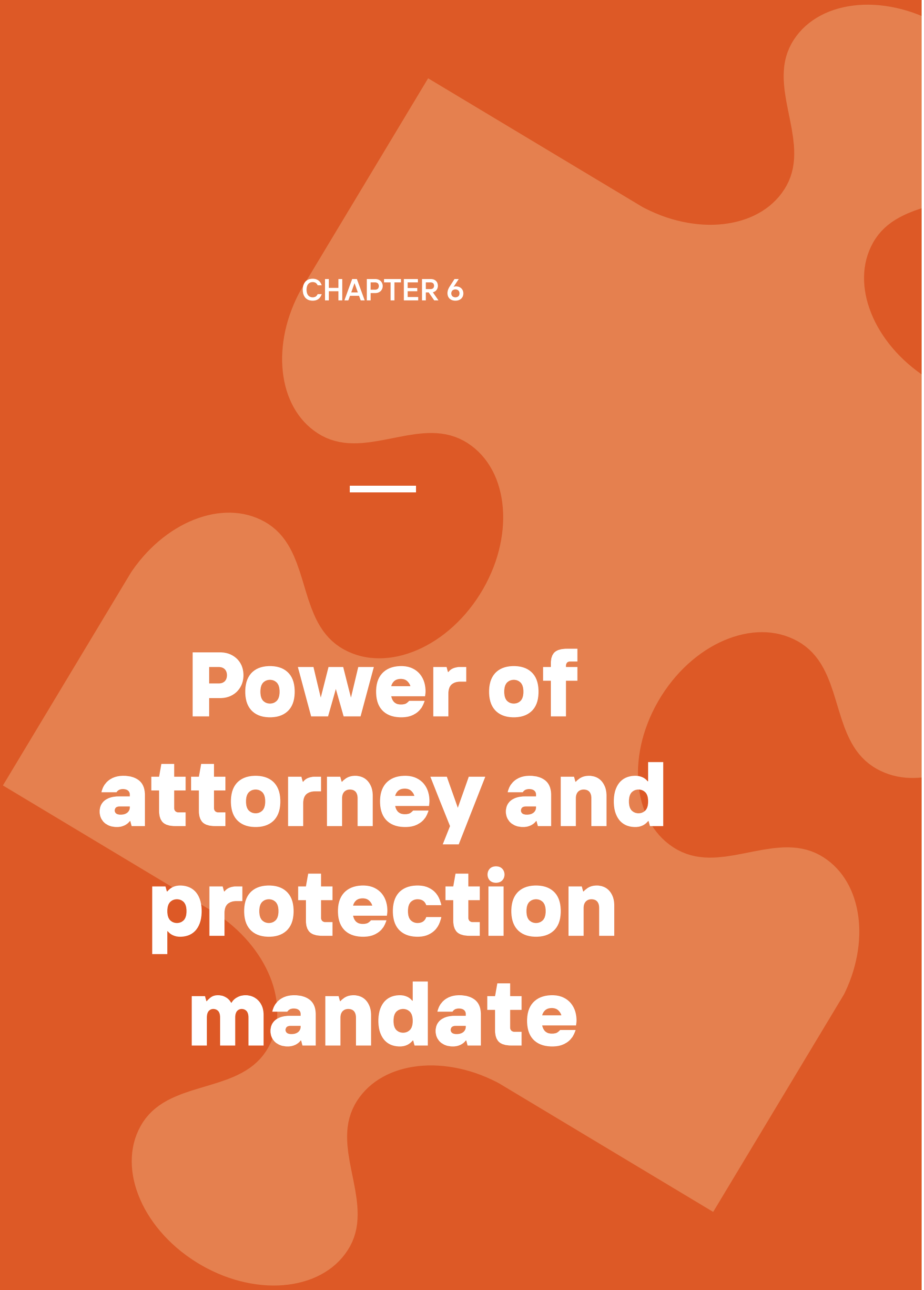
Advanced neurocognitive disorders progress differently from one person to another. The disease develops slowly, insidiously, and gradually. Remember that not all people with the condition necessarily have all the symptoms listed.

There are several stages according to the literature. To help us understand them, we have grouped them into three stages here.

MILD	MODERATE	ADVANCED
Short-term memory loss	Memory problems worsen	Knows their name, but forgets the names of loved ones
Asks the same question several times in the same week	Asks the same question several times a day	Experiences gaps in memories of their own past
Difficulty following a conversation	More and more difficulty following a conversation, struggling to find words	Often uses words that are incomprehensible, limited vocabulary
Difficulty concentrating, limited attention span	Decline in attention span	Attention is increasingly waning
Difficulty learning new things	Difficulty making decisions	Decisions are made by the caregiver
Difficulty doing two tasks at once	Difficulty accomplishing a task	Unable to complete a task
May become intermittently disoriented to time/space	Time/space disorientation more frequent	Can remember their past, but in an imprecise way

MILD	MODERATE	ADVANCED
Difficulty with abstract thinking	Complex tasks (planning a meal, a trip, etc.) increasingly difficult, sometimes impossible	Unable to do complex tasks (planning a meal, a trip, etc.)
Mild coordination problems (risk of falls)	Problems with coordination and/or movement, frequent falls	Increased problems with coordination and/or movement
Forgetfulness, activities of daily life are affected (budgeting, meal preparation, etc.)	Difficulty with routine tasks (shopping, cooking, finances); needs help	Constantly needs help with activities of daily living
Sometimes forgets to wash, use the toilet, needs reminders	Needs help bathing, using the toilet, getting dressed	Needs constant help using the toilet, bathing, eating, dressing
Anxiety, depression, apathy	Possible paranoia and hallucinations	Unaware of their surroundings (summer, winter, etc.)

N.B. Different levels of progression can be present in the stages mentioned above.



CHAPTER 6

Power of attorney and protection mandate

Warning

Laws are constantly changing. We suggest you visit the Éducaloi website (educaloi.qc.ca/en/web-guide/seniors/) for the information you need.

The information contained in this guide should not be considered legal advice; it is for information purposes only. **It is always a good idea to consult a lawyer or a notary.**

In the moderate and advanced stages of the disease, a person with am advanced neurocognitive disorder will no longer be able to make important decisions. In order to avoid family arguments, it is therefore important to make legal arrangements while the person is in full possession of their faculties.

What is the difference between a protection mandate and a power of attorney?

A power of attorney allows you to appoint one or more persons to act on your behalf, to manage your property only, and not in matters related to your person.

E.g., go to the bank, pay bills, pay rent, sell the house, etc., but when you are still able to do so.

The power of attorney ceases to be valid the moment you become incapable. At that point, only a protection mandate is effective.

A protection mandate allows you to designate one or more persons, in the event of your incapacity, to perform certain legal acts intended to protect your person and your property.

What is incapacity?

Incapacity is defined as a person's inability to take care of themselves or their property. There are varying degrees of incapacity: partial or total, temporary or permanent.

Two assessments are required to declare a person incapable:

1 **A medical assessment** by their attending physician, who will assess the person's health and ability to take care of themselves and their property. The assessment must conclude that the person is incapable and indicate whether the incapacity is total or partial.

The form is available on the Curateur public du Québec website.

2 **A psychosocial assessment** by a social worker, who will assess the person's psychosocial situation by analyzing, among other things, their lifestyle and family situation, and degree of autonomy for activities of daily living. The assessment must conclude that the person is incapable and indicate whether the incapacity is total or partial.

The form is available on the Curateur public du Québec website.

The notary will then be able to rule on the situation.

What if the person is incapable?

If the person has prepared a mandate, the agent will have to go to a notary or the court to have it approved (homologated).

If the person does not have a protection mandate, to some extent, the law often allows relatives of an incapable person to take care of their affairs. For example, a person who is married or in a civil union with a person who becomes incapable has the right to continue to assume basic family responsibilities on their behalf, e.g., paying bills (electricity, heating, rent), buying groceries, etc.

However, where the incapable person has significant assets or a greater need for protection, it may be necessary to institute a protective supervision regime. Any member of the incapable person's circles can ask for the institution of a protective supervision: advisor to the person of full age, tutorship or curatorship.

If no one in the incapable person's circles can or wants to take care of the incapable person, this responsibility falls to the Curateur public du Québec.

Homologation

Homologation is the process of obtaining a court judgment that makes the protection mandate "official." This judgment is needed to exercise the powers given to you in the mandate (managing bank accounts, choosing medical treatments, etc.) in the event the person becomes incapable.

Associated costs?

You need to meet with a notary or a lawyer to determine the costs. It all depends on the procedures and research that need to be done.

How long does it take?

It can take at least 6 months to gather all the necessary documents for the homologation procedure, after which the procedure itself takes about 2 to 3 months.

The most important thing is to ensure that the incapable person is well protected. It is not always necessary to have the protection mandate homologated.

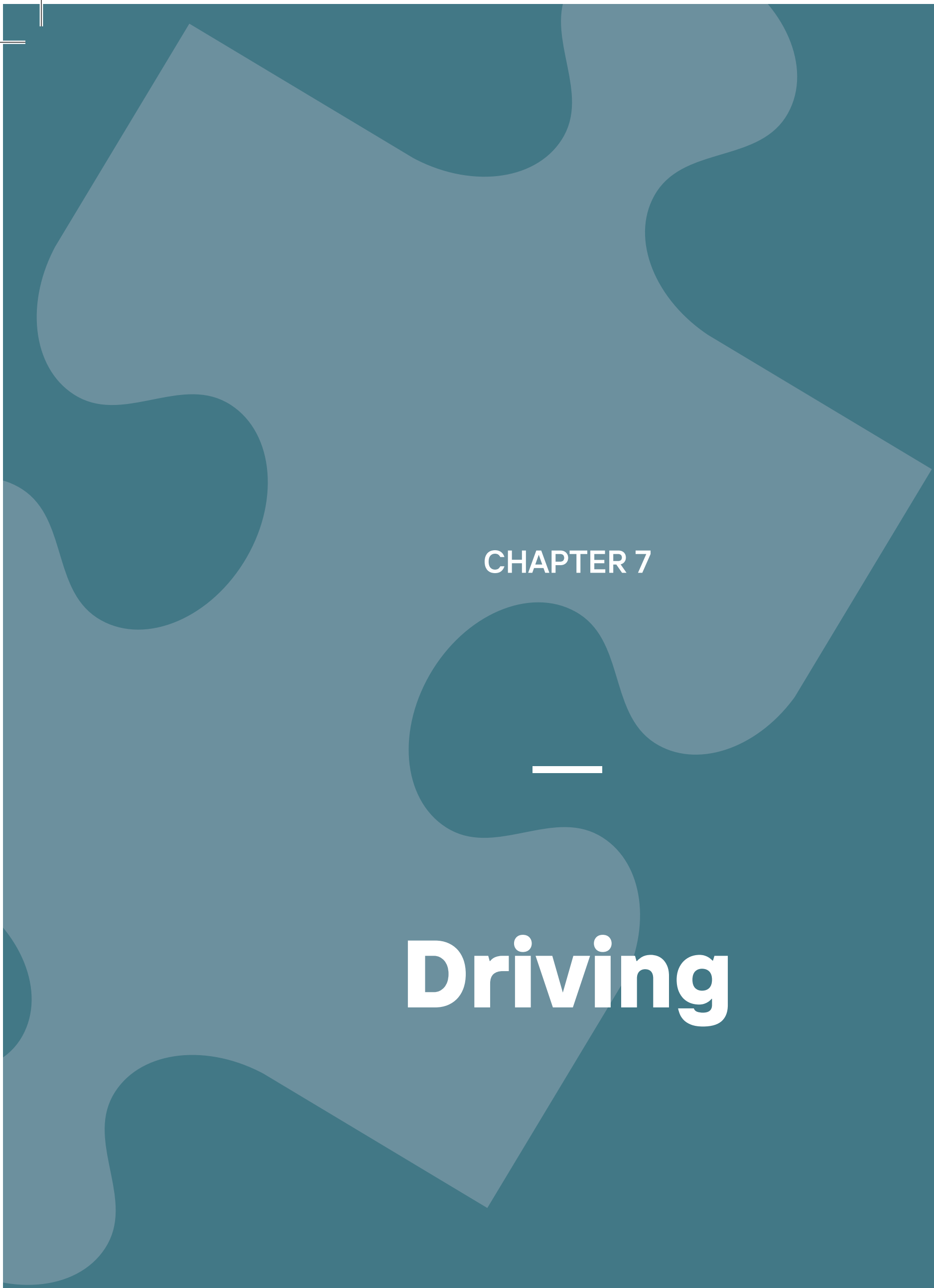
If there are clearly identified individuals who can make decisions on behalf of the person with an advanced neurocognitive disorder, and there is no disagreement between the relatives, it is not necessary to take legal steps, which are very expensive and time consuming.

For legal and financial matters, consult your family medicine group's case worker, who can refer you to the right places.

The information contained in this document is taken from ÉDUCALOI.

Phone service

1-800-NOTAIRE



CHAPTER 7

Driving

A diagnosis of advanced neurocognitive disorder does not automatically mean the person has to stop driving. But it's important to remember that driving involves many competencies and skills (memory, concentration, judgment, orientation, reaction time, etc.).

Statistics show that:

30% of people with NCD (neurocognitive disorder) drive;

40% of people with NCD have been involved in an accident;

80% of those cases will continue to drive;

80% of the latter will be involved in a second accident.

Sooner or later, as the disease progresses, the person with the disease will have to stop driving, which is why it's important to start discussions on this topic at the onset of the disease and to find alternatives.

The person's loved ones should be alert to any changes that may occur.

It is essential to start the discussion and identify strategies to support the person during the driving assessment process.

Questionnaire from the Société de l’assurance automobile du Québec

Even though you are healthy and have several years of driving experience, health or vision problems can develop with age.

You will receive a form to be filled out by various

- 6 months before your 75th birthday;
- 6 months before your 80th birthday;
- Every 2 years thereafter.

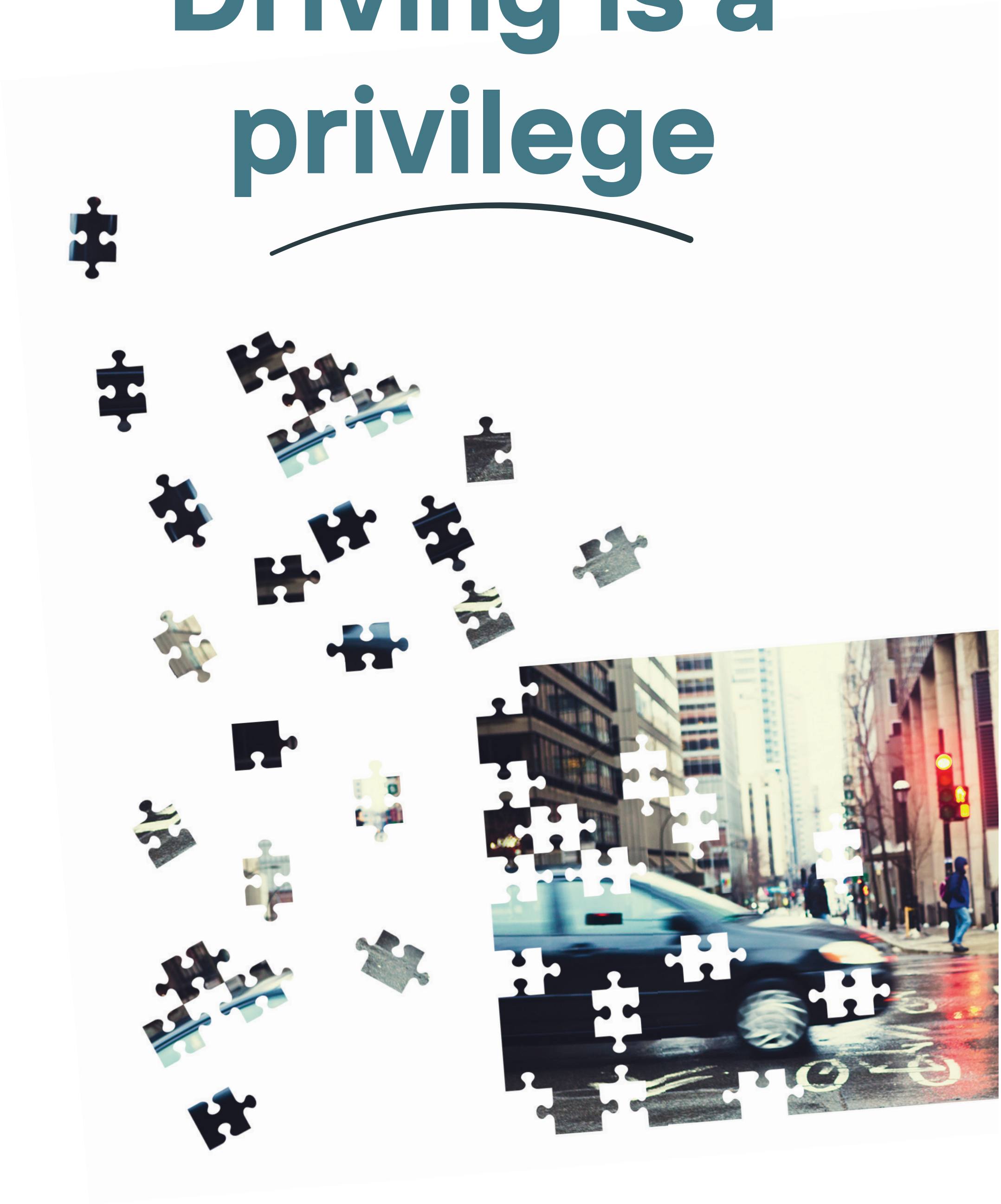
Some signs you may notice in the person with the disease:

- Driving too fast or too slowly;
- Violations of the Highway Safety Code, tickets;
- Difficulty estimating distances;
- No longer wanting to go out at night or when it’s raining or snowing;
- Getting lost on a familiar route;
- Dents/scratches on the car;
- Always blaming others;
- Impaired judgment.

Health professionals (doctors, nurses, occupational therapists, psychologists and optometrists) can report a person for dangerous driving or if they have reason to believe the person is a danger to themselves or others.

- The doctor does not rule on the ability to drive.
- The doctor does not revoke the driver’s license.
- It’s very important not to break the bond of trust with the person.
- **The SAAQ will revoke the driver’s license, if necessary.**

Driving is a privilege



CHAPTER 8

Home or change of living environment

Advanced neurocognitive disorders lead to many changes in the life of the person with the disease and those around them. Understanding the impact of the disease on daily life helps to prepare for it better. As soon as the diagnosis is announced, decisions need to be made to facilitate the process and avoid certain obstacles.

Home layout and security

The person affected can stay at home for as long as possible, provided ways are found to help them do so safely. (You can get advice from your family medicine group, an occupational therapist at your CLSC, or your local chapter of the Alzheimer Society).

Wandering

This is a common phenomenon that can happen. The person is simply trying to find a familiar place; they are not running away, because they do not know what they are doing. There are tools that will help you keep your person safe:

- The Alzheimer Society's Safe Return Program;
- Geolocation systems;
- Smart phones and watches;
- Alert services (Lifeline, etc.);
- Gadgets to secure the doors on your home.

The new responsibilities of caregivers

A person living with a neurocognitive disorder can stay at home for a long time with light supervision. However, there comes a point where the caregiver must spend more time there because of the increasing losses. The caregiver must often prepare meals, do household chores, take charge of hygiene care, provide a constant presence, and administer and supervise medication.

Often, the caregiver must take on this new role while continuing to do their regular work and take care of their own family. They have less and less time to take care of themselves. They may even have to quit their job, which can lead to financial problems. They may experience periods of discouragement, frustration, and physical and psychological exhaustion.

As a caregiver, it is important to recognize your limitations and needs, and to ask for help.

To avoid exhaustion, there are various organizations that can help you:

- Your local chapter of the Alzheimer Society offers home respite programs, day centres and support;
- Baluchon Alzheimer offers home respite care for 4 to 14 days, allowing you to take a short vacation;
- The CLSC offers different programs to help you;
- Community organizations in your area are there to help you (see page 52);
- Talk to your case worker at your family medicine group.

It’s very important that you **not wait until you are “at the end of your rope”** before asking for help.

Both the caregiver and the person with the disease will benefit.

Conclusion

Despite all the research underway around the world, neurocognitive disorders are extraordinarily complex diseases.

Neurocognitive disorders have a major impact on the quality of life of the person affected, and on that of those around them.

It’s important to try to focus on the things the person can still do, as opposed to what they can no longer manage, which will make the disease easier to face together.

The 11 “musts” of a caregiver for a person living with a neurocognitive disorder

- Avoid debating; **agree instead**;
- Avoid reasoning; **divert instead**;
- Avoid shaming; **distract instead**;
- Avoid preaching; **reassure instead**;
- Avoid reminiscing; **chat instead**;
- Avoid “I told you”; **repeat instead**;
- Avoid “you can’t”; **say “do what you can” instead**;
- Avoid giving orders; **ask instead**;
- Avoid belittling; **encourage and congratulate instead**;
- Avoid forcing; **reinforce instead**;
- Avoid interrupting; **be patient instead.**

Author unknown

11 musts

Community resources in your area

Société Alzheimer de l'Outaouais
440 Boulevard Maloney O,
Gatineau, QC J8P 6W2

Phone: 819-777-4232

Centre intégré de santé et des services sociaux (CISSS) de l'Outaouais

24/7
Phone: 811

L'Appui pour les proches aidants d'aînés Outaouais

92 Boulevard Saint-Raymond,
Gatineau, QC J8Y 1S7
Phone : +1 855-852-7784

Les Centres d'action bénévole de Gatineau

Hull
256a boul. Saint-Joseph, #201,
Gatineau, QC J8Y 3X8
Phone : 819-778-2900

Gatineau
42 avenue Gatineau,
Gatineau QC J8T 4J3

Phone : +1 819 568-0747

Aylmer
67 rue Principale,
Gatineau, QC J9H 3L4

Phone : 819-684-2242

Campus 3

Day workshop: day centre for clients with loss of autonomy and advanced neurocognitive disorders.

Phone : 819-663-3305

www.campus3.ca

Hébergevac

1 week's accommodation for people with intellectual disabilities, Parkinson's disease, or mild cognitive impairment

Phone : 819-457-2474

www.bit.ly/hebergevac

For additional resources, ask your family medicine group

References

TANGUAY, A. M.D. (2011). *Alzheimer et diagnostics différentiels,* 2nd edition: Éditions Nouvelles.

MSSS (2014). Protocole de soins-Protocole interdisciplinaire en première ligne: *Maladie Alzheimer et les maladies apparentées et les annexes* (PDF).

M. BOURQUE and P. VOYER (2013). "*La gestion des symptômes comportementaux et psychologiques de la démence,*" in P. Voyer (Ed.), Soins infirmiers aux aînés en perte d'autonomie, 2nd Edition, Saint-Laurent: Pearson ERPI.

Alzheimer Society of Canada
info@alzheimer.ca
Phone : 1-800-616-8816

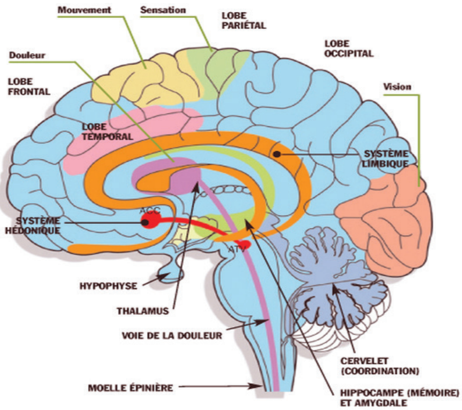
Éducaloi
www.educaloi.qc.ca

Find out if you are eligible for legal aid
Call the legal aid office closest to you.

Curateur public
www.curateur.gouv.qc.caPhone : 1-800-363-9020

To speak with a notary for free
Call the legal information help line
Phone : 1-800-NOTAIRE (1-800-668-2473)

Glossary

Akathisia	Inability to sit still, need to move around
Akinesia	Loss of ability to move muscles voluntarily
AND	Advanced neurocognitive disorder
Dystonia	Involuntary muscle contractions
Hippocampus	A structure that plays an important role in memory 
Irreversible	Unable to be undone or altered
Gnosis	Visual and auditory recognition
Praxis	The planning of movement to achieve a purpose.
Mental rigidity	Inability to adapt to change

It's important to try to focus on the things the person can still do, as opposed to what they can no longer manage.