Elements to consider during the process leading to the diagnosis ...........................................................................4
Clinical examination ...........................................................................4
Referral to specialized services .........................................................6
Diagnosis ..................................................................................................6

Elements to consider when administering screening tools ..........................................................7
Assessment of functional autonomy .....................................................8
Assessment of cognition ..................................................................8
Assessment of BPSD ........................................................................10

Elements to consider when disclosing the diagnosis ......................................................................11
Consent, confidentiality and obligation ................................................12
Possible sources of help and information ........................................12

Elements to consider during the follow-up .................................................................................13
Patient and caregiver referral ..................................................................................14
Progression of Alzheimer’s disease (AD) ......................................................14

Sign of abuse or neglect ...........................................................................15
Legal documents and levels of care ..........................................................15
Driving .....................................................................................................16
Maintaining autonomy, and safety at home ...........................................17
Incapacity ..............................................................................................18
The patient’s ability to manage their affairs ........................................18
The patient’s ability to take care of themselves ..................................19
The need for protection .........................................................................20
An incapacitated person of full age and refusal of health care .........................20
Assessment: An activity consisting in taking indicators (symptoms, clinical manifestations, difficulties, etc.) obtained through observation, tests or instruments into consideration. An assessment is a non-reserved intervention that can be performed by any professional within the limits of their respective qualifications.

Evaluation: An evaluation involves making a clinical judgment regarding an individual’s situation based on the information that the professional has and communicating the conclusions of this judgment. Professionals perform evaluations within the context of their respective areas of practice. Reserved evaluations can be performed only by authorized professionals.

Screening: The identification process leading to a thorough evaluation of the patient. It consists in recognizing the signs and symptoms associated with cognitive problems in a subgroup of the population at greater risk. These warning signs may be noticed by the patient and their family (or friends) or by health and social services professionals.

Neurocognitive disorder (NCD): See the new nomenclature in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). The subtypes of mild and major NCDs included in this project are NCDs due to Alzheimer’s disease, mixed NCDs, vascular NCDs, NCDs due to Parkinson’s disease, Lewy body NCDs and frontotemporal NCDs.
Starting the process

It is essential to **screen for the signs of functional impairment** from the outset and to interview the patient and a family member (or friend). **A family member’s (or friend’s) involvement** should be a priority.

### Diagnostic approach

Only in patients with **symptoms or warning signs** suggestive of a cognitive decline signaled by:

- A complaint concerning a cognitive change (memory or another cognitive function);
- An impairment or an unusual difficulty reported by family members;
- Clinical suspicion in patients at greater risk for developing AD or an NCD.

### Interventions

<table>
<thead>
<tr>
<th>Interventions</th>
<th>Screening</th>
<th>Evaluation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Examining the complaint and checking with a family member.</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>A focused clinical examination of the patient.</td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>An objective assessment of the <strong>functional impairment</strong> with the patient and a family member using effective screening tools.</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>An objective assessment of the patient’s <strong>cognitive functions</strong> using effective screening tools.</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>An objective assessment of the <strong>behavioural and psychological symptoms of dementia (BPSD)</strong> with the patient and a family member using effective screening tools.</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>Laboratory tests.</td>
<td></td>
<td>x</td>
</tr>
</tbody>
</table>

**Note:** The overall evaluation leading to the diagnosis can be carried out over one or more visits.

### About the patient

Regardless of their ability to take care of themselves:

- The patient is the first one to receive the information;
- They* should remain the focus of the screening and the process leading to the diagnosis;
- They should give verbal consent, which is to be documented in their record and checked prior to screening if there is clinical suspicion, even if they have not expressed a memory complaint.

*Singular “they” is used in this document to render it gender-neutral.

### For health and social services professionals

It is advisable to:

- Adjust your practice:
  - To each patient’s needs (sociocultural diversity, beliefs, language, ethnic origin, etc.);
  - To each patient’s sensory limitations (hearing and/or visual impairment);
- Designate, with the patient, a caregiver who could occasionally accompany them to subsequent visits.
# Medical conditions associated with a high risk for developing an NCD

Be vigilant for the following medical conditions, which may be associated with an increased risk of developing AD or an NCD:

- A history of stroke or transient ischemic attack (TIA);
- A family history of NCDs;
- A lifetime history of major depressive disorder;
- Nonstabilized sleep apnea;
- A nonstabilized metabolic or cardiovascular morbidity;
- A recent episode of delirium;
- A first major psychiatric episode at an advanced age (psychosis, depression, mania);
- A recent head injury;
- Parkinson’s disease;
- A mild NCD.

## Symptoms and warning signs

Warning signs are an indication of a significant decline from the patient’s previous level of functioning and usual abilities:

1) They can appear gradually over several years; 2) They are listed here for illustrative purposes only; and 3) They cannot be used alone as a diagnostic tool.

<table>
<thead>
<tr>
<th>Warning sign</th>
<th>Example of everyday manifestations</th>
</tr>
</thead>
</table>
| Memory changes (amnesia)                 | ▶ Difficulty learning and retaining new information.  
▶ Forgetting important information (recent conversations, scheduled or past events, appointments, birthdays), repetitive speech. |
| Loss of functional autonomy in the instrumental activities of daily living (IADL)/activities of daily living (ADL) | ▶ Deterioration or change in the ability to function independently (daily tasks, managing medications), being a decline from the previous level of functioning. |
| Problems organizing, planning and reasoning (executive functions) | ▶ Difficulty adjusting to new things or change.  
▶ Changes in the ability to organize and plan complex tasks.  
▶ Impaired judgment and difficulty making decisions. |
| Impaired visual recognition (agnosia)    | ▶ Difficulty recognizing objects in the home, images or people they know (family members, celebrities) that cannot be explained by defective vision. |
| Language and speech disorders (aphasia)  | ▶ Difficulty expressing themselves (word-finding hesitations, word substitutions or the use of deformed words, incomplete or incomprehensible sentences).  
▶ Changes in spelling or handwriting skills (shape of letters).  
▶ Decreased ability to understand instructions, follow conversations, read or understand texts. |
| Impaired ability to perform a motor activity, despite intact motor capabilities (apraxia) | ▶ Difficulty planning complex tasks; unusual slowness or difficulty coordinating movements for performing daily tasks (use of everyday objects, getting dressed or drawing). |
| Personality, behaviour and mood changes  | ▶ See the complete list of BPSD on the next page. |

## For health and social services professionals

- If the patient or a caregiver reports a cognitive complaint, provide reassurance by telling them that the symptoms do not necessarily imply AD or another NCD.  
- If there is clinical suspicion or if the patient has a medical condition associated with an increased risk of AD or another NCD, ask the patient or caregiver questions in order to identify any other warning signs.  
- Explain to the patient or caregiver that a more thorough evaluation will be done and that different tools will be used to determine the nature and cause of the symptoms.
Initial suspicion of an NCD arises at the hospital

If an NCD is suspected at the hospital in the context of a decompensated acute medical condition, the physician, in conjunction with the care team, should reassess the patient’s cognitive and functional status after their medical condition has been stabilized, in order to confirm the diagnosis.

List of the most commonly observed BPSD

The examination of patients with AD or another NCD should include identifying BPSD and other neuropsychiatric symptoms associated with these disorders.

The earliest BPSD in AD

- **Apathy/indifference***
  Loss of or decrease in motivation affecting behaviour, thoughts and emotions

- **Depression***
  Sadness, crying, despair, a feeling of powerlessness, low self-esteem, guilt

- **Anxiety***
  A feeling of an imminent, undetermined danger.
  An internal state characterized by:
  - Thoughts (apprehension, various worries);
  - Emotions (anxiety, fear);
  - Physical sensations (muscle tension, shortness of breath, sweating, gastrointestinal discomfort, headaches);
  - Behaviours (avoidance, repetitive requests, excessive dependence, agitation).

- **Irritability***
  Irritability of mood, low tolerance threshold

- **Aggression*/agitation***
  Verbal (shouting, screaming, talking constantly) and physical (throwing things, spitting, pinching, scratching) agitation, with or without aggression

Classification of BPSD

- **Affective and emotional disorders**
  - Depression
  - Anxiety
  - Apathy
  - Irritability
  - Emotional lability
  - Exaltation of mood (euphoria*)

- **Behavioural disorders**
  - Wandering
  - Repetitive vocalizations
  - Repetitive or stereotyped movements*
  - Aggressive disinhibition
  - Sexual disinhibition
  - Gluttony
  - Utilization behaviours
  - Imitation behaviours

- **Psychotic disorders**
  - Hallucinations*
  - Delusions*
  - Identification disorders

- **Neurovegetative disorders**
  - Sleep (night wandering, sundowning, sleep-wake cycle reversal)*
  - Inappropriate eating behaviours and hyperorality

* 12 behavioural disorders that can be identified with the short version of the Neuropsychiatric Inventory (NPI-R).

For health and social services professionals

- The NPI-R can be used to quickly identify 12 of the most commonly observed types of behavioural disorders in AD and to guide the discussion between the professional, patient and caregiver.
- The objective assessment of depressive symptoms in NCD patients should include a face-to-face interview with the patient and their family members (together or individually) using a questionnaire such as the Patient Health Questionnaire (PHQ-9).
- Using specific scales to evaluate the other BPSD is not recommended in primary care. Patients with behavioural disorders should be referred to local teams specializing in BPSD or mental health.
The diagnosis is based on the documented occurrence of cognitive impairment and/or the observation of a behavioural change which:
- Interferes with the patient’s usual activities of daily living;
- Constitutes a decline from their previous level of functioning;
- Cannot be explained by a physical problem or a recognized psychiatric illness.

### About the patient

The patient’s previous personality, skills and abilities should always be taken into consideration during the process leading to the diagnosis and for interpreting screening tool results.

### For health and social services professionals

- Any health and social services professional can screen for the signs of functional impairment, a cognitive decline or a behavioural disorder.
- Any authorized professional (e.g., an occupational therapist, a nurse, a physician, a neuropsychologist or a social worker) can objectively assess a functional impairment, cognitive functions or a behavioural disorder with screening tools.
- Only occupational therapists can draw conclusions regarding the nature and extent of a loss of functional autonomy in a person in whom NCDs or mental disorders have been diagnosed or evaluated by an authorized professional*.
- Only neuropsychologists and physicians can draw conclusions regarding the nature of observed NCDs and make the link, if necessary, between the type of impairment and a suspected brain dysfunction.
- Only physicians can make a diagnosis concerning AD and other NCDs and communicate it to the patient and caregiver. The other professionals concerned, too, can communicate their results, in accordance with their area of practice.

### Clinical examination

#### Contents

The clinical examination should include the following:
- An objective assessment of the reported or suspected impairments using screening tools;
- A thorough physical examination with emphasis on the neurological and cardiovascular systems and with the objective of checking the patient’s vision, hearing and mobility (or other factors that can interfere with the use of psychometric screening tools);
- Paraclinical and complementary tests/examinations if necessary;
- A review of the patient’s medications (prescription and nonprescription, natural products) and a verification of their therapeutic adherence;
- A review of the patient’s medical and psychiatric history and relevant current medical conditions or other comorbidities;
- An evaluation of the patient’s mental health and level of vigilance.

#### Confounding factors to be taken into consideration

The following situations or medical conditions can be the cause of the identified NCD or a source of exacerbation:
- An adverse effect of a drug or a combination of drugs, a new drug, a drug interaction or a cascade of adverse effects of several drugs;
- A mental health problem;
- A physical health problem (a metabolic or deficiency disorder, a systemic disorder1, sleep apnea, delirium);
- The abuse of certain substances (drugs or alcohol).

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* Reserved activity under Bill 21.
1 A disorder that can affect several systems of the human body. Certain diseases, such as heart or respiratory failure and certain systemic infections or sexually transmitted and blood-borne infections (STBIs), can affect cognitive functions.
### Objective assessment of reported or suspected impairments using screening tools

- For the precautions and recommendations concerning the use of screening tools, see the section [objective assessment using screening tools](#).
- An informed choice can be facilitated by consulting the sections concerning the different screening tools.

### For health and social services professionals

Any professional other than physician who suspects an NCD in a patient, especially when using screening tools, should refer the patient to a family physician for a more thorough evaluation.

### Paraclinical and complementary tests/examinations

**Blood work should be done before making an initial diagnosis, in order to identify any comorbidities that can impair cognitive functions. The items to be checked are as follows:**

- Complete blood count;
- Blood glucose;
- Blood calcium;
- Vitamin B<sub>12</sub>;
- Thyroid-stimulating hormone (TSH);
- Renal function test (creatinine);
- Electrolytes.

**Structural neuroimaging** (brain MRI [magnetic resonance imaging] or CT scan) may be useful for the differential diagnosis in patients who exhibit a cognitive decline with any of the following*:

- Age < 60 years;
- A rapid (a few months), unexplained deterioration in the cognitive faculties or functional autonomy status;
- A recent severe head injury;
- Unexplained neurological manifestations or focal abnormalities on neurological examination;
- A history of cancer (especially one that gives rise to brain metastases);
- Anticoagulant use or a history of coagulation disorders;
- A gait disorder or urinary incontinence during the early stages of the decline;
- Cognitive symptoms or an unusual or atypical clinical presentation.

**Tests to be ordered only if needed** and in light of the clinical context:

- Liver profile, alanine aminotransferase (ALT) level;
- Serological tests for syphilis and the human immunodeficiency virus (HIV);
- A folate level.

* A **brain MRI (magnetic resonance imaging)** or **CT scan** should be performed if the presence of an unexpected **cerebrovascular disease** is likely to lead to changes to the patient’s clinical management.

### Medication review

- Check the medications (prescription and nonprescription, natural products) with the patient or caregiver with regard to:
  - Any recent change to or addition of drugs;
  - and
  - The possibility of:
    - A drug interaction;
    - An adverse effect;
    - A drug cascade.

**Note**: It is advisable to consult INESSS’s usage guide on the pharmacological treatment of AD and mixed dementia ([OUG Tx](#)) and, if in doubt, to talk to a pharmacist, who is more qualified to assess the consequences of any change to the patient’s drug profile.
If, despite the memory complaint, the initial evaluation shows that the cognitive functions, the performance of the activities of daily living and the instrumental activities of daily living, and the clinical context (no mood or behavioural disorders) are normal, do a follow-up within 6 to 12 months, depending on the context, or earlier if there is a specific need for a second evaluation.

If the diagnosis is uncertain, refer the patient and caregiver to the appropriate specialized services.

If the diagnosis is clear, disclose the diagnosis and do a follow-up and take the appropriate steps.

Certain medical conditions are associated with an increased risk of developing AD or an NCD. See "Screening - Starting the process" for a detailed list.
Elements to consider when administering screening tools

For health and social services professionals

- Only professionals with the necessary skills can administer screening tools and interpret the results in accordance with the current standards and their area of practice.
- The use of screening tools should be adjusted according to:
  - The patient’s symptoms;
  - The available time;
  - The specific skills that might be required for using the tools, for scoring and for interpreting the results.
- Using screening tools is part of the process leading to the diagnosis, and they should not be used in an isolated manner.
- The diagnosis cannot be made solely on the basis of raw scores with no further clinical contextualization.
- Using certain tools repeatedly (≤ 6 months) can lead to a learning effect, especially in patients with a previously high level of functioning or a mild NCD.
- If it is suspected that the patient knows the contents of a given tool, consider using replacement versions, if available.
- Psychometric screening tools can be used to confirm the presence of NCDs, but they are not designed to draw any conclusions about the nature of cognitive function impairments.

Factors that can influence the performance of screening tools

The factors that can influence the performance of screening tools should be taken into consideration when interpreting the results. These factors are as follows:

- The patient’s level of education and cultural or linguistic group;
- A severe psychiatric illness that has persisted over the years;
- Physical problems (handicap or paralysis) or movement limitations (e.g., arthritis of the fingers);
- The patient’s emotional state during the screening (e.g., first-visit anxiety and depression);
- Previously existing language disorders (e.g., stuttering);
- Uncorrected sensory impairments (hearing or visual);
- The patient’s level of vigilance or cooperation;
- The use of medications that can have an effect on cognitive functions;
- The surroundings in which the tools are administered.

* Age-related hearing loss (presbyacusia) is often underestimated by the patient or those around them and can have a considerable impact on the patient’s performance.

For health and social services professionals

Check that:

- The patient is sufficiently stable from a medical and pharmacological standpoint;
- The screening tools are administered in a quiet environment with no noise or distractions;
- The patient’s hearing, vision and motor activity are optimal.

NOTE: If the patient is found to have a hearing or visual impairment when a screening tool is being administered, it should, if possible, be corrected with the use of an appropriate hearing aid, a personal amplifier or corrective lenses.

1 The previous level of functioning is defined in terms of education > 12 years, postsecondary education, the type of work, intellectual and cultural interests, etc.
2 It is advisable to talk with the pharmacist, who will generally have the patient’s complete medication file containing all the information regarding their medications.
Assessment of functional autonomy

Rapid screening tools

For rapid screening, check with the patient or caregiver (to the extent possible) if:

- In the past few months, either has noticed a deterioration or significant changes in the performance of simple tasks or in the activities of daily living (neglecting personal hygiene, wearing the same or seasonally inappropriate clothes, problems with managing urinary incontinence, etc.);
- In the past few months, either has noticed a deterioration or significant changes in the performance of complex tasks or the instrumental activities of daily living (difficulty learning and getting acquainted with the use of new devices, such as a remote control or an automatic teller machine, difficulty managing medications, difficulty preparing meals, difficulty doing housework, difficulty managing ordinary finances, etc.).

If a change has been noticed:

- Have the caregiver complete a questionnaire that gives a general idea of the loss of functional autonomy and serves to guide the discussion, such as:
  - The Pfeffer Functional Activities Questionnaire (FAQ);
  - The Disability Assessment for Dementia (DAD).

If no change has been noticed by the patient or caregiver:

- Assess the patient’s functional autonomy again during the annual follow-up, or earlier if there is a specific need to do so.

Assessment of cognition

For health and social services professionals

- Rapid psychometric screening tools (Dubois’ 5-word test, the Memory Impairment Screen (MIS) or the clock test; administration time: 5 minutes) are useful:
  - For providing summary information about cognitive functions;
  - For quickly detecting an NCD in at-risk patients with warning signs;
  - If there is a limited amount of time with the patient (e.g., suspicion/complaint at the end of a medical visit, a follow-up visit for a chronic illness, a home visit or a visit to a health service, such as audiology or ophthalmology).
- Time permitting (> 10 minutes), preference should be given to using a more comprehensive psychometric screening tool (the Modified Mini-Mental State (3MS) examination, the Mini-Mental State Examination (MMSE) or the Montreal Cognitive Assessment (MoCA)) over rapid psychometric screening tools.

Rapid psychometric screening tools

- The use of rapid psychometric screening tools is optional and is left to the professional’s judgment according to the clinical context and the time available with the patient.
- Increase sensitivity and permit the objective assessment of several cognitive functions by combining:
  - Dubois’ 5-word test and the clock test
  - The MIS and the clock test

- Use Dubois’ 5-word test and the MIS to quickly detect any memory problems.
- Use the clock test to detect other types of impairments, such as visuospatial1 and/or executive function impairments (e.g., organization and planning).
- Depending on the results, the patient’s profile, the professional who administered the screening tools and their level of suspicion, the patient should be seen again by a family physician or an interdisciplinary primary care team for a detailed evaluation using more-comprehensive screening tools (the MMSE, MoCA or MIS).

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1. Visuospatial functions play a role in visually determining the relative positions of objects in one’s environment or in relation to oneself.
**Assessment of cognition (Cont’d)**

**More-comprehensive psychometric screening tools: MoCA**

Preference should be given to using the MoCA:
- In patients with a previously high level of functioning (education > 12 years, postsecondary education, the type of work, intellectual and cultural interests, etc.);
- If an NCD is suspected in a patient with no significant functional autonomy impairment;
- When there is some question about the integrity of the patient’s cognitive functions and when the MMSE score is within the normal range (24 to 30);
- To monitor the course of the disease after the diagnosis is made.

<table>
<thead>
<tr>
<th>Score &lt; 26</th>
<th>Score ≥ 26</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Probable NCD:</strong> Continue the process with a more thorough evaluation of the patient.</td>
<td><strong>NCD not detected:</strong> Assess the patient’s cognitive functions again during the annual follow-up, or earlier if necessary.</td>
</tr>
</tbody>
</table>

**More-comprehensive psychometric screening tools: the MMSE and the 3MS**

Preference should be given using to the MMSE or 3MS mental status scale:
- In patients with a low level of education;
- If an NCD is suspected in a patient with a loss of functional autonomy;
- To monitor the course of AD from the mild to moderate stage;
- To evaluate the effectiveness of a pharmacological treatment and to ensure coverage of the drugs by the Régie de l’assurance maladie du Québec (RAMQ), if indicated.

<table>
<thead>
<tr>
<th>MMSE score &lt; 24</th>
<th>MMSE score 24-30</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Probable NCD:</strong> Continue the process leading to the diagnosis.</td>
<td><strong>MoCA</strong></td>
</tr>
</tbody>
</table>

The 3MS scale:
- Permits a more detailed screening of cognitive functions (better assessment of memory and executive functions);
- The total score is out of 100, but the 3MS also enables one to calculate the MMSE score out of 30 for the purposes of submitting a drug reimbursement request (RAMQ).

**Floor and ceiling effects of the more comprehensive psychometric screening tools**

The scores on the 3MS, MMSE and MoCA scales can be:
- **Normal** in the early stages or in the atypical forms of the disease;
- **Abnormal** in patients with no NCDs but whose previous level of functioning was low.

**For health and social services professionals**

If the MMSE score is 27 or 28:
- An **MoCA score < 26** can be used to obtain authorization for drug coverage by the RAMQ.

**Note:** Systematically and simultaneously administering the MMSE and the MoCA in other circumstances does not provide a gain in diagnostic accuracy and is not recommended.

* The MoCA score alone is not considered for granting authorization for drug coverage by the RAMQ.
Assessment of cognition (Cont’d)

Caregiver questionnaires

To obtain information in addition to that provided by the other psychometric screening tools, or if the patient is unable to answer the questions on the screening tools (lack of time or uncooperative), have the caregiver complete a questionnaire for identifying a cognitive and/or functional change, such as:

The AD8 questionnaire (Ascertain Dementia 8)

The short version of the IQCODE (Informant Questionnaire on Cognitive Decline in the Elderly)

Note: The results can guide the choice of appropriate psychometric screening tool to be used during the follow-up and enrich the qualitative data concerning the cognitive and functional decline.

Assessment of the psychological and behavioural symptoms of dementia (BPSD)

Rapid screening tools

For rapid screening, check with the patient or caregiver (to the extent possible) if, during the past few months, either has noticed a personality, behaviour or mood change.

If a personality and behaviour change has been observed*:
► Use a screening tool such as the short version of the Neuropsychiatric Inventory (NPI-R).

If a mood change has been observed*:
► A more thorough evaluation could be performed with a screening tool such as the Patient Health Questionnaire-9 (PHQ-9).

If no change has been observed:
► Do another BPSD assessment during the annual follow-up, or earlier if there is a specific need to do so.

* If a personality, behaviour or mood change has been observed, an appropriate medical intervention should be provided.

For health and social services professionals

For help in determining what the most appropriate tool is, consult the quick-reference guide.
Every person, including those under protective supervision or a mandate, is presumed to be capable of consenting to care.

If there is any doubt:

"The patient’s capacity to consent to care should be checked whenever care is proposed and during each “medical” decision requiring their consent.

The disclosure process can take place over several visits and include a discussion regarding:

- Expectations, with the professional attempting to reassure the patient and caregiver, insofar as possible, and offering realistic hope;
- The available treatment options, pharmacological and nonpharmacological (see GUO Tx MA);
- A reminder of the importance of preparing or updating the different legal documents (advance medical directives [AMDs], will and mandate in case of incapacity)*;
- The determination of the levels of care*;
- Driving-related issues and the possibility of the Société de l’assurance automobile (SAAQ*) revoking the patient’s driver’s license;
- The objectives of maintaining the patient’s autonomy, and safety at home*;
- Capacity-related issues (the ability to manage their affairs, take care of themselves and consent to health care) and the determination of incapacity*; and
- The possible aids offered by the health and social services network and the existence of associations that can provide services to the patient and of caregiver support groups.

A patient’s inability to consent to care is temporary or permanent, depending on the nature of their medical condition.

Regardless of their capacity to consent to care, the patient is the first person to receive the information.

The disclosure should be made with compassion and sensitivity, using an empathetic approach centred on the patient that respects their integrity.

The diagnosis should be communicated clearly by the physician in terms that the patient can understand (e.g., “memory illness”).

After giving the patient and their family members the information, it should be checked that they understand it.

For health and social services professionals

The disclosure process can take place over several visits, depending on the circumstances.

Once the diagnosis has been made, it should be communicated to the patient, the caregiver, the care team, if it is not present during the disclosure, and then to the other health professionals who contributed to making the diagnosis, in line with the wishes expressed by the patient and with their consent.

The disclosure should be made with compassion and sensitivity, using an empathetic approach centred on the patient that respects their integrity.

The diagnosis should be communicated clearly by the physician in terms that the patient can understand (e.g., “memory illness”).

After giving the patient and their family members the information, it should be checked that they understand it.

For health and social services professionals

The assessment of a patient’s capacity to consent to care does not look at the nature of the decision, but rather at the process, that is, the patient’s ability to:

- Understand, process or make sense of the information;
- Express a choice* and adhere to it consistently over time.

* This choice can be expressed in different ways (orally, in writing and non-orally with pictographic and gestural support) to accommodate the language skills of any patient.

About the patient

A patient’s inability to consent to care is temporary or permanent, depending on the nature of their medical condition.

Regardless of their capacity to consent to care, the patient is the first person to receive the information.

Contents of the disclosure

The disclosure process can take place over several visits and include a discussion regarding:

- Expectations, with the professional attempting to reassure the patient and caregiver, insofar as possible, and offering realistic hope;
- The available treatment options, pharmacological and nonpharmacological (see GUO Tx MA);
- A reminder of the importance of preparing or updating the different legal documents (advance medical directives [AMDs], will and mandate in case of incapacity)*;
- The determination of the levels of care*;
- Driving-related issues and the possibility of the Société de l’amusement automobile (SAAQ*) revoking the patient’s driver’s license;
- The objectives of maintaining the patient’s autonomy, and safety at home*;
- Capacity-related issues (the ability to manage their affairs, take care of themselves and consent to health care) and the determination of incapacity*; and
- The possible aids offered by the health and social services network and the existence of associations that can provide services to the patient and of caregiver support groups.

* For further information, see
The patient can be referred to specialized services or a memory clinic if they want a second opinion about their diagnosis or treatment plan.

If the patient expresses an interest in participating in diagnostic or therapeutic research, they can be given the necessary contact information for the organizations concerned.

Emotional reactions or anxiety
- Stop disclosing the diagnosis and calm and reassure the patient;
- Continue the disclosure when the patient asks you to do so;
- Plan a follow-up with a family member, if possible, or with the local health services or local social services.

Patient denial or impaired awareness of the disease (anosognosia)
- Do not try to convince the patient;
- Tell the patient that their family will be informed of the situation and that only the relevant information will be shared if there is an imminent risk to the health or safety of the patient or those around them;
- Inform local home support services, as needed, and tell the patient that a request for assistance has been made.

Refusal of care
- If the patient is incapacitated and refuses health care, go to the section steps to be taken after the diagnosis and during the follow-up.

Consent, confidentiality and obligation

For health and social services professionals
- The patient’s verbal consent should be obtained and recorded in their record and confirmed in anticipation of a worsening of the disease so that the family can have access to the information on the patient’s health during subsequent medical visits.
- If there is reasonable doubt, you should obtain written consent, to the extent that the patient is capable of giving consent, to avoid any possible misunderstanding with them or their family.
- In the event of a refusal, and if there is an imminent risk to the safety or health of the patient or those around them, tell the patient that their family will be informed of the situation and that only the relevant information will be shared.

Possible sources of help and information

For the patient
- The Alzheimer Society
- Dementia community programs
- The local Centre intégré de santé et de services sociaux (CISSS) and Centre intégré universitaire de santé et de services sociaux (CIUSSS)

For the caregiver
- L’Appui
- Baluchon Alzheimer
- Home support services
- A day centre
- Carpe Diem
- aidants.ca
- The local CISSS or CIUSSS

In the event of caregiver exhaustion
Always be on the lookout for signs of exhaustion and physical and cognitive deterioration in the caregiver, which can occur at any stage of the disease. If necessary, you should:
- Refer the caregiver to their family physician or the appropriate local help services that provide support or respite to this type of clientele, such as the Alzheimer Society, L’Appui, Baluchon Alzheimer, home support services, a day centre, Carpe Diem or aidants.ca;
- Give them supportive literature;
- Assess, using tools such as the Zarit scale*, the burden of looking after a patient diagnosed with an NCD who lives at home.

* The Zarit scale is mentioned as an example only, since INESSS has not done an in-depth analysis of this instrument as part of this project.
### Elements to consider during the follow-up

#### An NCD initially diagnosed in hospital in the context of an acute, decompensated medical condition

The physician, in conjunction with the care team, should **reassess** the patient’s cognitive and functional status after their **medical condition** has been **stabilized**, in order to **confirm** the diagnosis.

#### For health and social services professionals

A patient with an NCDs should have:

- **A regular** follow-up (telephone or appointment) **within 6 to 12 months after the diagnosis**, or sooner if there is a specific need;
- **An annual** follow-up (appointment) together with the caregiver. It may be useful to assess the patient’s cognitive functions, functional autonomy, and behavioural and psychological symptoms of dementia (BPSD) again to document the course and progression of the disorder and to adjust the necessary interventions and level of supervision according to their needs;
- **A closer follow-up** (telephone or appointment) together with the caregiver, based on the severity of the disorder or after initiating pharmacological treatment, in order to assess the patient’s tolerance of and adherence to the treatment, and the degree to which the treatment objectives are being met **GUO Tx MA**.

If they wish, the patient and caregiver should be able to be seen again quickly to assess the negative psychological consequences that disclosing the diagnosis may have caused.

### Elements to check | Steps to be taken
--- | ---
Clinical examination | ▶ Do another objective assessment of the patient’s:
  - Cognitive functions;
  - Functional autonomy;
  - BPSD.
Nutritional status | ▶ Be especially vigilant for:
  - Malnutrition;
  - Weight loss;
  - Check with the caregiver to see if the patient is able to feed themselves properly.
  - If need be, and depending on the resources available at the facility, the patient and caregiver should be referred to a nutritionist.
Medications | ▶ Check the medications and therapeutic adherence with the patient or caregiver:
  - Any changes to or addition of drugs;
  - Drug interactions;
  - Adverse effects;
  - Drug cascades.
  - It is advisable to consult INESSS’s optimal usage guide on the pharmacological treatment of AD and mixed dementia **(OUG Tx)** and, if in doubt, to talk to a pharmacist, who is more qualified to assess the consequences of any change to the patient’s medication profile.
Autonomy, capacity, need for protection and documents | ▶ Review and check the following as needed:
  - The patient’s capacity to consent to care;
  - The maintenance of autonomy, and safety at home;
  - The patient’s ability to manage their affairs and take care of themselves;
  - The patient’s fitness to drive a road vehicle;
  - The level of care;
  - Signs of abuse or neglect;
  - The available support network and the patient’s need for protection.
Patient and caregiver referral

For health and social services professionals

- **Refer** patients with any of the following characteristics to specialized services:
  - Any complex neuropsychiatric manifestation or if the patient is refractory to first-line interventions, which can significantly impair their functioning or relationships with their family;
  - A **rapid deterioration in their physical or cognitive status**, despite pharmacological treatment prescribed specifically to treat AD;
  - An atypical course for the diagnosis made.

- **Be** on the lookout for **signs of exhaustion and physical or cognitive deterioration in the caregiver**. If necessary:
  - Refer the caregiver to their family physician or appropriate local help services that provide support or respite to this type of clientele, such as the Alzheimer Society, L’Appui, Baluchon Alzheimer, home support services, a day centre, Carpe Diem or aidants.ca;
  - Give them supportive literature;
  - Assess, using tools such as the Zarit scale*, the burden of looking after a patient diagnosed with an NCD who lives at home.

*The Zarit scale is mentioned as an example only, since INESSS did not do an in-depth analysis of this instrument as part of this project.

- **Refer** all patients with AD or another NCD who agree to this and their caregiver to **help services** for these disorders that offer information, support and training:
  - The Alzheimer Society;
  - Dementia community programs;
  - A caregiver support forum.

Progression of AD

**Reisberg’s Global Deterioration Scale (GDS)** is used to monitor the progression of AD. It also permits better organization of patient management, easier communication and education regarding the disease, and better planning of the organization of services.

*The scale proposed here is just one example. Other staging scales can be used as well.

<table>
<thead>
<tr>
<th>Reisberg and collaborators’ Global Deterioration Scale, 1982¹</th>
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</thead>
<tbody>
<tr>
<td><strong>Stage 1</strong> No cognitive decline (normal functioning):</td>
</tr>
<tr>
<td>- Experiences no problems in daily living.</td>
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<tr>
<td><strong>Stage 2</strong> Very mild cognitive decline (it may be normal age-associated changes or early signs of AD):</td>
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<tr>
<td>- Forgets names and locations of objects;</td>
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<tr>
<td>- May have difficulty finding words.</td>
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<tr>
<td><strong>Stage 3</strong> Mild cognitive decline (present, in some cases, in the initial phase of AD):</td>
</tr>
<tr>
<td>- Has difficulty travelling to new locations;</td>
</tr>
<tr>
<td>- Has difficulty functioning at work.</td>
</tr>
<tr>
<td><strong>Stage 4</strong> Moderate cognitive decline (mild stage of AD):</td>
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<tr>
<td>- Has difficulty performing complex tasks (finances, shopping, planning a dinner for guests).</td>
</tr>
<tr>
<td><strong>Stage 5</strong> Moderately severe cognitive decline (moderate stage of AD):</td>
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<tr>
<td>- Needs help to choose clothing;</td>
</tr>
<tr>
<td>- Needs to have someone remind them that it is time to take a shower or bath.</td>
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<tr>
<td><strong>Stage 6</strong> Severe cognitive decline (moderate to severe stage of AD):</td>
</tr>
<tr>
<td>- Loss of awareness of recent events and experiences in their life;</td>
</tr>
<tr>
<td>- Requires assistance taking a bath; may have a fear of taking a bath;</td>
</tr>
<tr>
<td>- Needs an increasing amount of help toileting or is incontinent.</td>
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<tr>
<td><strong>Stage 7</strong> Very severe cognitive decline (severe stage of AD):</td>
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<tr>
<td>- Uses a very limited vocabulary, which will soon shrink to only a few words;</td>
</tr>
<tr>
<td>- Loses the ability to walk and sit;</td>
</tr>
<tr>
<td>- Requires help with eating.</td>
</tr>
</tbody>
</table>

Be vigilant and always be on the lookout for signs of abuse or neglect in patients diagnosed with an NCD.

**If in doubt**
- Encourage the patient to tell a social services professional, a friend, a family member or the police.
- Contact the appropriate resources for information and psychological support and assistance for the patient in medical or legal procedures (the Aide Abus Aînés helpline, Tel-Aînés, etc.).

**Types of abuse**
Abuse in patients diagnosed with an NCD can assume the form of:
- Physical abuse or sexual assault;
- Emotional or psychological abuse;
- Financial abuse (theft of money, misuse of their property);
- Neglecting their basic needs (food, clothing, shelter).

**Legal documents and levels of care**

The physician should have an informed discussion with the patient at an early stage of their cognitive decline.

**To be discussed with the patient**
- Encourage the patient to prepare or update the different legal documents in order to express and have respected their wishes in terms of medical care and treatment in the event that they become incapable of giving consent (advance medical directives [AMDs], will, and mandate in anticipation of incapacity).
- The physician should initiate or continue the discussion with the patient (and the caregiver, if the patient so desires) for the purpose of determining or reviewing the level of care (NIM).

**For health and social services professionals**
- Only a physician can determine the level of care on the basis of the patient’s health and the care objectives previously discussed with them.
- Other health and social services professionals can participate in the discussion, if relevant and if the patient so desires.

**When the patient becomes incapacitated**
The process (determining and reviewing the levels of care) is carried out in the patient’s presence, to the extent possible, with the legally mandated representative or with the public curator on the treating physician’s recommendation.
Driving

Quickly initiate a discussion with the patient about their fitness to drive and inform them that a closer follow-up and periodic assessments will be necessary:

- Every 6 to 12 months or sooner if a significant change is noticed in their health and functional autonomy;
- If there is an incident (e.g., a traffic accident).

Public safety

If, when driving, the patient poses a risk to public safety:

- Inform them of the option of using other means of transportation with their network (family members or community organizations);
- Explore with the patient strategies for handing over their keys and, possibly, their vehicle, to the extent that they agree to the order not to drive;
- Tell the patient that those around them might be kept abreast of the situation;
- Inform the patient that a report might be filed with the Société de l’assurance automobile du Québec (SAAQ) if they do not comply with the order not to drive;
- Advise them that everything will be documented and entered into their medical record.

Note: Screening tools may help identify driving-related risk factors, but they cannot be used to determine a patient’s unfitness to drive a road vehicle.

Report filed with the SAAQ

If there is a risk to public safety or if in doubt, anyone, including the patient, can file a report on them with the SAAQ.

For health and social services professionals

- Only physicians, nurses, occupational therapists, psychologists and optometrists are legally authorized to file a report with the SAAQ concerning a patient they deem unfit to drive:
  - The Highway Safety Code permits only these professionals to breach the confidential relationship between them and the patient and states that no action in damages may be brought against them.
- All professionals who do not have legal protection should share their suspicion regarding the patient’s fitness to drive a road vehicle with the other members of the care team designated in the Highway Safety Code, in order to arrive at a collective decision about filing a report with the SAAQ. In the event of a disagreement, it is up to each team member to exercise their professional judgment in the situation.

Note: Filing a report with the SAAQ is strongly recommended when a professional advises a patient not to drive for health reasons that fall within their area of expertise and the patient does not seem to want to comply with the order not to drive.

- An occupational therapist can carry out an on-road evaluation if there is, for example:
  - Some question as to the patient’s fitness to drive;
  - The possibility of adjusting or modifying the patient’s driving habits or if rehabilitation is an option.
Maintaining autonomy, and safety at home

- **Maintain and foster** the patient’s autonomy for as long as possible within the limits of their decision-making abilities and without jeopardizing their safety.
- **Check** if the patient’s physical or mental condition is jeopardizing their **safety at home**.

**If in doubt**

- Refer the patient and caregiver to home services.
- If there is an **immediate danger** to the patient or others, the patient should be referred to emergency services.

**Socially isolated patient living at home**

Set up a team to monitor the patient from a medical, psychological and social standpoint in a timely manner.

**Note:** The opinion of a team highly specialized in the behavioural and psychological symptoms of dementia (BPSD) and that of other second-line services may be required.
Incapacity

- A diagnosis of AD or another NCD alone is not enough to make a declaration of incapacity. Such a declaration is based on:
  - A medical and psychosocial evaluation that takes the patient’s previous level of functioning into account;
  - The assessment of a functional impairment;
  - Their living environment, culture, beliefs and values;
  - The presence of exacerbating factors.

- Based on all the risks and the risk level for the patient or those around them, and on the severity of the consequences, a patient may be deemed partially or totally incapable of managing their affairs and/or taking care of themselves.
- The incapacity is temporary or permanent, depending on the nature of the medical condition.
- If a patient deemed incapacitated is well supported, preference should be given to less restrictive solutions (nonlegal measures) for the activities of daily living.
- The treating physician and their team should discuss nonlegal protection measures with the caregiver.

Nonlegal protection measures for patients deemed incapacitated

- Involve the family members in providing the patient with more frequent support:
  - By providing meal support on a more regular basis;
  - Increasing the frequency of visits and phone calls.
- Provide support in their financial transactions:
  - Limit their pocket change;
  - Lower or cancel the options on their credit or debit cards or take the cards away, together with their checks;
  - Set up preauthorized payments;
  - Monitor their bank transactions online, with their authorization.
- Initiate home services (Meals on Wheels, telemonitoring, help with personal hygiene, volunteer transportation).
- Help them choose a living environment suited to their needs.
- Supervise and streamline their medication-taking and check their adherence to pharmacological treatments.

This list is not exhaustive and is provided as an example only.

Capacity vs. incapacity

- By law, a patient is presumed capable.
- Incapacity must be assessed and proven, if applicable.

The patient’s ability to manage their affairs

Check if the patient’s physical or psychological condition is jeopardizing their ability to manage their affairs.

If in doubt

- Evaluate their daily financial management (handling cash, understanding statements, writing checks, remembering purchases or bank transactions, etc.).
- Assess their awareness of their financial situation (awareness of their estate, assets, debts, and monthly income and expenses).
- Evaluate their perception of their incapacity and their need for assistance (recognizes their inability, uses compensatory measures and gets things done).

Ability questioned

An NCD patient’s ability to manage their affairs is often questioned when they:

- Seem to be at risk for abuse or vulnerable to influences and pressure;
- Are a victim of undue pressure or influence;
- Are socially isolated;
- Make decisions or do things that those around them find inappropriate and unusual.

Note: The kit known as the Échelle de Montréal pour l’évaluation des activités financières (ÉMAF) can be used to measure a person’s functional ability to manage their affairs when this ability is in doubt.
The patient’s ability to take care of themselves

Check if the patient’s physical or mental condition is jeopardizing their ability to take care of themselves independently.

The following should be taken into consideration:

- The patient’s autonomy in their activities of daily living (ADL)/instrumental activities of daily living (IADL) (bladder function, maintaining their living environment, shopping, managing their medical and pharmacological treatments, etc.);
- Their awareness of their state of health (recognizes their health problems, assesses the risks and consequences of treatments);
- Their ability to protect themselves (protects themselves, reacts to emergency situations and has action plans).

*The situation may require an evaluation by an occupational therapist.

Elements to be taken into consideration when determining if the patient’s physical or mental condition is jeopardizing their ability to take care of themselves independently

** This list is not exhaustive and is provided as an example only.

| **All risks** | • Inadequate medication management;  
| • Diet inadequate in terms of quantity or quality;  
| • The condition of their residence (cleanliness, signs of fire);  
| • The inability to get the appropriate help in an emergency (a fire, an illness or a fall);  
| • The state of their affairs;  
| • Estate. |

| **The frequency or probability of the risks occurring** | • Possible  
| • Probable  
| • Imminent  
| • Uncertain |

| **The extent of the consequences** | • Severity (mild, moderate, severe);  
| • Duration (temporary or permanent);  
| • Nature. |

| **The presence of exacerbating factors** | • Human situational demands (e.g., dependents);  
| • Physical situational demands (e.g., a house or other property that needs to be maintained, residence in an isolated or difficult-to-access location, etc.);  
| • A reported or suspected abusive situation;  
| • Isolation. |

| **The presence of attenuating factors** | • Adequate family support and a reliable social network;  
| • Responsible and safe behaviour;  
| • The ability for self-critique regarding their situation. |

If recent events suggest that the patient is no longer able to ensure their well-being or look after their health, especially if they live alone.

The need for protection

A need for protection should be suspected if an incapacitated patient has to be assisted or represented in the exercise of their civil rights. The need can result from isolation, the duration of the incapacity, or the nature or state of their affairs.

If there is any uncertainty regarding the need for protection

- Refer the patient and caregiver to a social worker for a psychosocial assessment of the situation and a possible recommendation to open protective supervision (e.g., tutorship or curatorship) that will meet the patient’s needs.
- Check if there is a mandate in case of incapacity:
  - If there is one, request that it be homologated;
  - If there is not, ask the court to open protective supervision commensurate with the determined degree of incapacity.

Legal protection

A patient’s incapacity does not always require the opening of legal protective supervision, especially if their needs are being met and they have an adequate support network.

For health and social services professionals

- Evaluations required for an application to open protective supervision or for the approval of a mandate in anticipation of incapacity:
  - Physician: a medical evaluation (determines the degree of the patient’s incapacity);
  - Social worker: a psychosocial evaluation (determines the patient’s support network and need for protection).
- Evaluations useful for obtaining a complete profile, if necessary:
  - Occupational therapist: an evaluation of the patient’s functional skills and level of autonomy;
  - Neuropsychologist: an evaluation of the patient’s cognitive functions or superior mental functions;
  - Nurse: an evaluation of the patient’s physical and mental condition.

Note: Under Bill 21, some of these evaluations are reserved activities.

An incapacitated person of a full age and refusal of health care

In the event that an incapacitated person of full age categorically refuses care that is deemed necessary, an application for a treatment or housing order must be presented to the court.

Treatment or housing order

The physician must:

- Determine if the patient’s health is interfering with their capacity to give consent;
- Document the patient’s problems understanding, processing or making sense of the following information:
  - The nature of their illness;
  - The nature and purpose of the care;
  - The risks associated with the care;
  - The risks involved if the care is not provided.

Note: An order for treating or housing a patient against their will must be obtained in order to treat or house them without their consent.

Capacity to consent to care

A person of full age under protective supervision, such as tutorship or an approved mandate:

- May be deemed capable of consenting to or refusing care.
- Conversely, a capable patient may occasionally or temporarily be incapable of consenting to care.
# Information for Health and Social Services Professionals

|--------------------------|--------------------------------------------------|

# Information for the Patient or Caregiver

Main references


