

*This decision support tool is provided solely for guidance, does not replace a professional's judgment and can be adapted to institutional circumstances. The recommendations were developed using a systematic approach supported by the scientific literature and the knowledge and experience of Québec clinicians and experts. For further details, go to [inesss.qc.ca](http://inesss.qc.ca).*

## Elements to consider when disclosing the diagnosis



### 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.



### Capacity to consent to health care

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**.



### 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.



### 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.

\* 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.



### 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 non-pharmacological (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\*;
- ▶ 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 [SECTION 6 OF 6](#)



## For the patient (and caregiver)

- ▶ 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.



## Special cases

Emotional reactions or anxiety	<ul style="list-style-type: none"> <li>▶ Stop disclosing the diagnosis and calm and reassure the patient;</li> <li>▶ Continue the disclosure when the patient asks you to do so;</li> <li>▶ Plan a follow-up with a family member, if possible, or with the local health services or local social services.</li> </ul>
Patient denial or impaired awareness of the disease (anosognosia)	<ul style="list-style-type: none"> <li>▶ Do not try to convince the patient;</li> <li>▶ 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;</li> <li>▶ Inform local home support services, as needed, and tell the patient that a request for assistance has been made.</li> </ul>
Refusal of care	<ul style="list-style-type: none"> <li>▶ If the patient is incapacitated and refuses health care, go to the section <b>steps to be taken after the diagnosis and during the follow-up</b>.</li> </ul>

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## 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* (CISSSS) 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.