

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.

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	<ul style="list-style-type: none"> ▶ Do another objective assessment of the patient's: <ul style="list-style-type: none"> • Cognitive functions; • Functional autonomy; • BPSD.
Nutritional status	<ul style="list-style-type: none"> ▶ Be especially vigilant for: <ul style="list-style-type: none"> • Malnutrition; • Weight loss; • Check with the caregiver to see if the patient is able to feed themselves properly. <p>If need be, and depending on the resources available at the facility, the patient and caregiver should be referred to a nutritionist.</p>
Medications	<ul style="list-style-type: none"> ▶ Check the medications and therapeutic adherence with the patient or caregiver: <ul style="list-style-type: none"> • Any changes to or addition of drugs; • Drug interactions; • Adverse effects; • Drug cascades. <p>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.</p>
Autonomy, capacity, need for protection and documents	<ul style="list-style-type: none"> ▶ Review and check the following as needed: <ul style="list-style-type: none"> • 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.



Reisberg and collaborators' Global Deterioration Scale, 1982¹

Stage 1	▶ No cognitive decline (normal functioning): <ul style="list-style-type: none"> • Experiences no problems in daily living.
Stage 2	▶ Very mild cognitive decline (it may be normal age-associated changes or early signs of AD): <ul style="list-style-type: none"> • Forgets names and locations of objects; • May have difficulty finding words.
Stage 3	▶ Mild cognitive decline (present, in some cases, in the initial phase of AD): <ul style="list-style-type: none"> • Has difficulty travelling to new locations; • Has difficulty functioning at work.
Stage 4	▶ Moderate cognitive decline (mild stage of AD): <ul style="list-style-type: none"> • Has difficulty performing complex tasks (finances, shopping, planning a dinner for guests).
Stage 5	▶ Moderately severe cognitive decline (moderate stage of AD): <ul style="list-style-type: none"> • Needs help to choose clothing; • Needs to have someone remind them that it is time to take a shower or bath.
Stage 6	▶ Severe cognitive decline (moderate to severe stage of AD): <ul style="list-style-type: none"> • Loss of awareness of recent events and experiences in their life; • Requires assistance taking a bath; may have a fear of taking a bath; • Needs an increasing amount of help toileting or is incontinent.
Stage 7	▶ Very severe cognitive decline (severe stage of AD): <ul style="list-style-type: none"> • Uses a very limited vocabulary, which will soon shrink to only a few words; • Loses the ability to walk and sit; • Requires help with eating.

1. Reisberg B. et al. Am J Psychiatry 1982; 139: 1136-39