

# Development of a Patient Decision Aid for deprescribing cholinesterase inhibitors

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**Background:** Engaging consumers (people living with dementia and their carers) in the shared decision-making process with their healthcare professional is an essential element of providing patient-centred care. Decision aids are tools that can facilitate shared decision-making and produce treatment decisions that align with the consumer's goals and preferences.

**Aim:** To develop a Decision Aid for deprescribing or continuing ChEIs. This is designed to complement an evidence-based deprescribing guideline for ChEIs and memantine, which includes an algorithm to help clinicians deprescribe these medications appropriately.

We developed a decision aid for consumers to facilitate shared decision-making with their healthcare professional about continuing or stopping their Cholinesterase inhibitor (ChEI)

## Should I continue or stop my dementia medicine?

This information sheet helps people living with dementia, their carers and family to have a conversation with their healthcare professional. Do not change your medicine(s) without speaking with your doctor, nurse practitioner or pharmacist.

### 1. Why is this choice being offered?

Donepezil (Aricept®), rivastigmine (Exelon®), and galantamine (Razadyne®) are used to treat the symptoms of dementia. These medicines are called **cholinesterase inhibitors**. In some people living with dementia these medicines can offer some relief from symptoms for a limited time.

In some situations, it is a good idea to consider a trial of stopping the dementia medicine:

- It has **not been helpful** since it was started or is **no longer helpful**
- The condition has progressed to **later stages of dementia** (e.g. receiving palliative care)
- The **harms** of the medicine (side effects) outweigh the **benefits**

### 2. What are the options?

- ● ● Continue taking the dementia medicine  
The same care and monitoring will be provided. You will be given the opportunity to try stopping the dementia medicine in the future.
- Trial stopping the dementia medicine  
This may involve slowly reducing the dose before stopping. You will receive extra monitoring during the process, and be told what symptoms can occur. The medicine can be started again if necessary.

### 3. What else should I know?

- There is not one **"right"** decision. The right decision for you depends on what is important to **you** and your health.
- Stopping the medicine **doesn't mean giving up** - it means being on the right medicines at the right time for you.
- Stopping the medicine **doesn't accelerate the disease**, hasten death or cause irreversible damage.
- The medicine **can be started again** if necessary.

If you are making this decision for a loved one, this may seem hard. The healthcare professional is here to help. Consider what your loved one would choose. What do they value the most?

### Design and methods:

Development involved defining the purpose, scope and target audience, and assembling a steering group to review the prototype draft's content and format. It also involved conducting one-on-one interviews with healthcare professionals and consumers.

**Results:** A steering group composed of clinicians and consumer representatives was assembled. The group reviewed the prototype and changes were made for further testing. One-on-one interviews were conducted with 3 General Practitioners and 7 consumers (one person living with dementia and 6 carers). The research team synthesised the findings to complete two rounds of modification. Iterative changes to improve the content, format and structure of the decision aid were made.