

Empowering people living with dementia and their carers to talk to their healthcare professionals about their medicines: Co-designing the PRIME tool

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People living with dementia often take a large number of medications. Some of these medications may have been beneficial when originally prescribed but may become inappropriate overtime with changing goals of care.

Deprescribing is reducing or stopping harmful medications. Taking a **smaller number of medications has many potential benefits** (e.g. fewer falls, better quality of life). The aim of our research is to co-design a consumer-centric, educational tool – the PRIME tool – to empower people living with dementia and their carers **to initiate a deprescribing conversation with their healthcare professionals.**

The PRIME tool stands for **PR**eparing people living with dementia and their caregivers to **I**nitiate deprescribing conversations about Medications (PRIME) tool. We are interested in your **feedback on the content and formatting of the tool as well as its usability in practice.**

Our questions for you

- 1- Can you think of a time the PRIME tool would be useful to use to initiate conversations about your medications in practice?
- 2- Do you think we should have the same or different versions of the tool for people living with dementia and their carers? Why?
- 3- In what format (*paper brochure* or *mobile application* or *website*) would you it be best for you to receive and use the PRIME tool?

Future involvement opportunities

- Why:** We have co-designed the first version of the PRIME tool with a steering group and now we want consumer and healthcare professional views on the usability of the tool
- Who:** People living with mild cognitive impairment or mild-to-moderate dementia who are able to provide their own consent and are prescribed at least one regular medication, and/or their carers, or healthcare professionals who care for them
- How:** Participating in a 1-hour Zoom interview. Participants will receive a \$60 Coles or Woolworths gift card as a token of our appreciation for their time participating in the interview
- When:** Between October 2022 to January 2023
- Where:** Online via Zoom

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The purpose of the PRIME tool is to:

- Empower you to start a conversation with your healthcare professional about how your medicines may be impacting your day-to-day activities
- Increase your awareness that some of your medicines may be linked to falls, confusion, or sleepiness

Get familiar with your medicines or the medicines the person you care for takes by checking what medicines they take and understanding the reason they take them. Medicines can include prescription medicines or medicines purchased over the counter.

Do not change your medicine(s) without speaking with a healthcare professional

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CONTACT US

Do you have questions about the PRIME tool?

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The PRIME tool was co-designed with people living with dementia, their carers, healthcare professionals and researchers from:



How to PRIME a conversation about your medicines with your healthcare professional



This brochure is the PRIME tool for people living with dementia or mild cognitive impairment, their carers and healthcare professionals. It can help you or your carer start a conversation with your healthcare professional about stopping or reducing one or more of your medicines.

↑ Front, middle and last page of the PRIME brochure

| BACKGROUND | SELF REFLECTION | CALL TO ACTION |
|---|--|--|
| <p>The benefits and harms of medicines can change over time</p> <p>It important to regularly review the benefits and harms of your medicines with your healthcare professional.</p> <p>Your medicines may provide you benefits or cause harms, such as falls. The potential benefits and harms of your medicines can change over time and if what is important to you changes or if your goals of care change. It is important to consider the trade-off between your medicines' potential benefits and harms.</p> <p>Reasons why you stop a medicine</p> <ul style="list-style-type: none">• You or the person you care for is experiencing side effects from the medicine(s) such as: • The potential harms of the medicine(s) outweigh its possible benefits• The condition has progressed to later stages of dementia• You want to manage the condition with less medicines• The condition and its symptoms (e.g. behaviors) may change over time | <p>Please circle your answer</p> <ol style="list-style-type: none">1. Do you think you take too many medicines? Yes No Maybe2. Do you think that you are taking any medicines that you don't need anymore? Yes No Maybe3. Do you get stressed if changes are made to your medicines? Yes No Maybe4. Have you had a bad experience in the past when a medicine was stopped? Yes No Maybe5. Do you know what medicines you take? Yes No Maybe6. If your doctor said it was possible, would you stop one of your medicines? Yes No Maybe7. Overall, are you satisfied with your medicines? Yes No Maybe <p>Reflecting on your medicine list, what medicine(s) you would like to reduce or stop?</p> <p></p> | <p>Thinking about your medicine list</p> <p>Are there any medicines you want to talk to your healthcare professional about? List them here.</p> <p></p> <p>How to start a conversation with your healthcare professional about your medicines</p> <p>You may choose to bring a copy of this PRIME tool to your next medical visit to share with your healthcare professional. To start a conversation with your healthcare professional about your medicines, you could say: "I'm taking a lot of medicines; are there any that could be stopped?" or "I don't like taking _____ (write name of medicine). I'm worried it's giving me side effects, or I don't think it is working. Could you please review it?" or "I'm not sure why I take _____ (write name of medicine). Could we talk about this?" or "I would like you to please review if I still need this medicine. Could I possibly stop taking this medicine?" or "I'd like to have all my medicines reviewed."</p> |

↑ Inside pages of the PRIME brochure



Scan the QR Code to get in touch with Nagham about consumer involvement on this project.

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