



MONASH  
University

For consumers

# 10 Guiding principles

to support the safe and appropriate use of medication for the management of **urinary incontinence** in **people living with dementia**





# Urinary Incontinence

**– the accidental leakage or involuntary loss of urine - is a common and often distressing condition for people living with dementia. It can affect a person’s comfort, dignity and overall quality of life.**

Managing urinary incontinence can be challenging, but support is available. You, or the person you are caring for, should work together with your healthcare professional to find the approach that best suits the person living with dementia.

The healthcare professional you first speak to, may be the general practitioner (GP), who can provide support by assessing symptoms and discussing initial strategies. If needed, the GP may refer you to other health

professionals such as a continence nurse, pharmacist, geriatrician or urologist for further advice or assessment. Throughout this resource, we use the term ‘healthcare professional’ to refer to the range of people who may be involved in helping manage urinary incontinence. This includes doctors, nurse practitioners, nurses, pharmacists and other health professionals who work together in the community or residential aged care facilities.

The decision to use medication to manage urinary incontinence can be complex and is generally only considered after non-medication strategies have been trialled. Safe and appropriate use of medication is best supported by the use of a shared decision making approach, therefore it is important that you feel informed and supported during this process. To help with this, we have developed this resource together with people living with dementia, their carers and healthcare professionals.

# Who is this resource for?

This resource is for consumers, people living with dementia or mild cognitive impairment and their carers.

# How to use the resource

The ten Guiding Principles have been developed to help you feel more confident when considering medication treatment options for the management of urinary incontinence. The Guiding Principles will support you through the full journey from considering medication, to starting a medication, monitoring the medication and stopping the medication.

This resource has been developed to support shared decision making, empowering you or the person you are caring for to advocate for care that aligns with your goals, values and preferences. You may wish to use the resource before, during or after your discussion with your healthcare professional.



The question prompts may be helpful to start a conversation with your healthcare professional, or to ensure you have all the information you need to make an informed decision.



Quotes from those who helped shape this resource are included throughout.

# Guiding Principles

This page provides an overview of the ten Guiding Principles. The rest of the resource will walk you through each Guiding Principle in more detail.

**#1**

**Consideration of urinary incontinence type and contributing factors is important to guide the decision-making process of choosing the most appropriate medication to manage symptoms.**

**#2**

**Individualised treatment goals for the management of urinary incontinence should be discussed and documented.**

**#3**

**Non-medication strategies for urinary incontinence should be trialled before medications and continued alongside medications.**

**#4**

**Shared decision making should be utilised to identify the urinary incontinence medication that most aligns with goals of care.**

**#5**

**Treatment expectations should be discussed and documented.**

**#6**

**Medication for urinary incontinence should be started at a low dose and date of next review should be planned in advance.**

**#7**

**Information about urinary incontinence medication should be provided in an appropriate format.**

**#8**


**Medication for urinary incontinence should be monitored to ensure meaningful, person-centred benefits and ongoing need.**

**#9**

**Medication for urinary incontinence should be proactively monitored for potential harms to guide ongoing use.**

**#10**

**Medication for urinary incontinence should be regularly reviewed and deprescribed as appropriate.**



## Guiding principle

# #1

**Consideration of urinary incontinence type and contributing factors is important to guide the decision-making process of choosing the most appropriate medication to manage symptoms.**

Before thinking about using medication to help with urinary incontinence, it is important to know what type of urinary incontinence is being experienced. There are different types of urinary incontinence (e.g., needing to use the toilet urgently, leaking when you cough or move, or not being able to recognise a full bladder) and not all medications work for every type.

If you or the person you are caring for is experiencing new or worsened symptoms of urinary incontinence, it is important to look into what may be causing it. Things to check could include:

- current medications that are being used (e.g., medications taken for the treatment of dementia)
- existing health conditions that may affect the bladder (e.g., urinary tract infections, progression of dementia)
- how safely a person can move around and their daily habits (e.g., how often the toilet is used, how much fluid is consumed, how physically active someone is)

It is a good idea to speak about this with a healthcare professional, making sure everything is written down in your medical record to help everyone involved make informed choices.



***“... really, the starting point is getting the diagnosis of the right kind of incontinence.”***

*- Prescriber*



### Question prompts

What type of urinary incontinence do I have?

Could any of my current medications, health conditions or daily habits be making my urinary incontinence worse?



## Guiding principle

# #2

**Individualised treatment goals for the management of urinary incontinence should be discussed and documented.**

It is important to have a thorough conversation about how you, or the person you are caring for, would like to manage urinary incontinence symptoms and the specific treatment goals.

Everyone’s goals can look different, and may change over time. Some people might want to reduce how often leaks happen during the day or during the night, while others may focus on feeling more comfortable and confident during outings.

Once the goals of treatment are clear, it is helpful to make sure they are written down in your care plan so that the healthcare team and carers are on the same page and treatment stays aligned with what matters to you or the person you are caring for.



***“I prefer to go on the goals. What they [person living with dementia] specifically have come to achieve. Some [people] don’t actually want treatment... they just want containment and funding [for continence aids].”***

- Continence nurse



### Question prompts

What am I hoping to achieve with treatment (e.g., reducing leakages, feeling more confident when going out, better sleep)?

Does my healthcare team know what I am hoping to achieve with treatment?



## Guiding principle

# #3

**Non-medication strategies for urinary incontinence should be trialled before medications and continued alongside medications.**

Medications to help manage urinary incontinence should only be used after person-centred, non-medication strategies have been trialled and have not met the goals of care.

Non-medication strategies may include behavioural and lifestyle strategies such as regular toileting, dietary changes such as reducing caffeine, or containment with the use of continence care products (e.g., pads or pants).

You should speak to your health professional to learn more about non-medication strategies and options, including which strategies would be best for you. If a medication is started, non-medication strategies should still be used alongside medications.



***“If all these [non-medication] strategies fail and the client’s goal is not met, then based on their cognitive capacity and considering other factors, we recommend medication.”***

- Continence nurse



### Question prompts

What non-medication strategies should I try?

How long should I try the non-medication strategies for?



## Guiding principle

# #4

**Shared decision making should be utilised to identify the urinary incontinence medication that most aligns with goals of care.**

There are different types of medications to help manage urinary incontinence. Before choosing a medication, it is important to have a conversation with your healthcare professional to discuss the different options. This conversation should include talking about how each medication might help with urinary incontinence symptoms, possible side effects, whether the medication might impact thinking and memory as well as how much it might cost.

Everyone's goals and needs are different, so the best choice will depend on what matters most to you or the person you are caring for. The type and symptoms of dementia that you, or the person you are caring for, are experiencing, can impact whether or not a certain medication is safe to use. This conversation should be documented in your medical record.



***“[The urinary incontinence medication] was so expensive... I’m not sure I would have accessed it if I had to pay the \$80. So, the fact that I was going to get it at the PBS [Pharmaceutical Benefits Scheme] price was an attraction.”***

*– Person living with dementia*



### Question prompts

Are there medications that might help my urinary incontinence symptoms?

What are the possible benefits and harms of the different medication options?



## Guiding principle

# #5

### **Treatment expectations should be discussed and documented.**

Before starting a medication to manage urinary incontinence, it is important to talk through what to expect with the healthcare professional. Together, it is helpful to set realistic goals for what the medication might help with, discuss how long it may take to notice improvement and talk about the possible side effects and when they might happen. These details should be written down in your medical record so that you, or the person you are caring for, can keep track of these points and notify the health professional if there are any health-related changes.



*“I think there needs to be a more in-depth discussion of ‘this could happen’... making sure that there is a plan B, plan C if things don’t quite work out with that medication... to feel both informed and have expectations of what it [medication] could potentially do in a positive way, but also kind of anticipating what negative consequences could also happen.”*

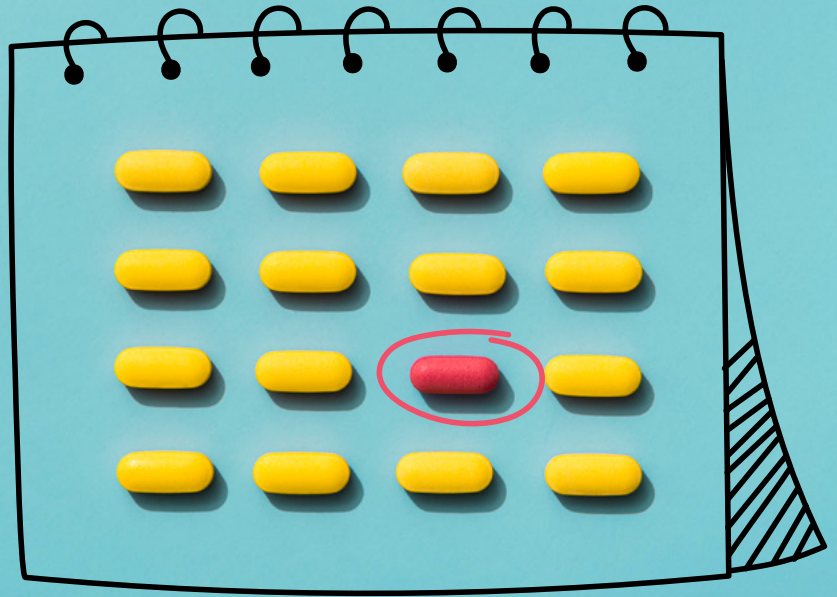
– Carer



#### **Question prompts**

What improvement in my symptoms should I expect with this medication?

What potential side effects may occur, and when might they appear?



## Guiding principle

# #6

**Medication for urinary incontinence should be started at a low dose and the date of next review should be planned and documented in advance.**

If the decision is made to start a medication for management of urinary incontinence, it is best to begin with a low dose. If you or the person you are caring for feels okay on this low dose, and the medication has not completely met the treatment goals, the dose may be gradually increased.

To make sure the medication is working and is safe, you or the person you are caring for should check in with the healthcare professional every 2-4 weeks during this process.

It is also important to talk about, plan and write down the next date to review the medication to ensure regular planned reviews are occurring.



*“But I would say that they [medications for urinary incontinence] should be trialled.... a professional person keeps an eye on them [person living with dementia] for the time that they are using it, [including] what the results are...”*

– Carer



### Question prompts

Do I need to start on a low dose of this medication?

When should I check back in with my healthcare professional to review if the medication is working?



## Guiding principle

# #7

**Information about urinary incontinence medication should be provided in an appropriate format.**



*“As a carer, I kind of really appreciate it when things are really clear and [written in] bullet points, very clear, plain English, so it’s just quick for me to digest. I felt like I’ve understood it and I feel like I’m informed. And therefore, more confident about what’s being prescribed, and what I should be looking out for.”*

– Carer

When starting a new medication to manage urinary incontinence, the healthcare professional should clearly explain key information about the medication. This information could include:

- why the medication is being used
- what the medication looks like
- how and when to take the medication
- what benefits the medication may offer
- what side effects might happen and how to manage them

This information should be shared in a way that is easy to understand. It is ideal for the healthcare professional to provide both spoken and written explanations so that you, or the person you are caring for, can ask questions, refer back to details and feel confident starting a new medication.



### Question prompts

Have I received enough information to take my medication safely?

Have I received written information, or written down my own notes, so that I can refer back to the information at a later date?



## Guiding principle

# #8

**Medication for urinary incontinence should be proactively monitored to ensure meaningful, person-centred benefits and ongoing need.**

Once a medication is started to help with urinary incontinence, it is important to check regularly whether the medication is actually helping in ways that matter to you or the person you are caring for. How often monitoring occurs will depend on you or the person you are caring for and the medication. This should be discussed with your healthcare professional.

Monitoring can include looking at whether urinary incontinence symptoms are improving (e.g., reducing number of leakages at night, increased comfort during outings) and checking if the changes align with the goals of care. This monitoring should involve you, or the person you are caring for, as well as your healthcare team.

Keeping track of changes in urinary incontinence symptoms can help decide if the medication is still needed or if changes should be made.



***“I wanted so much for it [newly prescribed medication for urinary incontinence] to be better [more effective compared to previously trialled medication] that I think it was better. But honestly over time, I’m not sure it was any better.”***

*– Person living with dementia*



### Question prompts

Do I know how to monitor if the medication is helping with my urinary incontinence symptoms?

Do I know how often I should be checking with my healthcare professional to monitor if my medication is helping?



## Guiding principle

# #9

**Medication for urinary incontinence should be proactively monitored for potential harms to guide ongoing use.**

Once a medication is started to help with urinary incontinence, it is important to monitor for signs that the medication might be causing problems. This means looking for changes such as increased confusion, falls, dry mouth, constipation, or anything different in your health or behaviour.

Regular monitoring helps you to notice and manage potential side effects before they get worse and ensure that the medication is still a good fit. If something changes in your health that could be related to the medication, it is important to write it down and discuss it with your healthcare professional. This information is helpful when deciding whether or not to keep using the medication.



***“The first question we want to know when you’ve started a drug... is, can you tolerate it...if the side effects are intolerable, even if it’s causing good then it’s often difficult to justify. So, you might have to try more than one drug.”***

– Prescriber



### Question prompts

Do I know what signs or symptoms to look out for that might mean the medication is causing harm?

Do I know what to do if side effects occur?



## Guiding principle

# #10

**Medication for urinary incontinence should be regularly reviewed and deprescribed as appropriate.**

Over time, it is important for you, or the person you are caring for, and your healthcare professional to regularly check if the medication is working well, is safe and continues to meet your personal goals of care. If the medication is not helping as expected, or if there are concerns about side effects or other health changes, it may be time to consider lowering the dose or stopping the medication. This might happen when the goals of care are not being met, the harms or risks from the medication start to outweigh the benefits or when there are changes in your goals of care. If you take multiple medications, it might be helpful to ask your healthcare professional for a comprehensive medication review.

Any decision to deprescribe (i.e., lower or stop) the medication should be made together with a healthcare professional in a way that respects your values, preferences and evolving needs.



***“... there are some medications that may worsen their [person living with dementia] cognition or their memory, and it may be worth trialling a reduction of the dose and seeing if that helps to improve the symptoms... So, I give them the pros and cons of the choice and let them be involved in that decision-making process.”***

– Pharmacist



### Question prompts

Is continuing this medication still the best option for me?

When and how should I stop taking this medication?



