



Medication: It's Your Choice

How much do you know about your medication?

Did you know that what medications you take is your choice and that you have control over what you take?

This booklet equips you with the ability to have an informed and active role in your decisions about what medications you take.



Australian Government
Aged Care Quality and Safety Commission

Supported by funding from the Australian Government

Ray's story.

Ray* returned to his aged care facility after a surgery. His daughter Susan noticed he'd been prescribed a new medication and recalled the changes she saw in Ray:

"At that stage he couldn't walk, only shuffle, he was very, very depressed, just crying all the time. And he couldn't swallow... He would say, "My mind is a hell to me." He wouldn't be engaged in a conversation."

Susan was extremely disturbed by the changes with her father, but she was unable to convince the nursing staff to stop giving him the drug. She decided to move him to a new facility, where he immediately began to wean off the medication. Susan described the change:

"Now he's very, very much like his old self. He's Irish, with a thick Irish accent, and he's hilarious. He's very funny. He likes to just go out and have lunch. We'll often take a picnic. We'll go for walks on the beach. If there's music on in a pub, we'll go in the afternoon, when he's not too tired."

(Case study from ADA Australia - "Fading Away: How Aged Care Facilities in Australia Chemically Restrain Older People with Dementia", Human Rights Watch 2019)





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For more information and resources, visit opan.com.au/yourchoice
opan.com.au | 1800 700 600

**All names in real life stories/case studies have been changed to protect the identity of those individuals.*

It's your choice. It's your right.

It doesn't matter what age you are or what medical condition you might have – you always have the right to be involved in decisions about your care. This includes decisions about your medication and how you wish to live your life.

Everybody involved in your care must respect your rights, as well as your values and preferences – whether it's your GP, nurse, carer, family, friends or representatives.

Medications can play an important role in helping you to live comfortably, stay safe and live longer. However, some medications may not work as expected, may make you feel unwell, and may bring on unwanted side effects or changes in behaviour.

You have the right to be provided with information about your medication, including how it works and if there are any potential side effects that may impact on your quality of life.

There are often alternative treatment options that will be more effective than medication in supporting you. It is your role to choose if medication is right for you. Sometimes, that may include making an informed choice to say no to a recommended medication option.



Remember, it is your right to have control over your medication.

Kevin's story.

Kevin*, a gentleman in a rural aged care facility, would become very frustrated because he was locked inside. He could see out the window but was not allowed outdoors as some of his carers thought that this was safer for a person living with dementia.

Eventually someone said, "Let him out and just watch, he can't go far." So they did. Kevin walked out to the garden, through

a small gate and across to the main wire fence. After standing there and looking at the cows for a while, he turned around and walked calmly back inside. Kevin was a farmer all his life, and he wanted to check on the cows. That walk was a meaningful activity for him and something that he was still able to do.

The opened door was better than a dose of medicine.



What is an informed choice?

An informed choice is when you make a decision about your medical care, or the care of your loved one, with the knowledge and understanding of the benefits and potential risks involved.

It is both your right and your role to choose which option is right for you, or for the person you care for, and to commence or discontinue a medication.

Informed choice means being able to:

- ★ Understand the reason for the medication
- ★ Understand the available options to you (including not taking the medication)
- ★ Understand the risks and benefits of those options
- ★ Come to a considered decision, without any undue pressure from others
- ★ Communicate your decision
- ★ Organise a review of your treatment plan regularly
- ★ Have ongoing discussions about your medication



You can say 'no' and choose not to take a medication.

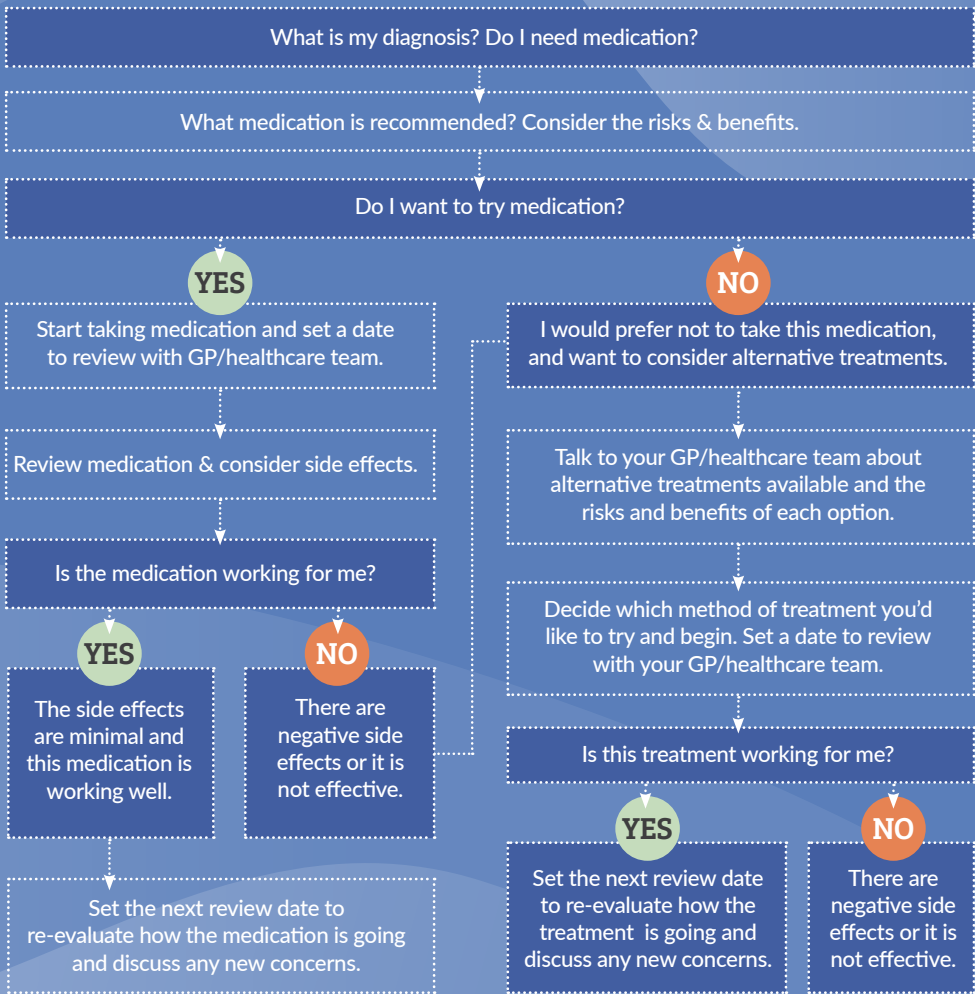


You can also change your mind at any time, even after you have started to take a medication.



How to decide what's right for you.

This process can help you discuss your medication with your doctor and make informed choices around medication. It can also be helpful to use this process for any medicines you're already taking or want to review.





Psychotropic medications.

Some medications can change thoughts or behaviour or have an impact on your day to day life.

These medications are called **psychotropics**, but they can be known by many other names.

These have often been overused in Australia amongst older people and can have serious side effects.



It's important that you understand what these medications are, why you might take them and how they may affect your ability to make decisions.

(For a list of common psychotropic medications, go to: www.agedcarequality.gov.au/sites/default/files/media/acqsc_psychotropic_medications_v10_hr.pdf)

When should I take these medications?

- ★ There will be instances when these medications are appropriate for the person's medical condition, such as when they're experiencing severe agitation, depression, aggression and psychosis, which may put you at risk of harm.
- ★ These medications should only be used in specific circumstances. When they are used to control a person's behaviour, rather than for treatment, it is called chemical restraint.
- ★ When you are taking these medications, they should be monitored closely and reviewed on a regular basis

What can happen if I take these medications?

- ★ Evidence shows that psychotropic medications can lead to increased falls, fractures and confusion amongst older people, as well as an increased risk of pneumonia, stroke and early death.
- ★ These medications can also reduce your awareness, ability to interact, and ability to experience joy, happiness and a quality of life - which can result in you feeling disconnected, disoriented or distressed.
- ★ It's important that you ask questions about the potential side effects of any medication that your GP recommends, so that you can understand the impact this medication will have on your body.

What is a psychotropic medication?

- ★ A psychotropic is a type of medication that acts on the brain and affects a person's mood, perception, behaviour or thoughts. It's often prescribed for mental health conditions, including depression, schizophrenia and anxiety.
- ★ Taking these medications can effectively manage severe mental health conditions, but can make some people feel confused, unsettled, panicky or frightened.



Are there alternatives to medication?

In some cases you may want to try a non-medication option instead of taking a new medication.

Some medical conditions can cause changes in behaviours. You may be feeling anxious about the changes you've noticed.

There are resources to support you, that can help you to understand the changes you're experiencing and identify what might be causing those changes. Ask about alternatives.



Alternative treatments such as meditation, music and counselling support can help you to manage your condition.

Joseph's story.

Joseph* was recovering from a severe stroke in hospital. He often heard doctors and nurses talking about him and his future around his bed and also talking with his family members while ignoring him.

Joseph's daughter said, *"When he became very aggressive with them, he was put on antipsychotics. After my two visits he was able to explain to me how much he resented being ignored and discussed by others. I was able to convince the hospital staff that he could understand all they were saying even though his speech was impaired and he was paralysed. Once Joseph was included in discussions about his health and future, he regained his calm personality."*

Who is my decision-maker?

It's important to plan ahead and discuss your medical care and medication choices with your loved ones.

There are times when you may want to seek help and support from others to make a decision about your treatment options. There are other times when you may need someone you trust to make that decision for you, based on your values and preferences, and what you would want.

That's why you should have a conversation with them now,

so they know what decisions to make on your behalf if they are required to do so in the future.

It's important for everyone to have this conversation with their loved ones, but especially if you may be at risk of losing your ability to make decisions in the future.



You can choose who will speak for you. Your supporter or substitute decision-maker may be a family member, carer, friend, representative or support person – it should be someone you trust.

Do you need to know more about supported or substitute decision-making?

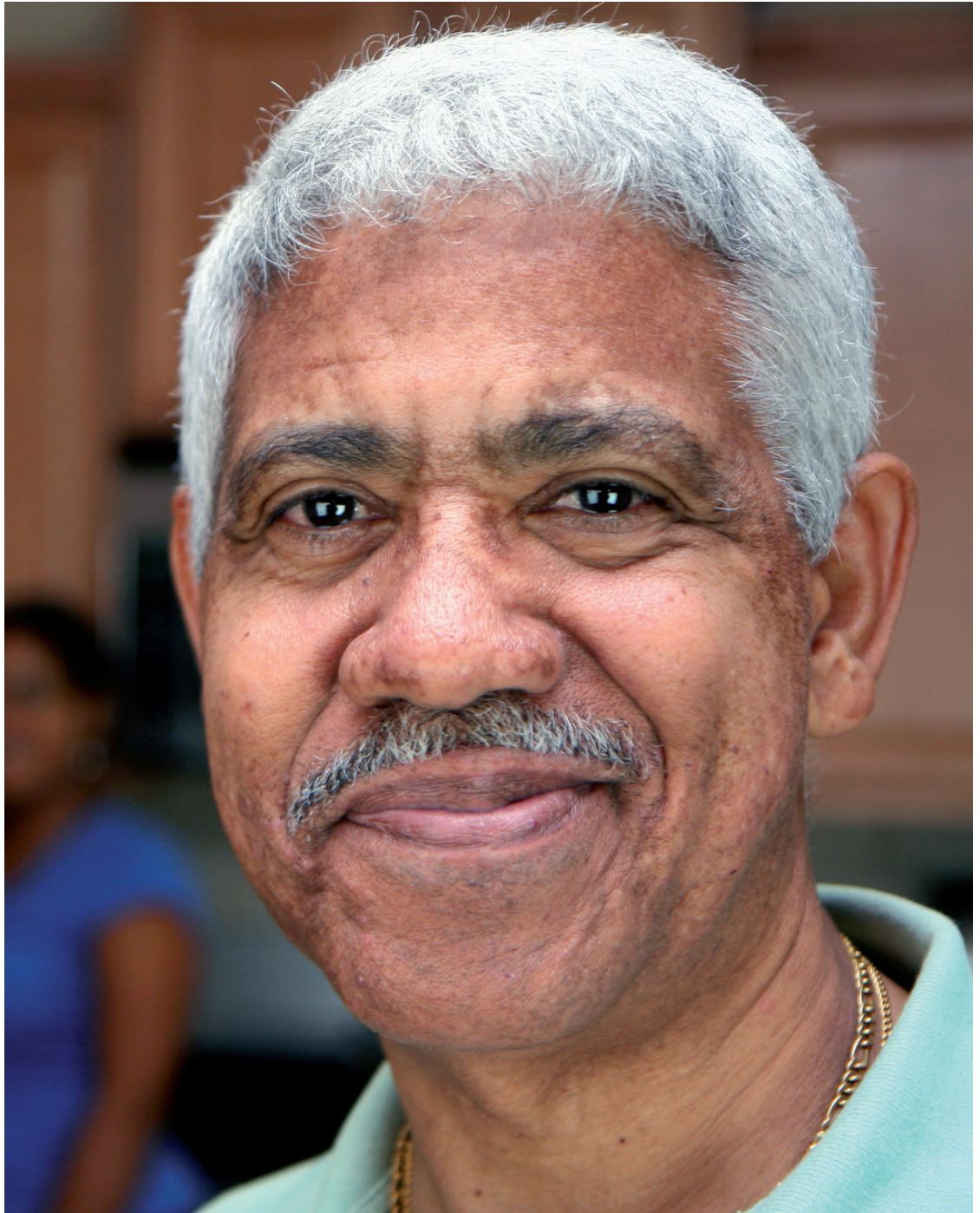
Your substitute decision-maker may be known as the person responsible, guardian or attorney, depending on which state or territory you live in.

Their role is to take into consideration your values and wishes when making decisions about your treatment and medication, if you can no longer make the decisions yourself.


For more information, visit the following websites:

ADACAS Advocacy
adacas.org.au/supported-decision-making/supported-decision-making/

Advance Care Planning Australia
advancecareplanning.org.au







Questions to ask about your medication.

Next time you visit your GP, take this list of questions with you.

These questions are also helpful for reviewing medication that you're taking.

- ★ What am I taking?
- ★ How should it help me?
- ★ What are the side effects?
- ★ What could happen if I don't take it?
- ★ What are the alternatives (including non-medication alternatives)?
- ★ When can my medication be reviewed?

Here are some other important questions you might want to ask:

- ★ What is my diagnosis?
- ★ What are the benefits of taking this medication?
- ★ What are the risks of taking this medication?
- ★ Will taking this medication affect how I live my life?
- ★ How long will I need to take this medication for?
- ★ How much does this medication cost?
- ★ What can I do if I am having trouble understanding my condition or treatment options?



You should also ask these questions about any medication you are already taking. It's never too late to ask.

What role does everyone play in the decision-making process?



Remember, it is always your right and your role to make the final decision.

What is my role?

- ★ To make an informed choice about your treatment options and medication, and how you wish to live your life.



What is the role of the pharmacist?

- ★ To support you with your medication management.
- ★ To review your medication and discuss how it's working for you.
- ★ To supply the correct medication.



What is the role of my GP?

- ★ To present treatment options that may be of medical benefit to you, in a way that you and your decision-maker can understand.
- ★ To provide you or your decision-maker with clear information about your medication.
- ★ To prescribe your medication after you consent to it, to review it regularly and look out for side effects.



What is the role of the aged care provider?

- ★ To support you or your decision-maker to make an informed choice about your treatment options and medication and to facilitate ongoing discussions and reviews
- ★ To provide you with person-centred care and support.
- ★ To uphold the Charter of Aged Care Rights.



What is the role of my decision-maker?

- ★ To make an informed decision about your treatment options and medication, when you have lost the capacity to do so, based on the decision that you would have made.
- ★ To make this decision based on your expressed values and wishes.



Help is available.

If you're concerned about the medication you or your loved one is taking, you should speak to your GP or aged care provider first. It is their responsibility to listen to your concerns and discuss your options with you.

If you are not getting all the information you need about your medication, you have the right to speak to someone who will give you this information.

For further support with this:

- 1) You can ask for an appointment with your doctor, or ask for a specialist review or second opinion.
- 2) If you are receiving clinical home care or you are in an aged care home, you can formally request a case conference or a medication review with your provider.
- 3) You can reach out for free and independent support by contacting OPAN, the Older Persons Advocacy Network on **1800 700 600** or by visiting **opan.com.au**
- 4) Or, you can raise a complaint with the Aged Care Quality & Safety Commission by calling **1800 951 822** or online at **agedcarequality.gov.au/making-complaint**



If you need an interpreter:

Advise the aged care advocate or the Commission when you call, or call the Translating and Interpreting Service directly on **131 450** and ask them to transfer you.



If you are hearing or speech impaired:

You may wish to make contact through the National Relay Service:

TTY users: **1800 555 677**

Speak and Listen users: **1800 555 727**

Internet relay users: connect to the **National Relay Service** and enter the phone number for the advocacy line or the Commission.



Remember, it is your right to be informed about, and to have control over, your medication. For more information, and for further resources on older people and medications, visit **OPAN at opan.com.au/yourchoice** or call **1800 700 600**.

You may find the following resources helpful.



healthdirect provides free, trusted health information and advice.

healthdirect.gov.au/medicines
1800 022 222

Free call: 24 hours, 7 days a week.
Information available in multiple languages.



National organisation supporting people living with dementia, and their families and carers.

dementia.org.au
1800 100 500



Dementia Support Australia work to improve the quality of life of people living with dementia and their carers.

dementia.com.au
1800 699 799



NPS MedicineWise remains committed to supporting quality use of medicines to improve health decisions and health outcomes in Australia.

nps.org.au
02 8217 8700



Care4Dementia App

This app is available only on the App Store for iPhone and iPad.

apps.apple.com/au/app/care4dementia/id1029281368



Free, independent and confidential advocacy services to help you raise and address issues around aged care.

For more information and resources, visit opan.com.au/yourchoice

opan.com.au
1800 700 600

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www.opan.com.au



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