



A resource for people with
dementia and their carers



What is the purpose of this resource?

Medicines do not have to be part of your care plan, and if they are, they do not have to play a large role in your life. We have prepared this information to help you ask questions and talk with people close to you and the health professionals involved in your care about how you would like to be supported.

This resource is designed to help you:

- ▶ plan a conversation about dementia with the people you choose, for example, your family and friends and health professionals involved in your care (eg, GPs, pharmacists, specialists, nurses)
- ▶ find out about advanced care planning
- ▶ find out what support is available to manage your symptoms
- ▶ find information on what treatment options may be best for you
- ▶ record details about symptoms, medicines, values and wishes when it comes to your care
- ▶ find out about support services available to help you and those closest to you.

What questions could you ask?

- ▶ If I am distressed, how can the cause of the distress be identified? What strategies can be used to relieve my distress?
- ▶ If I am in pain, how can my pain be assessed? What medicines and other methods can help to relieve pain?
- ▶ If I am experiencing signs of anxiety and/or depression, how will it be assessed? What therapies can help with my anxiety and/or depression?
- ▶ What medicines are available for dementia?
- ▶ If I am taking medicines for dementia, or to treat causes of distress (eg, pain, anxiety and/or depression), what are the benefits of this medicine for me? What are the side effects of this medicine that are relevant to me?
- ▶ If I am unable to make decisions or communicate my wishes, who will advocate on my behalf?
- ▶ Can I have a medicine review to determine if all my medicines are still effective and/or necessary?
- ▶ What are my rights with respect to my care?
- ▶ What support services are available for me?
- ▶ What support services are available for my family, friends and carers?
- ▶ Where can I go for more information?

Need more copies?

This resource for people with a diagnosis of dementia and the people closest to them is available in editable PDF format for download and print from:

NPS MedicineWise www.nps.org.au/dementia-brochure
Alzheimer's Australia fightdementia.org.au

We want to hear from you

Please send your feedback to info@nps.org.au

DISTRESS AND DEMENTIA

Dementia causes changes in the brain and these changes can affect your mood, personality and behaviour. These changes or expressions of distress are usually related to your health, external factors in your environment, or associated with difficulties in expressing your needs because you are finding it hard to communicate.

Health professionals refer to expressions of distress as behavioural and psychological symptoms of dementia (BPSD).

These changed behaviours can be managed in a number of ways. At no point in your care should you feel like you are being forced into a decision you are not comfortable with. It may be helpful to discuss ways to help manage your condition and your needs, and decide what you are comfortable with in your ongoing care. Once your wishes are known, the people closest to you and the health professionals caring for you will be able to tailor therapies that best meet your needs. A top 5 list of tips on how to overcome your distress may be useful for your carers, family or health professionals (your care team) who are involved in your care. For a sample top 5 list, see Appendix 1 'Overcoming distress: top 5 tips for carers' list in this resource.

Working together to understand the meaning of the distress

It may be helpful for you to talk about how you are feeling with the people closest to you as well as with health professionals, such as your GP or counsellor.^{1,2}

It's also useful to bring notes and questions to ask the doctor to your appointments and make notes of what is discussed during the appointment.²

Keeping a diary or record of situations surrounding times of personal distress will help to identify the potential cause of the distress.^{3,4} The diary can be useful when discussing personal distress and developing strategies for alleviating or preventing distress with the doctor, nurse or other health professionals.^{3,4} This can also be useful for people who are caring for you.

You or your carer can record in the diary:³⁻⁵

- ▶ your personal history, cultural background and language spoken
- ▶ your likes and dislikes
- ▶ details about your dementia diagnosis and medicines you may be taking
- ▶ details on medicines that have been helpful
- ▶ a description of your distress, including information such as where you were, time of day, who was with you and what was happening at the time
- ▶ descriptions of what helped and what didn't help to relieve your distress
- ▶ details on your usual weekly routine
- ▶ times and situations when you don't feel distressed or when you feel increasingly distressed.

It is important to have a regular medicines review by your GP and/or pharmacist to help maximise the benefits of your medicines and help ensure that your medicines are not causing side effects that may be contributing to expressions of distress.⁵

For a sample diary, see Appendix 2 'Keeping track of signs of distress' in this resource.

DEVELOP A PLAN FOR HELPING WITH EXPRESSIONS OF DISTRESS

It may be helpful to make a plan about how you would like any expressions of distress managed by your care team.^{3,5-7} An example is shown below:

- ▶ Please consider any medical issues that might be causing my distress before exploring other reasons. If a medicine is required to manage a medical condition please ask me (or my carer if applicable) for my consent.
- ▶ I have a history of back pain, particularly when I wake. Please consider an underlying cause of pain for expressions of distress. I would like my pain to be managed by heat packs and analgesia appropriate to my level of pain.
- ▶ I enjoy walking – if possible, please ensure I am able to take regular walks in a safe environment.
- ▶ I also enjoy gardening and painting and would like these to be part of my daily routine.

For more information on the causes of distress and strategies to help alleviate or prevent distress see:

- ▶ NPS MedicineWise's *Strategies to address distress* fact sheet
www.nps.org.au/dementia-distress

Use of psychotropic medicines in people with dementia

According to clinical guidelines, non-drug strategies should be trialled before prescribing psychotropic medicines (antidepressants, antipsychotics, sedatives, anticonvulsants) to help treat depression, anxiety, restlessness, agitation, sleeplessness and other changed behaviours in people with dementia.⁸

Talk to your doctor or other health professional about non-drug interventions that may help to alleviate changed behaviours you may be experiencing.

Psychotropic medicines, in particular antipsychotics, have limited use for people with dementia and therefore, should only be used in certain situations, after thorough assessment of symptoms and when non-drug strategies are not enough.⁸

Psychotropic medicines can also be associated with serious side effects so before starting these medicines ask your doctor whether it is effective and safe for you and when psychotropic medicines should be reviewed.

For more information on strategies to manage anxiety, aggression, agitation, disinhibited behaviours, hallucinations and other changed behaviours see:

- ▶ Alzheimer's Australia fact sheets
fightdementia.org.au/about-dementia/resources/help-sheets

For more information about psychotropic medicines and use in people with dementia see:

- ▶ Alzheimer's Australia report No. 38 *The Use of Restraints and Psychotropic Medications in People with Dementia*.
fightdementia.org.au/research-and-publications/publications/numbered-publications

Dementia and pain management

You may experience pain that is part of everyday life, such as joint pain associated with arthritis, headache, or toothache. Talk to your family, friends and carers about behaviours and signs that may indicate pain or discomfort, such as crying, facial or verbal expressions, reluctance to move, or expressions of frustration or anger.

Resources have been developed that can help your carers and/or family understand expressions of distress that may be caused by pain and encourage them to regularly ask you about your health and/or pain, using words such as discomfort, uncomfortable, hurting, aching or sore.⁹

People involved in your care are also advised and trained to be alert to expressions of distress that may indicate pain for a person with dementia and to discuss these concerns with you and your health professionals^{9,10}

Your formal and informal carers will be asked to discuss with the doctor or nurse:^{10,12,13}

- ▶ how pain is assessed, for example using an observational assessment tool such as the Abbey Pain Scale
- ▶ how the cause of the pain can be investigated
- ▶ what non-drug therapies can help to relieve the pain for example, heat packs, massage, physiotherapy, acupuncture, relaxation, gentle exercise or stretching
- ▶ what pain relief may be appropriate, for example, paracetamol may be enough to relieve mild pain but severe pain may need stronger medicines
- ▶ how pain and treatment will be monitored.

For more information on how pain may be assessed and managed see:

- ▶ Alzheimer's Australia *Pain* help sheet fightdementia.org.au/about-dementia/resources/help-sheets
- ▶ NPS MedicineWise fact sheet *Other conditions with dementia* www.nps.org.au/dementia-conditions

Taking care of your mood

DEPRESSION AND DEMENTIA

Depression is something that can affect any of us at any time of our lives, however people with dementia may be particularly at risk, especially in the early stages of the disease.⁷

Some signs you may be experiencing depression are:¹¹

- ▶ loss of interest in activities you once enjoyed
- ▶ lack of energy
- ▶ sleep problems/poor sleep
- ▶ loss of appetite and weight
- ▶ feelings of worthlessness and sadness
- ▶ unusual emotion, crying, anger or agitation
- ▶ increased confusion.

It is important to talk to your doctor if you think you may be suffering from depression. Your doctor will be able to do an assessment and create a treatment plan with you. This doesn't have to be medicine-based – you may wish to try alternatives to medicines such as cognitive behavioural therapy.^{3,11}

TAKING CARE OF CARERS

It is important that family, friends and carers of a person with dementia are also supported.

It may be helpful for carers to talk things through with family, friends or other people in a similar situation. Carer support groups can help give carers comfort, support and practical assistance as they meet and talk to others caring for people with dementia.⁸

Doctors, psychologists and counsellors can offer you or your carers help.⁸ A number of

national services provide counselling (online, phone or face-to-face) or can help with finding a local counsellor, psychologist or therapist (Table 1).

For more information on support services for carers see:

- ▶ Resources and support services on the NPS MedicineWise website.
www.nps.org.au/dementia

Table 1: Counselling and psychotherapy support services

Support service	What do they provide?	Contact number
Lifeline Australia	Online, phone, face-to-face crisis support and suicide prevention services.	13 11 14
beyondblue	Phone or online chats or email correspondence with trained mental health professionals.	1300 224 636 Email via link www.beyondblue.org.au/about-us/contact-us
Australian Counselling Association	Help with finding a counsellor service.	1300 784 333
Australian Psychological Society	Help with finding a psychologist via online, telephone or email referral.	1800 333 497
Psychotherapy and Counselling Federation of Australia	Help with finding a therapist.	03 9486 3077

GOOD MEDICINES MANAGEMENT

Treating cognitive symptoms of dementia

Talking to your doctor about therapies (medicines and non-drug options) to help slow down cognitive decline and improve memory and learning is an important first step and can be done as part of your advance care planning.

Medicines are available that have been shown to slow cognitive decline and improve memory.^{13,14} Some medicines are known to worsen cognitive function and it is important for all your medicines to be reviewed before starting medicines that might improve memory function.

For more information on medicines to treat cognitive symptoms of dementia see fightdementia.org.au.

Treating other conditions

Over time you may experience other health problems that may or may not be related to dementia. You may already have conditions that need management. It's important to plan how you want these conditions to be managed.

Some conditions are commonly experienced by people with dementia. These can include depression, anxiety, pain, sleep disturbances, incontinence and urinary tract infections.

Talk to the doctor about these conditions and how they could be treated as part of your advanced care plan.

For more information on the common conditions that can accompany dementia, see:

- ▶ NPS MedicineWise fact sheet
Other conditions with dementia
www.nps.org.au/dementia-conditions

Dementia and good medicine management

You may be taking medicines to treat your dementia as well as other pre-existing conditions or conditions that developed after you were diagnosed with dementia. All medicines have both benefits and side effects and how you respond to some medicines may change when you have dementia. For example, some medicines may make your memory a bit worse or may affect your balance and so increase your risk of falling. Like many people, you may find it difficult to remember when to take medicines.

You are entitled to a regular review of your medicines by a pharmacist. These reviews may help simplify the medicines you are taking. They can also identify any side effects, or medicines you might be taking that you no longer need. Sometimes taking more than one medicine cannot be avoided, but there are ways to help you manage them.

Speak with your doctor about whether the number of medicines you are taking can be reduced.¹²

For more information on how to manage medicines for a person with dementia, see:

- ▶ NPS MedicineWise fact sheet
Tips for good medicine management
www.nps.org.au/dementia-medicines

Five questions to ask your GP before starting medicines

Before starting a medicine for dementia or another condition, you should ask your GP these five questions:¹³

- ▶ Do I really need this medicine?
- ▶ What are the risks of taking the medicine?
Are there any side effects that I might experience?
- ▶ Are there simpler, safer options?
- ▶ What happens if I don't do anything?
- ▶ What are the costs associated with the medicine?

For more information see:

- ▶ Choosing Wisely Australia website
www.choosingwisely.org.au/5-questions-to-ask-your-doctor

PLANNING YOUR CARE: ADVANCE CARE PLANS

Legal rights when it comes to advance planning

You have a legal right to:¹⁴

- ▶ be fully informed about your condition and the treatment options available to you
- ▶ make your own decisions and be involved in decisions that affect you
- ▶ be supported in making decisions about the future that you find difficult
- ▶ put together an advance care plan
- ▶ appoint a substitute decision-maker who can make decisions in your best interests.

It is important to discuss these issues early – with your family, friends, carers and the health professionals involved in your care.¹⁴

You and your substitute decision-maker (if you have one) have the right to refuse treatment.¹⁵

However, your substitute decision-maker may only refuse medical treatment on your behalf if:¹⁵

- ▶ it would cause you unreasonable distress
- ▶ you would have considered the medical treatment unwarranted.

APPOINTING A SUBSTITUTE DECISION-MAKER

You may consider appointing a power of attorney for when you can no longer make or communicate your decisions about financial and legal affairs, your medical treatments and care.¹⁴

Your carer, a family member or a friend can apply to be a guardian. A guardian is a legally

appointed substitute decision-maker who can advocate for you when you can no longer make or communicate your decisions.^{14,15}

Each State and Territory has different rules about powers of attorney, enduring powers of attorney, enduring guardians and administrators.¹⁴

To find out more on legal matters such as legally appointed substitute decision-makers see:

- ▶ MyAgedCare website
www.myagedcare.gov.au/financial-and-legal/powers-attorney-enduring-powers-attorney-and-enduring-guardians
www.myagedcare.gov.au/financial-and-legal/guardianship-and-administrators

What is advance care planning?

Advance care planning allows you to continue to have a say in your medical treatment and care, even if you're not able to make or communicate decisions.¹⁴⁻¹⁷

Advance care plans can help you to discuss your values, beliefs and preferences when it comes to your future care with your family, friends, carers and the health professionals involved in your care.¹⁴⁻¹⁷

Involving family, friends, carers and health professionals in the advance care planning process is important as this will give them the strength and confidence to advocate on your behalf.¹⁴⁻¹⁷

An advance care plan may include:¹⁴⁻¹⁷

- ▶ your values, beliefs, and preferences for treatment and care
- ▶ an advance care directive
- ▶ an enduring power of attorney or legally appointed substitute decision-maker (guardian)
- ▶ a letter to the person who will be the substitute decision-maker
- ▶ instructions for family, doctors and other health professionals
- ▶ an entry in your medical record.

It is important to regularly review and discuss the advance care plan as your health, values, beliefs, preferences, and family and social situations change over time.^{15,17}

An advance care plan may be reviewed when:¹⁷

- ▶ a new health condition has been diagnosed
- ▶ when an existing health condition worsens significantly
- ▶ you become less able to live independently
- ▶ there are changes to your support network
- ▶ you need to choose a new substitute decision-maker.

The Dementia Care Plan (Appendix 3 in this resource) can be used – along with the legal documents specific to the State or Territory you live in – to discuss and document your values, beliefs and care preferences.

Each State and Territory has different legal documents that can be used to create an advanced care plan. You can access these documents, along with more information on advance care plans, at:

- ▶ Advance Care Planning Australia website www.advancecareplanning.org.au/resources

For more information on planning ahead and advance care plans for you and your family, friends and carers, visit:

- ▶ Start 2 Talk website www.start2talk.org.au

Support services for you and your family, friends and carers

PEER SUPPORT GROUPS FOR PEOPLE WITH DEMENTIA

Peer support groups for people with dementia¹⁸ are a good opportunity to share experiences, get support and develop management tools within a social context.

For more information on support groups and/or services in your State or Territory, call the National Dementia Helpline on 1800 100 500 or see the Alzheimer's Australia website

fightdementia.org.au/national/support-and-services/services-and-programs

SUPPORT GROUPS FOR YOUR FAMILY, FRIENDS AND CARERS

Carer support groups provide carers with:^{18,19}

- ▶ contact with others in similar situations to share ideas, management tips and techniques
- ▶ relevant dementia education and information
- ▶ the benefits of social outings
- ▶ information on local community services available
- ▶ an opportunity to learn mechanisms and techniques (eg, relaxation and managing stress) to cope with issues and emotions (eg, loss, grief, guilt, resentment, anger, relief).

To find a local carer support group:

- ▶ contact the Alzheimer’s Australia office in your State or Territory
www.fightdementia.org.au/about-us/contact-us
- ▶ call My Aged Care on 1800 200 422.

Education and training services

Alzheimer’s Australia provides a range of workshops and education and training courses for people with dementia and their family, friends and carers. Some of these courses and workshops are free of charge as they are funded by the Australian Government. Topics that may be covered in the courses and workshops include:²⁰

- ▶ understanding diagnosis, symptoms and impact of dementia
- ▶ adapting to change
- ▶ practical strategies
- ▶ planning for the future
- ▶ effective communication
- ▶ understanding and responding to behaviours
- ▶ understanding grief and transition to care
- ▶ looking after yourself
- ▶ relationships with family and friends
- ▶ legal issues.

For more information on training courses and workshops contact:

- ▶ Your local Alzheimer’s Australia office
fightdementia.org.au/about-us/contact-us
- ▶ A free online education workshop is available that provides information about changed behaviours that indicate pain in a person with dementia
www.painanddementia.ualberta.ca

References

See the references at the end of this document and also on the NPS MedicineWise website:

- ▶ www.nps.org.au/dementia-refs

APPENDIX 1: OVERCOMING DISTRESS TOP 5 TIPS FOR CARERS AND CLINICIANS

My personal details:

NAME _____ DATE OF BIRTH _____

ADDRESS _____

1.	
2.	
3.	
4.	
5.	

APPENDIX 2: KEEPING TRACK OF SIGNS OF DISTRESS

It can be useful to keep a diary to help identify triggers or causes of distress/changed behaviours, to help you discuss your concerns with the doctor, nurse or other health professionals and develop strategies to alleviate or prevent future distress. It may be helpful to keep a diary for a week. The form below can be used to make note of the circumstances surrounding the changed behaviour.

DAY _____ DATE _____

TIME OF DAY	
LOCATION (eg, home, inside, outside) Information on the environment (eg, bright, sunny, dark)	
How did your behaviour change or what did you feel?	
What was happening before you became distressed?	
What were you doing before you became distressed?	
Was anyone involved or affected and who were they?	
Strategies that didn't work to alleviate your distress	
Strategies that helped alleviate your distress	

APPENDIX 3: MY DEMENTIA CARE PLAN

This Dementia Care Plan is intended to be used with the specific legal document/s for the relevant State or Territory.

DATE _____

My personal details:

NAME _____ DATE OF BIRTH _____

ADDRESS _____

My substitute decision-maker(s):

NAME _____ DATE OF BIRTH _____

ADDRESS _____

CONTACT NUMBER (S) _____

NAME _____ DATE OF BIRTH _____

ADDRESS _____

CONTACT NUMBER (S) _____

My contact details:

	CONTACT NAME	CONTACT NUMBER
Nominated carer or family member		
GP _____		
Specialist _____		
Specialist _____		
Pharmacist _____		
Other _____		
Other _____		

My diagnosis:

My symptoms:

- | | | |
|--|---|---|
| <input type="checkbox"/> Memory loss | <input type="checkbox"/> Taking longer to do routine tasks | <input type="checkbox"/> Unusual or unpredictable emotional behaviour |
| <input type="checkbox"/> Difficulty in reasoning, planning, judgement, organisation, problem-solving, and logical thinking | <input type="checkbox"/> Becoming disoriented | <input type="checkbox"/> Changes in behaviour, personality and mood |
| <input type="checkbox"/> Language difficulties | <input type="checkbox"/> Inability to process questions or instructions | <input type="checkbox"/> Other:
_____ |
| <input type="checkbox"/> Loss of enthusiasm/motivation | <input type="checkbox"/> Decreasing social skills | _____ |

My medicines list:

My values and/or religious beliefs:

My preferred support approach during times of personal distress:

My wishes about treatment:

TREATING MY COGNITIVE SYMPTOMS OF DEMENTIA:

TREATMENT

- Cholinesterase inhibitors
(donepezil, galantamine, rivastigmine)
- Memantine
- Other

DETAILS

MANAGING MY PAIN:

MANAGING MY ANXIETY AND DEPRESSION:

TREATMENT

- Cognitive behavioural therapy
- Lifestyle measures
- Medicines
- Other

DETAILS

TREATING MY OTHER CONDITIONS:

CONDITIONS

TREATMENT DETAILS

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See these references online at:

▶ www.nps.org.au/dementia-refs



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NATIONAL DEMENTIA HELPLINE
1800 100 500

NPS MEDICINES LINE
1300 633 424