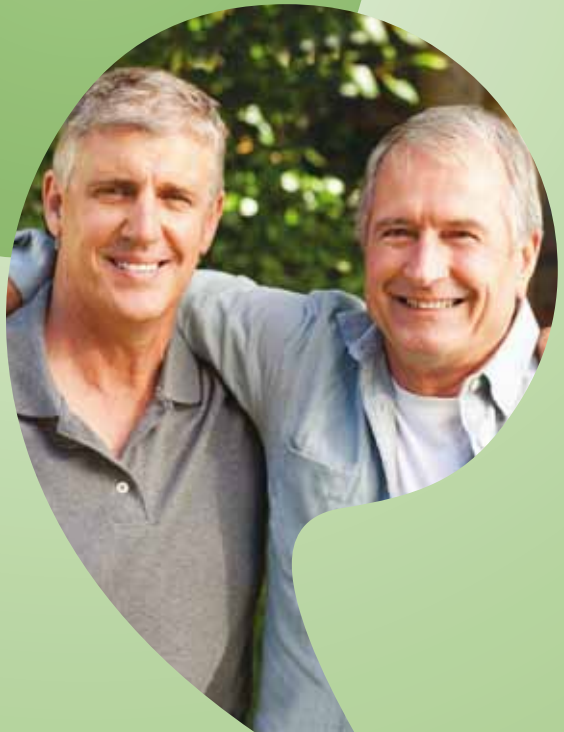


*Asking questions about
Dementia can help*

What to ask your
health professional
about dementia





Palliative Care NSW



Alzheimer's
Australia NSW
Living with dementia

Thankyou to Josephine Clayton MBBS PhD FRACP FChPM; Associate Professor of Palliative Care, Sydney Medical School, University of Sydney; Staff Specialist in Palliative Medicine, Hammond Care Palliative and Supportive Care Service, Greenwich and Royal North Shore Hospitals, Sydney; Senior Research Member, Centre for Medical Psychology and Evidence-based Decision-making (CEMPED), University of Sydney.

Graphic Design by Sarah Marsden Design, Phone 0450 506 441.

Contents

How to use this booklet	2
Definitions and explanations	4
Dementia	4
Advanced Dementia	5
Palliative Care	7
Advance Care Planning	7
Asking questions	9
Part 1: For people recently diagnosed with dementia	10
Part 2: For carers and families of someone recently diagnosed with dementia	16
Part 3: For carers and families of someone with advanced dementia	20
Part 4: About the Palliative Care Service and Team	26
Part 5: Questions carers or families may like to ask about end of life issues including Palliative Care	32

How to use this booklet

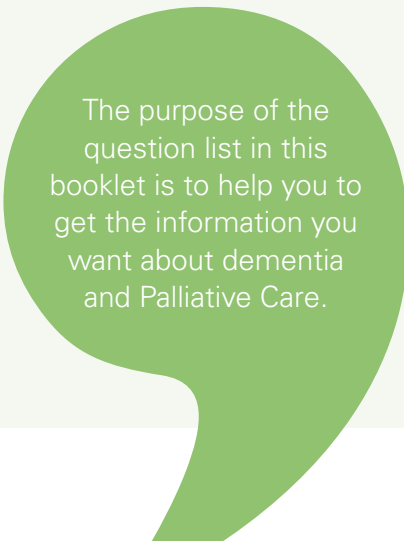
This booklet is for people who have recently been diagnosed with dementia and their families as well as families of people with advanced dementia.

The reason we are including questions for those with a recent diagnosis is because this is when Advance Care Planning needs to start. Advance Care Planning plays a vital part in the quality of care as Dementia progresses.

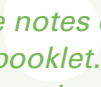
This booklet has been organised into topics. You may find that some of the topics and some of the questions are not relevant to you or the stage of the disease. There may also be some topics that you don't want to read about at the moment. Please have a look at the headings first and then decide what you want to read.

Most people who are seeing their doctor following a diagnosis of dementia will have many questions and concerns.

Often these are forgotten in the stress and rush of the moment. The purpose of this question list is to help you get the information you want about dementia, and if you need it, Palliative Care.



The purpose of the question list in this booklet is to help you to get the information you want about dementia and Palliative Care.



Feel free to scribble, make notes or add more questions throughout this booklet. If you need another copy of this booklet, please ask.

These questions have been developed after talking to people who have been through the end of life dementia journey with a loved one and who have said 'I wish I had thought to ask (this)' or 'I wish I had known (this)'. The people who provide care have also helped us to develop these questions.

Your GP, Geriatrician or Palliative Care doctor will be very happy to try and answer any questions you have. You can use this booklet while you are seeing a doctor. You may like to circle the questions you want the doctor to answer and add any of your own that are not listed. The doctor may answer some of your questions without you even asking, but this booklet can serve as a checklist so that you know that you have covered everything that is important to you.

People want to know different things at different times. You may wish to use this question list during consultations with your doctors, or you may choose to use it later, or to discuss some of these issues with other doctors or another member of the Palliative Care team (eg a nurse or social worker).

You may also find it helpful as a reference in the future. Please do not feel that you should ask any of these questions just because they are listed.

Dementia

Dementia is not a single specific disease but rather a range of diseases characterised by impairment of brain functions resulting in restrictions in language, memory, perception, personality, cognitive skills and activities of daily living.

The most common type of dementia is Alzheimer's disease. There is currently no cure for dementia. Dementia is a progressive disease that cannot be cured, so Palliative Care should be considered sooner rather than later. Palliative Care can help with people's physical and emotional needs as well as the needs of their families and carers.

The onset of dementia is often very gradual but it does mean that a person's abilities will deteriorate, sometimes rapidly over a few months, and sometimes more slowly over a number of years until 'advanced stage' dementia is reached. The fact that dementia will result in death is not easy to come to terms with and can often be a surprise to learn.

Dementia is unpredictable and varies from person to person but generally speaking, people with Alzheimer's disease can live with it from 2 years to 20 years with about 8 years being the average time.

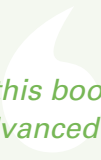
Advanced dementia

For detailed information about advanced dementia, please have a look at the fact sheets at the back of the workbook in this kit. This can be very challenging information and you might want to give yourself time to go through it at your own pace.

If you need to talk to someone about the information in those fact sheets, make an appointment with your GP.

It is important to understand that dementia is a terminal disease, though many people with dementia have other conditions as well, like heart disease, diabetes and cancer.





*In this booklet we will use the term
'advanced dementia'.*

A number of terms are used to describe the different stages of dementia. When discussing the final stages, terms like 'advanced', 'severe', 'terminal phase', and 'end stage' dementia may be used.

There are no clear definitions of when a 'stage' starts or ends, but here we are specifically talking about the most advanced stages of dementia, when a person needs care 24 hours a day, 7 days a week, and is usually living in a residential aged care facility.

On average, advanced dementia may last for three years or more, so any deterioration discussed in this section may be very gradual.

Changes to the brain start to occur to people with dementia from the early stages of the disease onwards. Changes in the brain cause changes to occur in four major areas:

1. Cognitive ability

The way the person thinks and remembers.

2. Functional ability

The way the person looks after their basic needs like bathing, dressing and eating.

3. Behaviours

The way the person acts and emotions (feelings).

4. Physical ability

The way a person moves.

Palliative Care

Palliative Care is the active total care of people whose disease is not curable. This includes people who are dying of cancer, heart disease, Motor Neurone Disease etc, as well as people who are dying from dementia. Control of pain, symptoms and psychological, social and spiritual problems is the priority.

The goal of Palliative Care is the achievement of the best quality of life for the person who is dying and their families. Many aspects of Palliative Care also apply earlier in the course of the illness.

Advance Care Planning

Advance Care Planning means planning your care preferences in advance of your condition worsening to the point where you are unable to make decisions for yourself.




Advance Care Planning is how you take control of your future health care decisions and helps you live more positively.




Asking questions

The following pages contain a list of questions, and takes you through discussions about admission to a residential aged care facility and then to end of life discussion.

It's best to start planning for end of life decision making as soon as possible following diagnosis. It's important to make plans while the person with dementia has the capacity to do so. Don't put it off!



Part 1:
For people recently
diagnosed with
dementia



*What symptoms
can I expect?*

My dementia and what to expect in the future

What kind of dementia do I have?

How long will it take for my symptoms to worsen?

What symptoms may occur in the future and what should I do if they arise?

Will any pain or other symptoms be controlled in the future?

Who decides when I have 'lost capacity' (the ability to make decisions)?

How do you decide when I have 'lost capacity'?

Planning for end of life

How do I get my affairs in order and write a Will?

How do I get started on an Advance Care Directive?

Who will make decisions for me when I am unable to?

Will you keep a copy of my Advance Care Directive? Will you make sure it is always available to whoever needs to see it as best you can?


Can I die at home?



What are the worst days going to be like?

What are the best days going to be like?





Part 2:
For carers and
families of someone
recently diagnosed
with dementia

What skills will I need as a carer of someone with dementia?

How long will I be able to look after my partner, relative or friend at home?

Can I get help if I cannot manage?

What can I do if I am not coping?

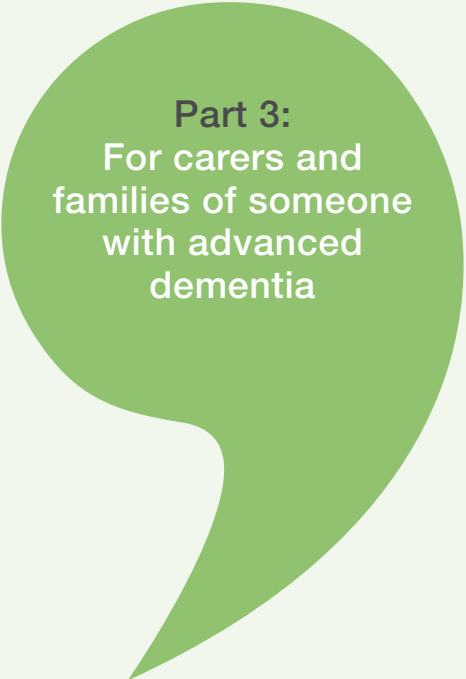
When will I know that it's time to accept we need admission to a Residential Aged Care Facility?

How can I best support my partner, relative or friend?

Are there any support groups for carers in my situation?



*I feel like I can cope
for a while yet.*



Part 3:
For carers and
families of someone
with advanced
dementia

Medical interventions

Should someone with advanced dementia be hospitalised for a serious medical problem like pneumonia or urinary tract infection? Are there alternatives?

Should someone with advanced dementia have screening tests? How will the person I'm caring for benefit from say, a mammogram?

What has my partner, relative or friend been prescribed?

I am the Person Responsible – do I have to give permission for these medications to be used?


Admission to a Residential Aged Care Facility

Can I keep using our current pharmacist?


Can I keep our current GP?

Will there be a choice regarding the level of medical intervention when my partner, relative or friend is in a Residential Aged Care Facility?


With whom should I discuss my partner, relative or friend's views about the treatment that they wanted to receive at this stage of their illness?



Caring for someone with dementia is time consuming and stressful for families. There will almost always come a time when your relative must be admitted to a Residential Aged Care Facility. You may wish to be more involved with their care, or less involved. You will need to speak with the Facility about how you can work together in providing care.



**Part 4:
About the
Palliative Care
Service and Team**



*Who are the members of the
Palliative Care Team and what
do they do?*

What is Palliative Care?

What does the Palliative Care service offer that is different to the services provided by the doctors and nurses my partner, relative or friend sees?

Will the Palliative Care team come to the Residential Aged Care Facility?

Is it possible for my partner, relative or friend to be admitted to a Palliative Care hospital for a short time to get symptoms under control?


Contacting the Palliative Care Team

How can we contact the Palliative Care team?

In what circumstances can we or should we contact them?


How often can we contact them?

Is the Palliative Care service available after hours or in emergencies?

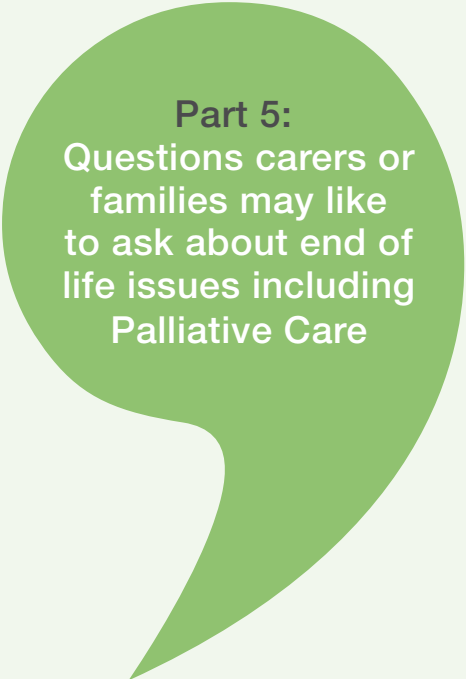


Can the Palliative Care team give me advice about treatment decisions that are being discussed with other doctors?





The goal of
Palliative Care is the
achievement of the
best quality of life for
the person who is dying
and their family.



Part 5:
Questions carers or
families may like
to ask about end of
life issues including
Palliative Care

The relationship between the Palliative Care Team and other health professionals

Does the Palliative Care team speak to or write to the doctor and other specialists about care provided?

What is the role of our doctor now that we have a referral to the Palliative Care team?

Who will be the main contact from now on? Our doctor or the Palliative Care team?

Can the Palliative Care team help me choose a doctor or other specialist?

End of life issues

Who can I talk to if I am concerned about the care my partner, relative or friend is receiving?

If my partner, relative or friend has a heart attack, will you try Cardio Pulmonary Resuscitation or will you allow a natural death?

If my partner, relative or friend eats more, will this make them live longer?

Will you prescribe antibiotics if my partner, relative or friend has an infection?

Will multivitamins help?

What are the pros and cons of inserting a feeding tube?

If I cannot manage to look after my partner, relative or friend at home, how can we come to terms with this?

Will you be able to tell me when it is getting close to the time that my partner, relative or friend will die?

When should I call the rest of the family? What should I say to them? Could you speak with them?

How do I know when partner, relative or friend has died?

What happens after partner, relative or friend dies? Eg what happens to them? How do we arrange the funeral?



What support is available for the family after my partner, relative or friend dies?



Palliative Care NSW

PO Box 487

Strawberry Hills NSW 2050

Phone (02) 9206 2094

Fax (02) 9281 0157

Email info@palliativecarensw.org.au

Web www.palliativecarensw.org.au



Alzheimer's
Australia NSW
Living with dementia

Gibson-Denney Centre

Building 21, Macquarie Hospital Campus

Corner Coxs & Norton Roads

North Ryde NSW 2113

Phone (02) 9805 0100

Email admin@alznsw.asn.au

Web www.alznsw.asn.au