Call the National Dementia Helpline on 1800 100 500
9 End of life issues

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Key points: End of life issues

As a person with dementia approaches the end of their life, there are a number of considerations to be made.

Whether the person with dementia is living at home, in hospital or in residential aged care, they will need quality care at the end of their life. Palliative care is specialised care and support that recognises the unique needs of a person with a terminal condition, as well as their family members and carers.

The goal of palliative care is to relieve the symptoms experienced by a person towards the end of their life, rather than on curing the condition or conditions causing their death. For family members and carers, palliative care concentrates on providing emotional and practical support at this time. Health care professionals can provide information about what support is available to assist with palliative care.
When a person with dementia has died, their family members and friends often experience a range of feelings. Sadness, shock, disbelief, guilt, anger, resentment, lack of purpose and even relief are all common.

It is important to remember that everyone reacts differently and there is no one right way to grieve.

There is professional support available during this time, such as counselling. And there are lots of things you can do that might help, including accepting support from family and friends, sharing your experiences with others and re-establishing relationships with old friends.
Palliative care

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Palliative care is specialised care and support that recognises the unique needs of the person with a terminal condition, as well as their family members and carers.

**What is palliative care?**

The goal of palliative care is to relieve the symptoms experienced by a person towards the end of their life, rather than on curing the condition or conditions that are causing their death. For family members and carers, palliative care concentrates on providing emotional and practical support up until the death of the person.

**Personal comfort measures**

Palliative care concentrates on providing comfort in an active way, including positioning to promote comfort, mouth care, assisting with difficulties in breathing, skin care, bowel management, mobilisation and pain management.

**Symptom management**

Managing symptoms will depend on the stage of the illness and any other conditions the person may be experiencing. Some symptoms that occur for people with dementia may also require difficult decisions to be made. The focus should be on the key palliative care questions:

- How useful is the treatment for the person with dementia?
- What choice would best promote the comfort of the person with dementia?
- What kind of care would the person with dementia want?
Pain

There is strong evidence that pain is often neither recognised nor appropriately managed in people with dementia. It is important that there is an ongoing and systematic approach to recording, assessing and managing pain.

Nutrition and hydration

A reduced desire to eat and difficulties with eating and swallowing are normal in the later stages of dementia and are often key indicators that the person is moving towards the end of their life. There is no evidence that artificial nutrition or hydration has any benefits towards prolonging life or providing a peaceful death for a person with dementia.

Antibiotics

Decisions about antibiotics need to be taken in context and on an individual basis.

Who provides palliative care?

Palliative care can be provided by a number of different health professionals including:

- general practitioners
- specialist doctors – oncologists, cardiologists, neurologists, respiratory physicians
- nurses
- allied health clinicians – pharmacists, occupational therapists, physiotherapists
- social workers
- grief and bereavement counsellors
- pastoral care workers
Planning palliative care

Palliative care in dementia can be facilitated when the person with dementia and their family members and friends have explored issues related to treatment and management in advance. It is also helpful to have discussions with health care staff about what support is available at this time.

For information about palliative care and services in your area contact Palliative Care Australia on 03 9662 9644 or visit palliativecare.org.au

Grief and bereavement

When a person with dementia is dying or has died, their family members and friends often experience a range of feelings. They may grieve for the loss of that person, and for the relationship they once had, even if they did not wish for the person to go on living with dementia.

Some people find that they have grieved so much during the course of the illness that they have no strong feelings left when the person dies. However, these feelings may surface at a later time, sometimes unexpectedly.

Everyone reacts differently. Some reactions to the death of a person with dementia amongst their family and friends may include:

- sadness for what could have been, or for what has been lost
- shock and pain
- disbelief and an inability to accept the situation
- guilt
- relief, both for the person with dementia and for themselves
- anger and resentment
- lack of purpose in life now that the caring role has gone

What you feel and how long you feel it for will vary from person to person. The death of the same person produces different responses amongst different family members and friends. There are no rules for grieving – we all react in our own way and in our own time.
**Professional help**
If you would like to talk about your feelings or would like help coming to terms with your loss, it may be useful to talk to a professional.

Speak to your doctor, call the National Dementia Helpline on **1800 100 500** or Carers Victoria on **1800 242 636** for further information about grief counselling.

**After death**
You may feel shocked and vulnerable in the immediate period after the death.

- Try to avoid making any major decisions.
- Accept that, even though you may generally be coping, you may at times feel sad or upset.
- Events such as birthdays or anniversaries may be difficult.
- Talk to your doctor. You are more likely to become physically ill or depressed following a bereavement.

**Remember, it will take time to adjust to your loss.**

**Getting back on your feet**
Moving on with your life is not always easy. However, the time will come when you are ready to re-establish your own life and move forward. Consider these ideas for getting back on your feet:

**Take time**
The length of time needed to adjust varies from individual to individual. Be patient, and don’t try to rush the process.

**Accept assistance**
Letting other people help you can provide you with support and an opportunity to express your feelings, reflect and talk. Over time this will help you understand and adjust to your loss.
Share your experience

Friends and family also benefit from the opportunity to share their feelings.

Remember the person

Talk about the person you have lost, especially in earlier times before dementia affected them. Reminiscing about happy times can help.

Celebrate the person with family and friends

Many people find this helpful on birthdays or anniversaries.

Re-establish your social networks

Start to see old friends again, or start looking around for new friends.

Keep trying!

You may not feel confident at first. You may find it difficult to make decisions, talk about ordinary things or cope with social gatherings. But don’t give up. Your confidence will gradually return.