

4.2 Later in Life Issues

Coping, Treatment and Decision Making at the End of Life

This Help Sheet offers information that can help when someone with Progressive Supranuclear Palsy (PSP) is at the end of their life. It helps you to prepare for the later stages of PSP, particularly in relation to treatment and end-of-life decisions. It also provides information about coping with feelings of grief and loss when the person has died or is nearing death.

PSP cannot be cured, so everyone with PSP experiences deterioration prior to death. As the condition progresses, people with PSP are at risk of developing serious complications, such as pneumonia or choking caused by swallowing difficulties or head injury caused by falls. These complications can be fatal. For further information about later-stage symptoms of PSP see PSP Australia's Help Sheet on managing symptoms later in life.

Making end-of-life decisions

When someone is in the later stages of PSP and becomes seriously ill, there may be discussion about whether to actively treat the illness: for example, with resuscitation after heart attack, antibiotic treatment for pneumonia, or tube feeding.

Giving or withholding treatment is not an easy decision to make. Ideally, these issues will have been discussed with the person with PSP in earlier stages of the condition when communication was easier. It then becomes a matter of implementing the person's wishes. PSP Australia's Help Sheet on Planning Ahead offers further information such as advanced care planning and delegation of decision-making powers.

If no formal orders are in place, the closest relative is legally allowed to consent to medical treatment and is expected to make decisions that, to the best of their knowledge, reflect the known wishes of the person.



*For PSP information and support phone
Parkinson's Australia on 1800 644 189*



End-of-life decisions need not be made alone. Seek advice and support from the person's team of health professionals and from Parkinson's Australia.

Palliative Care

What is palliative care?

Palliative care is specialised care and support provided for someone living with a life-ending illness. The aim of palliative care is to help the patient live as well as possible and is available to anyone who has a life-ending illness. It also involves care and support for family members and carers during the illness and in later bereavement.

Palliative care may include:

- Looking after the person's physical needs
- Reduction or prevention of pain and other symptoms
- Counselling and emotional support

Who provides palliative care?

Palliative care can be provided by a number of different health professionals depending on the illness and the needs and resources of the person with the illness, their family and carers. The palliative care team may include:

- Doctors
- Nurses
- Allied health professionals – pharmacists, occupational therapists, physiotherapists
- Social workers and counsellors
- Pastoral care workers
- Trained volunteers

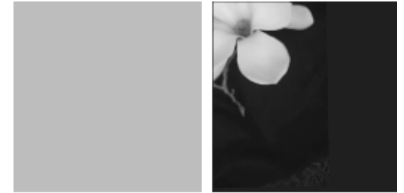
Some people may be referred to a specialist palliative care service in their area where a team of specialist professionals will work to meet their needs. Parkinson's Australia can also provide a secondary consultation service to the palliative care team looking after your family member and offer additional help by providing more detailed information about end-of-life issues.

Where is palliative care provided?

Palliative care can be provided:

- In the home
- In a hospital
- In an aged care facility
- In a specialised palliative care unit these are sometimes known as hospices.





Where possible the person and their family can choose where the care is given.

How can I access palliative care?

A doctor or other health worker can refer you to a palliative care service, or you can refer yourself. A palliative care worker will then help you to decide which services you need.

Where can I get more information?

For more information about palliative care:

- Talk to your doctor or health worker
- Contact your local Community Health Centre
- Telephone the National Palliative Care Information Line:
1800 660 055
- Visit the Palliative Care Australia website: www.pallcare.org.au
- Contact Parkinson's Australia

Coping with loss and grief

When someone with PSP dies, their family and carers may experience a range of feelings. These may include sadness, anxiety, despair, anger, disbelief, guilt or relief. These emotions are a natural and normal reaction to the loss of a loved one.

Help and support is available.

The Australian Centre for Grief and Bereavement offers a free counselling and support service. Phone 1800 642 066 or visit: www.grief.org.au).

24-hour telephone support is available via the:

- Suicide helpline – 1300 651 251
- Lifeline – 13 11 14
- Mensline Australia 1300 78 99 78
- Griefline – (noon to 3am) – 03 9596 7799

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The information below was provided by the Better Health Channel, a Victorian Government website. Material on the Better Health Channel is regularly updated. For the latest version of this information please visit: www.betterhealth.vic.gov.au

Grief - everyone's response is different

Grief is our response to loss. It is often thought that people progress through grief in similar ways, but this isn't the case. Everyone experiences grief differently because our reaction depends on a range of individual factors, such as our personality, age, relationship with the deceased, cultural practices, the level of social support and our spiritual beliefs.

There is no 'right way' way to grieve. Misconceptions about the grieving process can make the bereaved person question their feelings and sanity. Understanding what grief can be like, finding ways to safely express strong emotions and coming up with coping strategies can help you endure the pain of your loss.

Grief isn't predictable

One model of grief that once was popular suggested that people progress through various stages such as denial, anger, bargaining and acceptance. We now know that grief includes a wide range of emotions, thoughts and behaviours. It doesn't help to think that grief will always happen in a predictable and orderly way – everyone moves through grief in their own way.

If you believe that grief will follow predictable stages, you are likely to expect a bereaved person to put the experience behind them within a certain time. The reality is that most of us will continue to grieve in subtle ways for the rest of our lives.

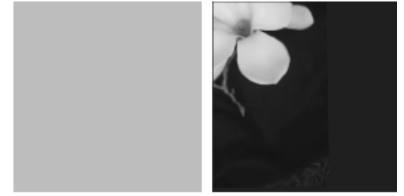
A wide range of normal reactions

Grief includes a wide range of emotions, thoughts and behaviours. You may experience some or all of the following reactions, as well as many that aren't included in the list. Your responses could even be contradictory at times.

Some of the many reactions associated with grief include:

- Anger
- Anxiety
- Change in worldview
- Confusion
- Sadness and depression
- Sleeping difficulties
- Drop in self-esteem





- Difficulties in concentration
- Feeling unable to cope
- Guilt and remorse
- Helplessness
- Hopelessness
- Loneliness
- Questioning of values and beliefs
- Relief
- Shock and disbelief.

Moving on with life

There is an expectation that accepting the death of a loved one means letting go of them and their memory. The reality is that many bereaved people continue to have a relationship with their loved ones for the rest of their lives through remembering them. Death ends a life, not a relationship.

You may like to talk about your loved one in general conversation or commemorate special events like the deceased's birthday. Keeping your relationship with the deceased 'alive' is a healthy, normal response. On the other hand, you may prefer to keep your memories to yourself and grieve more privately – and that's healthy and normal too.

Looking after yourself is important

Losing a loved one is a shattering event that affects you emotionally, physically and spiritually. Try to look after yourself.

Suggestions include:

- **Diet and exercise** – grief impacts on the body and can cause symptoms such as sleeplessness, anxiety and gastrointestinal upsets. Take care of yourself by paying attention to diet and getting regular exercise. Make sure that you receive good medical care.
- **Relaxation and sleep** – schedule time every day to wind down, using whichever method works for you: for example, meditation, tai chi, taking a bath, playing sport, reading, attending to hobbies or listening to music. Try to get adequate sleep – grieving can be

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exhausting work.

- **Avoid drugs** – try to avoid drugs such as cigarettes and alcohol to help you manage your grief. They may temporarily dull your pain but cause other health and behavioural difficulties.
- **Be realistic** – try to be kind and gentle to yourself. Accept that you need to grieve in the ways that feel natural to you. Don't judge or criticise yourself for not coping as well as you think you should.

Coping strategies

You may need to experiment to find out which strategies are most helpful for you. Suggestions include:

- **Crying** – some people feel that crying isn't appropriate or else they're afraid that once they start crying, the tears won't stop. If you feel the need to cry, go ahead and do it. Crying is a normal human response to intense feelings. However, if there are no tears, it does not mean there is no grief. Many people cry alone, perhaps in the car or in the shower.
- **Time alone** – schedule time alone every day to focus on your feelings and express them in whichever way feels natural to you. For example, you may choose to pray, cry, look through photographs of your loved one or write a diary.
- **Activity** – many people find it important to engage in physical activity as a way of releasing tension and distracting themselves for a time from the intensity of grief.
- **Time with your family** – schedule time to grieve as a family. This could include talking about the deceased, crying together and sharing your feelings.
- **Pampering** – include activities in your daily or weekly schedule that you enjoy.
- **Support team** – actively seek out support. This could include friends, workmates, doctors, community health centres, bereavement support groups or professional counsellors.
- **Memorial** – you may like to write letters to your loved one, plant a memorial tree, put together a special photo album or commemorate their life in whichever ways feel meaningful to you and your family.
- **Professional help** – see your doctor for help and referral if you feel dangerously out of control: for example, if you're angry enough to want to hurt yourself or someone else.



Where to get help

- Your doctor
- Your local Community Health Centre
- The Australian Centre for Grief and Bereavement Tel. (03) 9265 2111 or 1800 642 066
- A trained counsellor
- A bereavement support agency such as The Compassionate Friends Tel. 1800 641 091, Mercy Grief Services Tel. (03) 9364 9838 or Sids and Kids Tel. 1300 308 307

Things to remember

- Losing a loved one can be a shattering event that affects you emotionally, physically and spiritually.
- There is no one correct way to grieve. Misconceptions about the grieving process can cause difficulties for the bereaved person.
- The experience of grief depends on individual factors such as personality and age, the relationship with the deceased and spiritual beliefs.

For further information about living with PSP, including the full range of PSP Australia Help Sheets, visit: www.psp-australia.org.au

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