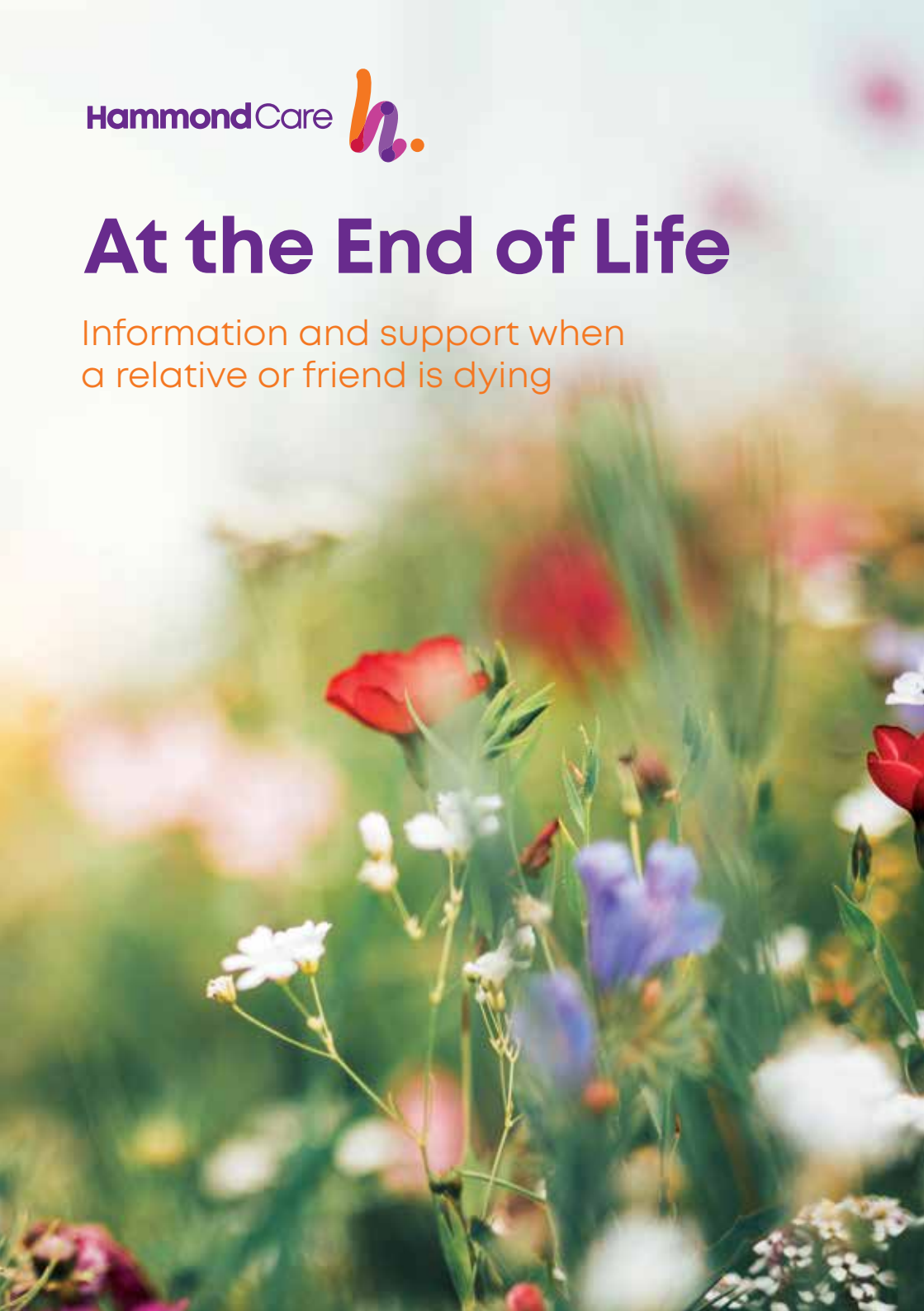


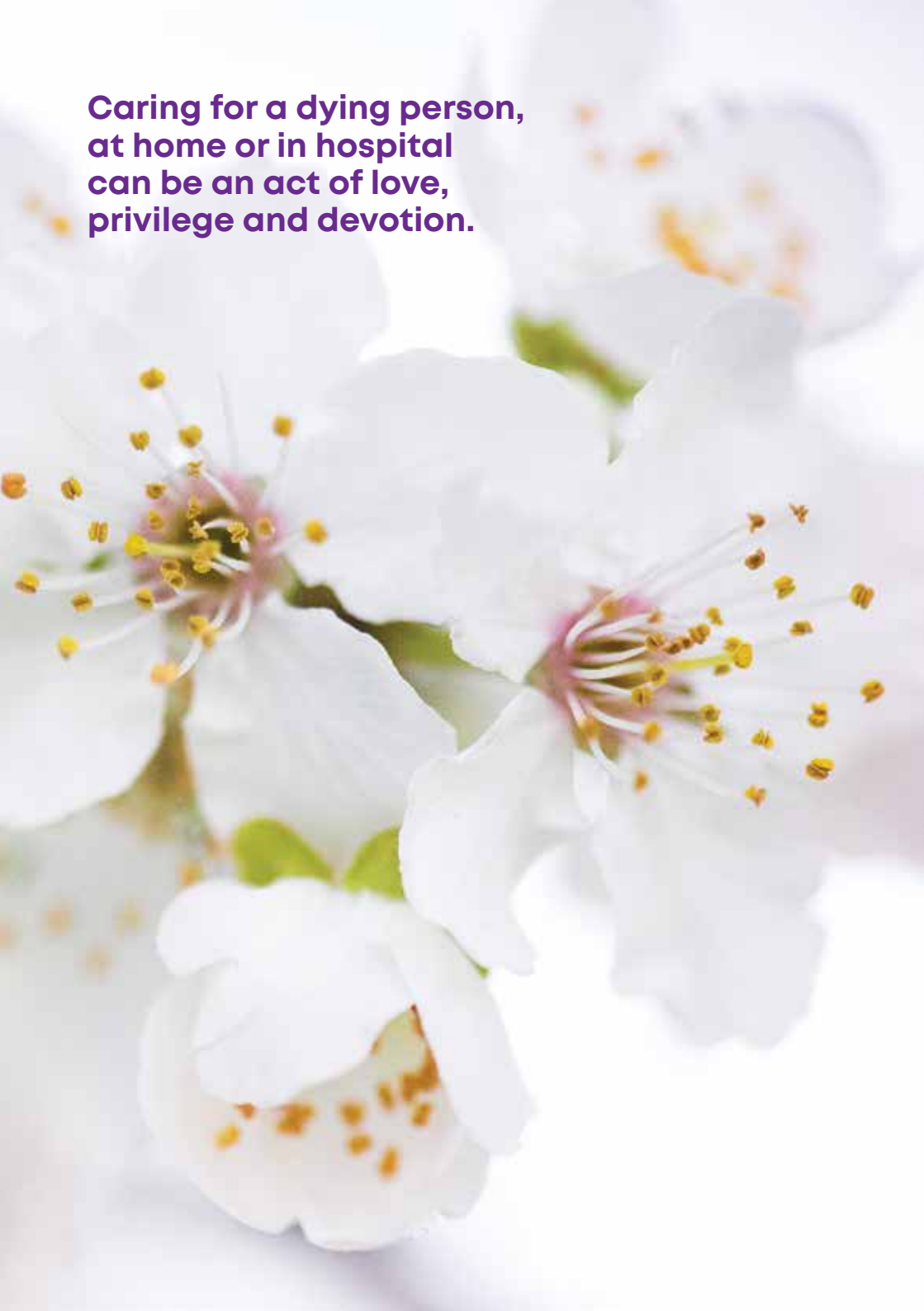


At the End of Life

Information and support when
a relative or friend is dying



**Caring for a dying person,
at home or in hospital
can be an act of love,
privilege and devotion.**



How to support your dying loved one

It is almost impossible to completely prepare for the death of a relative or friend. It can however be a little easier if you know some of what to expect and understand how you may be able to help.

The aim of this brochure is to:

- Help family and carers understand what to expect when death is approaching.
- Give some suggestions of ways you can help.
- Provide information on the assistance available to you after the person has died.

Planning for this time is important whether you are caring for a person at home or in hospital.

Being able to predict exact time of death is very difficult. You can discuss with your health team for further information regarding the signs that death may be imminent.

Advanced Care Plans

Your family or relative may have completed an Adult Ambulance Care Plan or Advanced Care Plan indicating their wishes for care when they are coming to the end of their life, including whether they would like to be at home or in hospital.

It is useful to have a copy of these documents at hand should you need to call an ambulance or home visiting doctor service.

Common Challenges of Caring

Caring for a dying person, at home or in hospital can be an act of love, privilege and devotion. It can also be both physically and emotionally exhausting. You may find your normal routine is disrupted and you may find it hard to concentrate. You may sometimes wish for “it all to be over” possibly due to exhaustion, uncertainty, feelings of helplessness and not wanting your relative or friend to suffer. Feelings such as guilt, anger, frustration and overwhelming sadness are common for carers and family members. This is normal when you are providing care to a relative or friend.

Sometimes caring for a dying person may raise issues from the past. It is important to discuss your concerns, feelings and fears with your family, friends and your healthcare team. The healthcare team can help you make choices and can inform you about other services that are available to you. Utilising family and friends to help through this last phase so you can have some rest is also important.

People often comment that the tasks of caring can make it difficult to attend to other important roles, for example being a spouse, friend, son/daughter etc. Accessing support can give you the opportunity to spend time with your friend or family member who is dying, to do important things, such as reminiscing, talking and spending time with them, rather than having to provide the ‘carer’ aspects that can be exhausting. It is important to prioritise these aspects of your relationship with the person who is dying.

Social, cultural, spiritual and religious wishes

As a friend or family member of someone who is dying, it is important to consider the beliefs and values of both the person who is dying and the important people providing support to them. Everyone has their own interpretation and view of the meaning and purpose of life and their own spiritual and religious beliefs. It is important to discuss these considerations with the person who is dying, so you are aware of any special rituals or religious ceremonies that are important.

The healthcare team can also be informed of any cultural, spiritual or religious needs or wishes of the dying person, so they can be supported.

Physical changes which may occur before death

Food and fluid intake

Loss of appetite and decreased thirst are common. The person's body is shutting down and does not need nourishment. Reduced thirst means there is usually no need for an infusion of fluids to keep the person comfortable. Attempts to give a person food or fluids may lead to gagging, choking and increased distress.

The most important factor at this time is keeping the person's mouth and lips moist with small sips of water, ice chips, swabs moistened in water and lip balm for comfort.

Restlessness and confusion

Near the end, it is not uncommon for the person to become increasingly confused. Restlessness may occur. This can take the form of moaning, calling out or trying to get out of bed, even when they are very weak. If restlessness becomes more pronounced, medication can be provided by the healthcare team for you to administer in the home.

You can be supportive by talking gently and reassuringly, maintaining a calm atmosphere, and having soft lighting or music can also help. Having a calendar and clock in the room may help reduce disorientation for the person who is dying. It may be helpful to orientate the person or support them in their current views without being challenging. It is important not to speak about the person as though they are not there. Sharing remembered stories and telling the person how much they have meant to you and others can be of support and comfort to everyone involved.

Sleeping

As a person is closer to death, they will often sleep for longer periods of time there will usually be increased periods of sleep; this can be deeply asleep or semi-conscious. If they have pain or other problems they will become more wakeful and restless. If this occurs, consult your healthcare team about the best way to treat the distressing symptom.

Most people who are dying become less responsive and eventually uncommunicative. However, some people may be quite alert to the very end. While the person may not be able to respond to you, they may still hear you and know that you are there.

Breathing and increased secretions and other body fluids

Subtle changes in the persons breathing pattern – including a pattern where several deep breaths are followed by prolonged periods without breathing, can indicate death is imminent.

If a person has had problems with breathlessness they will usually be more comfortable sitting reasonably upright. If they have been reliant on oxygen this may be continued however it is usually not essential and may cause distress and therefore be advised to be removed during the dying process.

Saliva and mucus from the airways can collect when the person is too weak to cough. This can cause ‘rattling’ breathing. The airway is never really obstructed and this sound is more distressing to the carers than to the person who is producing the sounds.

The main thing to remember is that the changes in breathing are not usually distressing to the person who is dying.

The doctor may prescribe medication to help dry up these secretions, however positioning the person on their side can be just as helpful. You can seek advice from your healthcare team to ensure the person is comfortable. A gentle breeze from a fan can be soothing.

People with certain types of illnesses may experience a haemorrhage or large bleed which precedes their death. If the person you are caring for is at risk of this occurring, the healthcare team will advise you and it is recommended that you have some dark towels and crisis medicines available.

Most often if a haemorrhage does occur it is quite a rapid event and it is best to remain with the person and be supportive and as calming as you can.

Incontinence

Although urine output may be less and bowel motions infrequent, incontinence can be a problem. The use of pads and waterproof sheets can help. A catheter may be inserted. Advice about practical aids can be obtained from your healthcare team.

It is important to discuss management of these issues with your nurse and ensure you are prepared. When the person cannot assist with their own personal care, you may need assistance from others in order to complete these parts of caring.

Circulation

A person's hands and feet can become cool, mottled and appear slightly blue in colour as their circulation closes down. The person is usually comfortable and unaware of these changes in colour and temperature.

There is no need to treat any of these changes. Although the person may feel cold to touch, they often will not tolerate heavy bedclothes. Use light bedclothes and keep the room at a comfortable temperature.

How will you know death has actually occurred?

Even though death is expected, you may not be entirely prepared for the moment death occurs. You may have been so busy supporting and keeping the person comfortable, dealing with enquiries and visitors and comforting other family members that you may find yourself suddenly confronted by your family member's death.

You may be focused on being present for the moment of death and being with the person who is dying while this happens. However, it is not unusual for death to occur when the relative or friend has left the room and it may be worth preparing that this may occur.

- There will be no breathing.
- There will be no pulse.
- The person will be totally unresponsive.
- They will begin to cool rapidly.
- Their eyes may be open or closed.
- Their jaw may relax and their mouth open slightly.
- After death occurs the person's body may relax and release air or fluids.

What needs to be done when the person has died?

- 1.** There is no urgency to do anything but you may wish to wash and dress them, lay their arms by their sides and close their eyes. This may be a good time to say goodbye and spend some time with the person who has died.
- 2.** Call your GP if it is within business hours or wait until the GP opens. There is no urgency or rush to make arrangements if you are comfortable. You can keep your loved one at home overnight until the GP opens.
- 3.** Call the Community Palliative Care Team on 1800 427 255. The team can offer you support and cancel any appointments that are booked with their team.

Who to call when a person dies at home

- HammondCare Community Palliative Care Service: 1800 427 255
- Palliative Care Home Support Package (if applicable): 1300 884 304
- Northern Sydney Home Nursing Service (if applicable): 02 9887 5444
- GP surgery/ mobile (if applicable) _____

If you are not comfortable with keeping the person who has died at home and are unable to contact their GP, you can follow the steps below:

1. Contact the after-hours home visiting doctor service on 13 SICK or 13 7425.
2. They can provide a Verification of Death form which allows the Funeral Director to collect the body. The funeral director will ensure all other required forms are completed by your GP as soon as practical.
3. If you can't contact your GP or 13 SICK, contact the Community Palliative Care Service (1800 427 255) who can arrange for the NSW Ambulance to be contacted on Triple Zero (000) to complete a Verification of Death. If you call the Community Palliative Care Service outside normal hours you may need to leave a message – please leave your name and phone number clearly. Wait up to 30 minutes to be called back.
4. Please advise the NSW Ambulance Paramedics that the person who has died is known to the Palliative Care Service (1800 427 255). If you have an NSW Ambulance Authorised Care Plan, please show this to the paramedics.

Definitions

Verification of Death: an assessment process to establish that a person has died. It can be done by a paramedic or any medical practitioner. Once completed, the funeral director can take a deceased person's body to the funeral home.

Certification of Death: a certificate outlining the cause of death which is required by the Births, Deaths and Marriages Registration Act 1995. This is usually completed by your GP (or other doctor within the same practice) within 48 hours of death. The funeral director can arrange for this to be completed.

Bereavement Support

A range of information about grief and bereavement is available on our website or from your healthcare team:

<https://www.hammond.com.au/research/dementia-resources/resources-for-grief-or-palliative-care>

If you are concerned about how you or someone else is coping and would like to access further information or counselling you can contact your family doctor or the following services:

Bereavement Counsellor/Coordinator Northern Sydney

Phone: 1800 427 255

Email: bereavement@hammond.com.au

Located at:

- Greenwich Hospital, Greenwich
- Neringah Hospital, Wahroonga
- Northern Beaches Palliative Care Service, Mona Vale

NSW Bereavement Counselling Service Directory

<http://www.palliativecarebridge.com.au/resources/25-nsw-bereavement-counselling-services-directory-2019>

Griefline

Phone: 1300 845 745

Phone: 03 9935 7400

Website: www.griefline.org.au

Solace (for widows & widowers)

Phone: 02 9519 2820

Website: www.solace.org.au

National Centre for Childhood Grief (for bereaved children)

Phone: 1300 654 556

Website: www.childhoodgrief.org.au

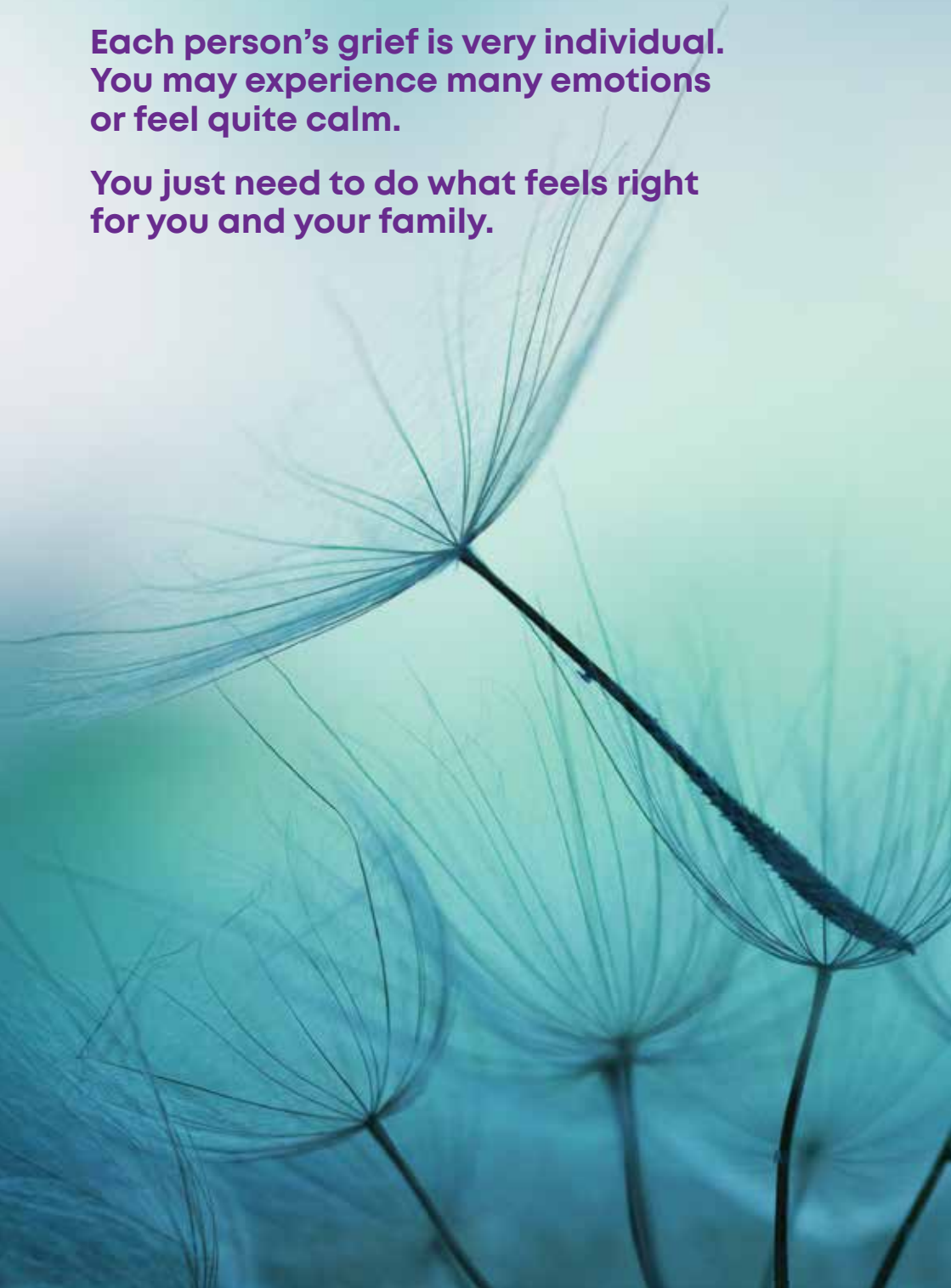
Compassionate Friends (for bereaved parents)

Phone: 02 9290 2355

Website: www.thecompassionatefriends.org.au

**Each person's grief is very individual.
You may experience many emotions
or feel quite calm.**

**You just need to do what feels right
for you and your family.**



Like to know more?

For further information please contact
Community Palliative Care



PHONE
1800 427 255



ONLINE
hammond.com.au/services/palliative-care



Stay connected:



facebook.com/hammondcare



twitter.com/hammondcare



youtube.com/user/hammondcare

Level 4, 207B Pacific Highway, St Leonards NSW 2065
Phone 1300 426 666 **hammondcare.com.au**