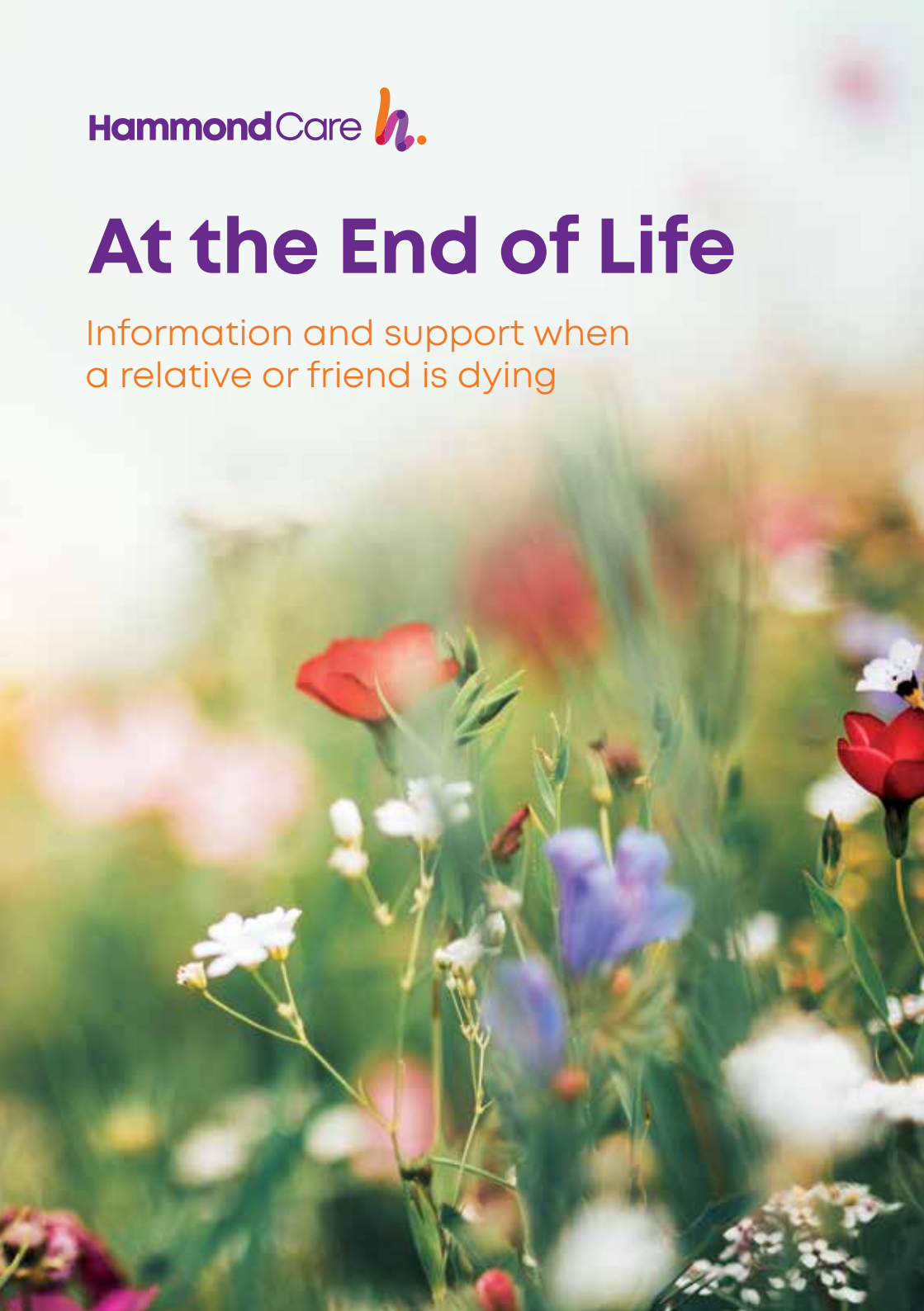


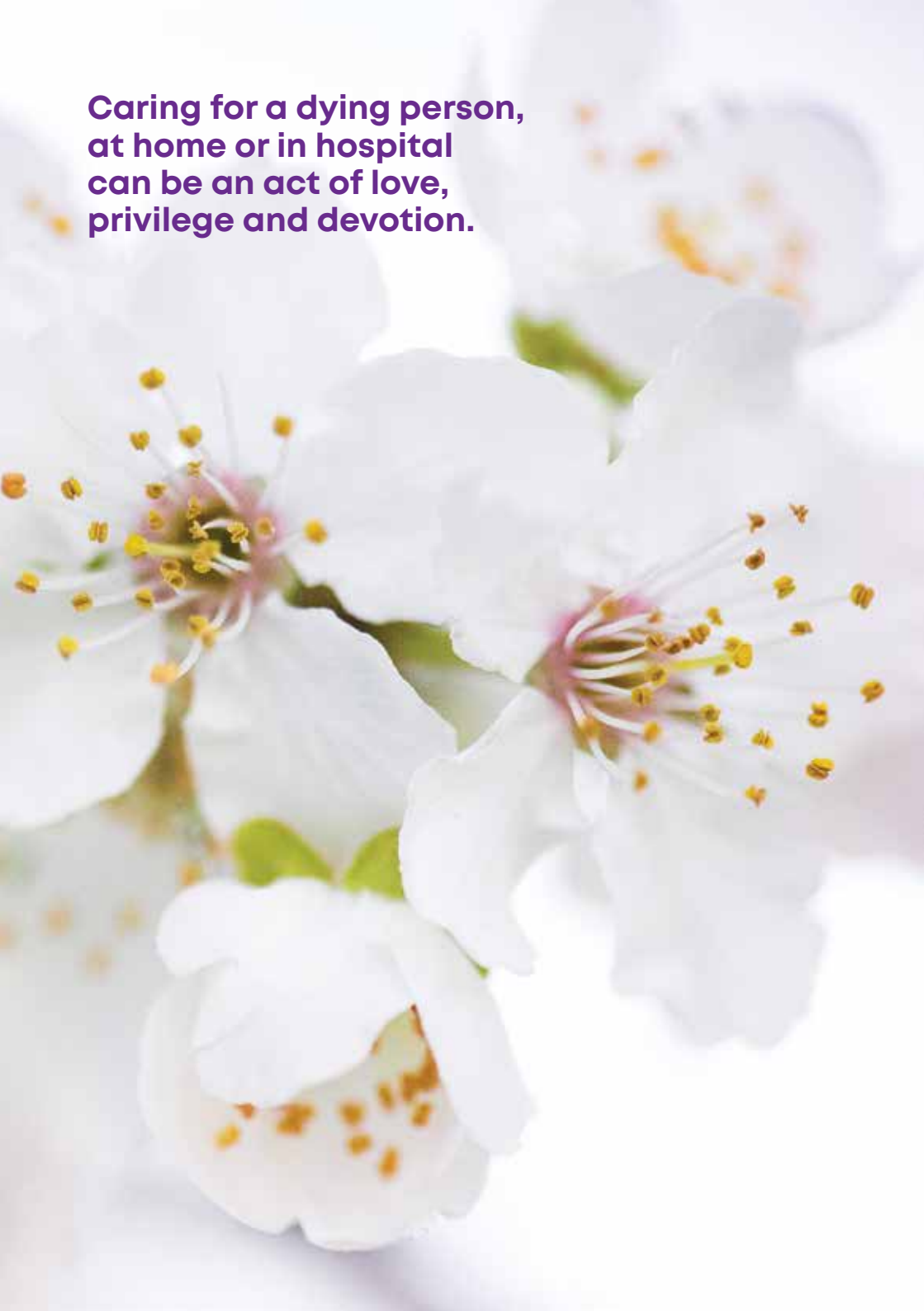


At the End of Life

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 a dying person

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 care givers understand what to expect when death is approaching
- give some suggestions of ways you can help
- provide information on the help 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 Advance Care Plan or Living Will 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 very rewarding but also very tiring. 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” due to feelings of helplessness or not wanting your relative or friend to suffer. Feelings such as guilt, anger, and sadness are common for caregivers 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. Asking family and friends to help is also important.

Support can give you the opportunity to spend time with your relative or friend to do important things, such as talking and spending time with them.

Social, cultural, spiritual and religious wishes

Everyone has their own interpretation and view of the meaning and purpose of life and their own spiritual and religious beliefs. You should talk about this with the person who is dying, so you know what is important to them. The healthcare team can also help with this.

Physical changes which may occur before death

Food and fluid intake

Not wanting to eat and drink is very common. The person's body is shutting down and does not need food. The dying person does not feel thirsty and often they cannot swallow. Trying to give them food or drinks may cause coughing and choking. Giving fluids through a drip is also not helpful.

The best thing to do is to stop the lips getting too dry at this time, 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, the person may become confused, which can be very distressing for caregivers. They may call out or try to get out of bed. The healthcare team sometimes use medication to help with this.

Keeping calm and talking to the person can help. Playing relaxing music can also help to relax the person. It may be helpful to support them in their current views without being challenging. Try 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 sleep more and for longer, until they sleep very deeply and you cannot wake them up. If they have pain or other problems, they will become more wakeful and restless. If this happens, ask your healthcare team about the best way to treat the distressing symptom.

Most people who are dying talk less and less and finally stop. However, some people may be wide awake at the very end. While the person may not be able to talk to you, they may still hear you and know that you are there.

Breathing and increased secretions and other body fluids

When the person is closer to death, breathing may change. They can breathe deeply and have long pauses in breathing.

If a person has had problems breathing, sitting upright may be more comfortable. Oxygen is not always needed and a fan may be just as helpful.

Pooling of secretions at the back of the throat can cause a rattling sound. Although this can be distressing for caregivers, like snoring, it does not bother the dying person.

Giving medication will not help but changing position may make the dying person more comfortable. Often lying on their side with the head of the bed slightly elevated can help reduce this sound.

Sometimes people may have a large bleed before death. If the person you are caring for is at risk of this happening, keep some dark towels nearby and stay with the person.

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 into the bladder. Advice about practical aids can be obtained from your healthcare team.

It is important to discuss management of these issues with your nurse and make sure you are prepared. When the person cannot wash themselves, you may need help from others to complete these parts of caring.

Circulation

A person's hands and feet can become cool 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.

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. You will know the person has died when:

- there will be no breathing
- there will be no pulse
- you cannot wake them up
- they will begin to cool rapidly
- their eyes may be open or closed
- their jaw may relax and their mouth open slightly
- after death 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 rush to do anything but you may wish to wash and dress them, lay their arms by their sides and close their eyes. You can use this 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 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 and NSHNS. You may need to call CareConnect on 1800 909 551, if the person was receiving an End of Life package.

In order for the deceased person to be cared for by a funeral care team, they need to have either a Medical Certificate Cause of Death (a legal certificate) completed by medical practitioner who has treated the person or a Verification of Death (an interim certificate only) by a suitably qualified Nurse or Paramedic. In order for a VOD to be completed your GP will have completed a Death Certification Arrangements for Expected Home Death form and available for viewing by the VOD provider and undertaker.

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/healthcare-services/bereavement-support-services>

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

Sydney Local Health District Bereavement Counselling Service

<https://slhd.health.nsw.gov.au/bereavement>

Griefline

Phone: 1300 845 745

Phone: 03 9935 7400

Website: www.griefline.org.au

Solace (for widows and 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

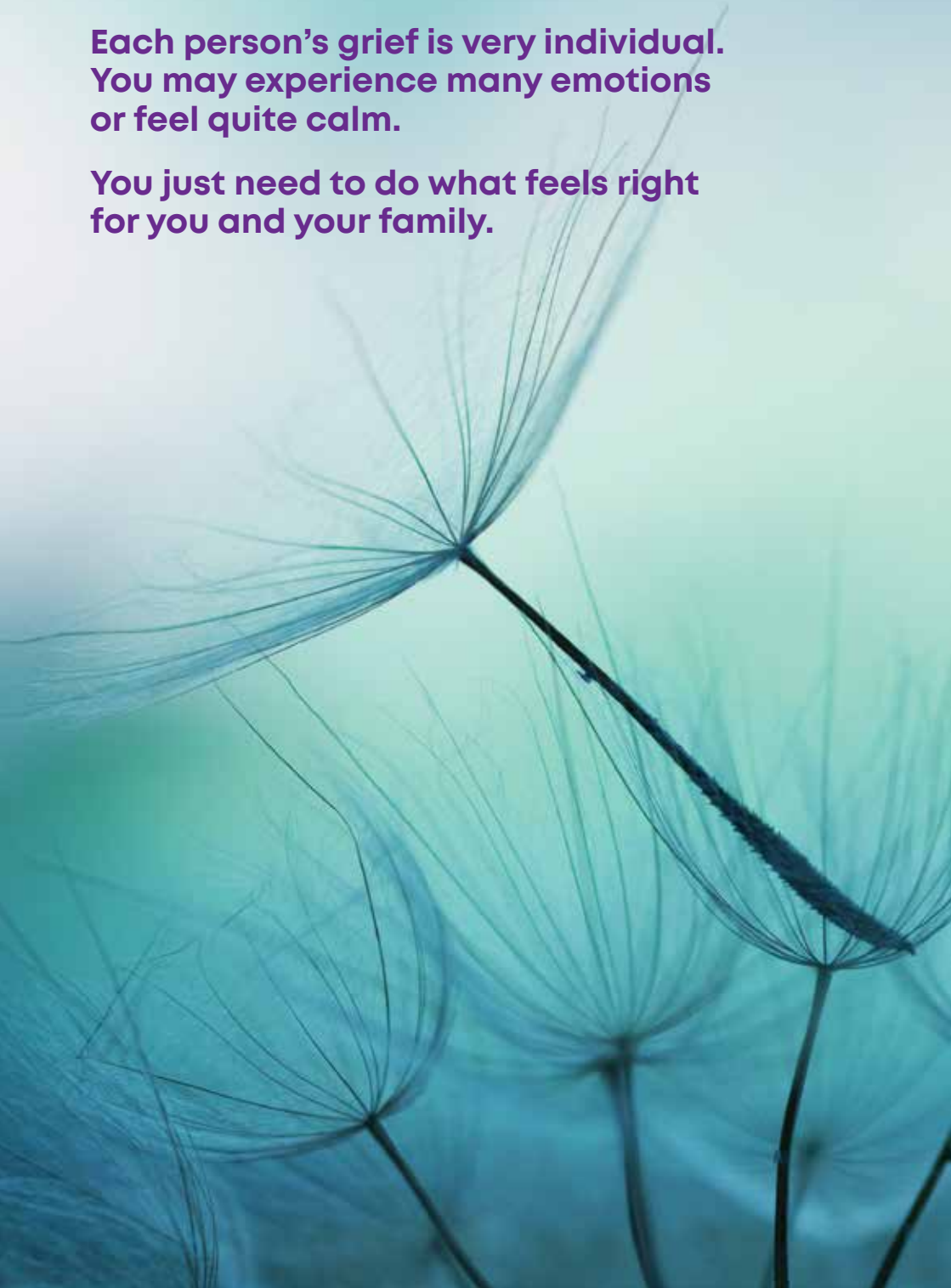
Compassionate Friends (for bereaved parents)

Phone: 02 9290 2355

Website: www.tcfa.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



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