

Dear Karuna Supporter,

The journey of a palliative care patient can be uncertain. When a person has a terminal illness, the anticipation of death can feel more present. From initial diagnosis, to advanced care planning. Through treatment, surgeries, and different options for care.

As the journey continues, it may be hard to know what kind of support is available. But there are people who do know, and they can be a valuable resource for you along the way.

This stage of the journey is guided by a conversation with Karuna's compassionate and dedicated Carer and Family Support team. Gonpo (Spiritual Care Practitioner), Linda (Social Worker), Bronwyn (Carer Wellbeing Partner), Christie (Counsellor), Liz (Carer Wellbeing Partner), and Ariella (Team Leader) combine lived experience with knowledge and empathy.

Together, they support patients and families from diagnosis, to death, and the grief that follows.

As you continue reading, please be aware that this is a conversation about death, grief, and loss. It may be confronting to some people, especially those who are currently navigating palliative care as a patient, carer, or family member.

Q: How can I recognise when my loved one is close to death?

A: Dying is usually a process rather than a single moment. And because every patient makes different choices about their end-of-life care, the process of dying is unique to the individual.

One of the most profound supports our team can offer families, is advice and reassurance for navigating those final moments.

There are some common signs and symptoms that indicate a person is nearing death. Recognising what these changes mean can be useful for families and carers who are supporting their loved ones at home.

Some near-death symptoms include decreasing mobility, such as losing balance or wanting to remain in bed. Patients may lose consciousness for long periods of time, or be uninterested in food and fluids.

Many palliative care professionals have also observed that people sometimes seem to wait for permission, or for certain loved ones to arrive, before they die.

Q: What happens after someone dies?

A: Although many families take steps to prepare for a loss, it can still be a shock when death happens. If you feel overwhelmed, it's important to remember that there are people who can help you navigate this period.

Some families choose to contact Karuna's nursing team following a death. The nurses can help with practical tasks, such as completing the patient's death certificate. They can also dispose of medical equipment such as injectables. Or, in some cases, help to wash and dress a loved one for their transfer to the funeral home.

Contacting the funeral home or funeral director is another important after-death step. Once the death has been confirmed, they can support you to make preparations. Whether it is for a funeral, memorial, burial, or any other wishes that the patient expressed.

Remember to be kind to yourself during this period. You don't need to rush tasks if you are feeling overwhelmed. This can be a valuable time to spend with your loved one or your community.

Q: What does grief feel like?

A: We often say that grief is like a fingerprint. The way you experience it will be 100% unique to you.

Grief is a response to significant change. It can occur after a big event – such as a person's death. But many people experience anticipatory grief as well. This is a grief that is felt early in the journey, before a loss. It can happen after receiving a sudden diagnosis, or following a noticeable decline in your loved one's health and abilities.

Grief can sometimes feel confusing. You might start to feel emotions that are unfamiliar to you. This is because grieving can affect everything. Our thoughts, feelings, and behaviours. Our family and relationships. Even our beliefs and physical health.

For example, you may cry more frequently or lose interest in an activity you enjoyed. But you can also feel the opposite. Some people cope with grief by completing practical tasks and activities. This could include planning the funeral, or phoning family and friends.

Many people have an idea of how they will feel when they lose someone. The reality can be completely different. It is important to recognise that there is no right or wrong way to grieve. The full range of human emotion is possible. From sadness, to anger, or even relief. There can also be moments of deep connection. Grief can create space for love to grow.

Not many people know how to talk about grief or the right way to support someone who is grieving. Don't be afraid to ask for help. Whether it is for yourself or for a loved one. There are people out there who can guide you along the way.

Q: How do I begin to talk about my loss? How can I support my friend who is grieving?

A: There is a deep cultural discomfort around talking about death. Many of us find it hard to talk about it. We may fear it will upset those we love, feel like we're giving up hope or have the perception that we are inviting it in. Because we want to protect each other, these important conversations are often avoided.

At Karuna, we encourage and support people to talk openly about life at every stage. This includes discussing death, grief, and loss. Sharing stories about your experience, your emotions, and your loved ones, can be helpful when you feel isolated or overwhelmed.

While it is hard to talk about death when you or your loved one has a terminal diagnosis, it can be even harder when the unexpected happens. When a patient is hospitalised, or has a sudden decline, emotions are heightened. And we may lose opportunities to have the conversations we were waiting for.

Always remember that you can share as much or as little as you choose. You can share different parts of your experience with different people. You can lean on Karuna for support through grief, while celebrating the memory of your person with friends and family.

When supporting someone else through grief, sometimes the simplest thing you can think of is exactly what they need. A gentle "I'm thinking of you" can mean a lot following a loss.

It may also be helpful to offer practical support for everyday tasks. Folding laundry, cooking a meal, or taking children to school when appointments are scheduled can provide relief for both patients and carers.

Remember that you know your person best. The way you have supported them in times of happiness, can also be the way you support them through grief and loss.

Q: What does spiritual care mean? Can I receive spiritual care if I'm not spiritual or religious?

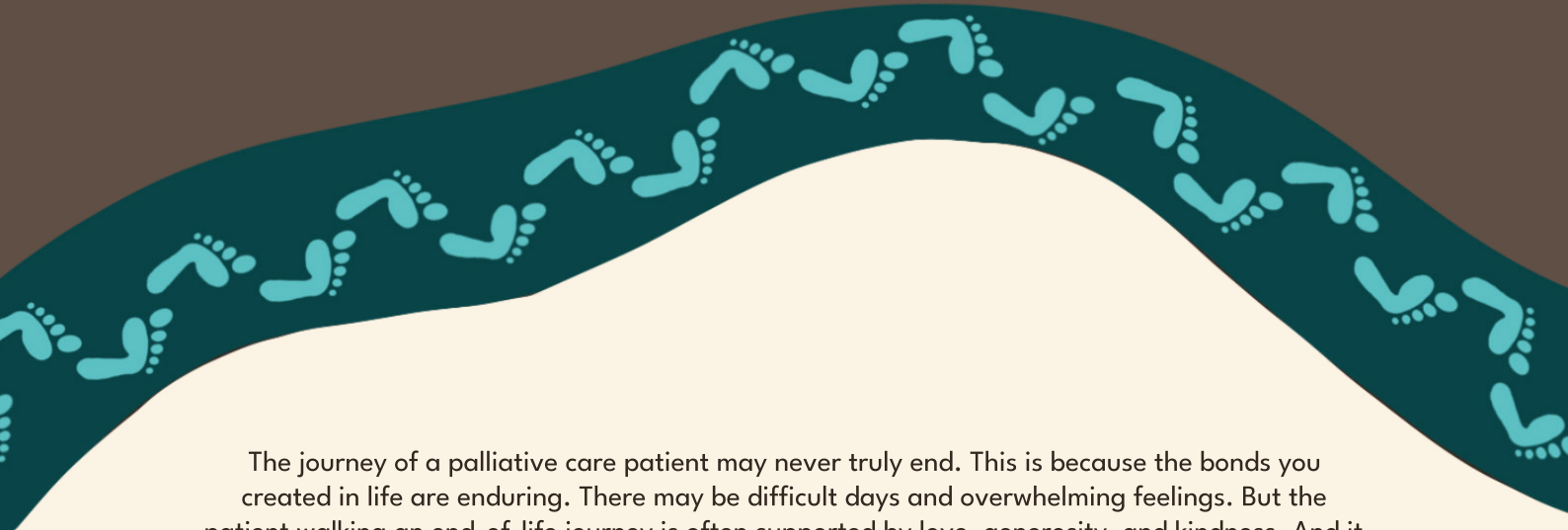
A: Spiritual care is a broad term that encompasses anything that is meaningful to the individual or their loved ones. It can be adapted to different faiths or cultures – or can exclude them altogether. Many Karuna families choose to engage with spiritual care simply because they are curious to learn more.

The spiritual side of life becomes more present for people in moments of transition. Dying is one of those moments. Engaging with spiritual care can strengthen the connection between mind and body before the end of life. It can also be helpful for families or carers who are processing a loss.

Focusing on simple techniques, such as breathing exercises, can help to ground individuals in the present moment. This creates room for open conversation. And then together, we can explore what is important to the person.

Whether a person has explored their spirituality before or not, they can still find value in these personal discussions. They can help to identify fears and anxieties. Or build a safe space to share wishes for end of life.

For us, as part of the Karuna team, spiritual care helps us to learn more about the patient's individual needs. It shows us how we can best support people to live as well as possible. Inclusive of their diagnosis, not in spite of it.



The journey of a palliative care patient may never truly end. This is because the bonds you created in life are enduring. There may be difficult days and overwhelming feelings. But the patient walking an end-of-life journey is often supported by love, generosity, and kindness. And it is through these emotions that a connection is maintained even after death.

Remember that every step you take in grief leads you further on a journey that you have never done before. Be gentle. Treat yourself with compassion. Know that your thoughts and feelings may change. Even many years later. It can depend on where you are in life and in grief.