

The Journey of a Palliative Care Patient

Dear Valued Supporter,

How can we begin to make peace with death?

A terminal diagnosis can feel like a hopeless situation. Especially when patients and families must navigate conversations around their now-uncertain future. Many people don't know where to begin.

This is where palliative care comes in. At a confusing and devastating time, palliative care offers individuals and their families one vital option: **choice**.

Choice in how they would like to receive comfort. Choice in how to manage their quality of life. Choice in a journey that feels uncontrollable.

Over the last 12 months, Karuna provided care to **more than 400 patients**. No two paths that our patients walked during this time were identical. But through the care of our multidisciplinary team, all Karuna patients had access to support, resources, and guidance along their journey.

You may have walked this path before, as a carer, family member, or friend. You may be walking it now, as a patient navigating your own diagnosis. Or maybe you heard about Karuna along the way, and believe in our mission of providing personalised care to everyone.

Wherever you joined this path: your support enables individual choices, offers hope in difficult circumstances, and guides every patient on their personal journey.

Although every journey is different, in the first part of this two part journey, you can walk in the steps of a palliative care patient and understand the different choices they may face, as they try to make peace with death.

The first step in any palliative care journey is receiving a diagnosis.

This can be one of two things: **life-limiting** or **terminal**. These terms are different points of the same trajectory.

Life-limiting is used to describe a condition that may shorten a person's life, although they can still live with their condition for many years after receiving this diagnosis. Many people with a life-limiting illness still engage with curative treatments and therapies.

A **terminal diagnosis** is the final stage of a life-limiting condition. Although there is no exact definition or timeline for a terminal diagnosis, it typically refers to the last six-to-twelve months of life. At this stage, treatment changes to focus on comfort, stability, and symptom management.

After a patient has received a terminal or life-limiting diagnosis, they have several options. They may choose to explore treatment with a hospital or alternative service. Or, in more advanced cases, they may look at care that is centred around providing comfort at end of life.

This is where a service like Karuna comes in.



Starting the journey at Karuna

When a patient is admitted to Karuna care, they meet with our team to determine the level of care they need. Depending on their condition, they will begin receiving either **palliative care** or **end-of-life care**. The goal is to develop a care plan that addresses individual needs, and provides comfort and reassurance as the patient navigates their diagnosis and treatment.

Palliative care improves the quality of life of an individual with a life-limiting illness. Can be provided alongside other treatment.

When treatment is no longer effective, palliative care progresses to end-of-life care.

End-of-life care is a vital resource for managing pain, providing comfort, and preserving dignity in the last months of a patient's life.

Learning to talk about Death

Many patients are admitted to Karuna care who don't know how to talk about death – or have never felt like they needed to before. Suddenly having to talk about a diagnosis to not just medical professionals but also their family, friends, and wider community can feel overwhelming.

Patients and their families may choose to spend time with a **Social Worker, Spiritual Care Practitioner, or Carer Support team member** who can provide guidance and help them to navigate difficult conversations.

Preparing for end-of-life

An important but often overlooked part of palliative and end-of-life care is advanced care planning. This includes documents such as a Will or Advanced Care Directive that outline a patient's wishes, from the kind of treatment they would like to receive to how they would like to be remembered or buried.

Many patients don't have formal documents when they enter Karuna care. But everyone has ideas of what does and doesn't feel right for them.

When Karuna's Carer and Family Support teams are engaged from the beginning of a palliative care journey, they can help to form those initial ideas into something more concrete.

Telehealth

appointments are a vital conversational support that allows our team to regularly check-in with patients and respond to changes in their condition quickly and effectively.



Home visits are a great support to people who are no longer physically capable of going to a clinic or a hospital. They are key to managing medication and building connection.

Conversations our team can help with:

- Talking to others
- Grief and loss
- Children and grief
- End-of-life wishes
- Advanced care planning
- Spiritual care
- + more



For now, the patient and family are taking these first important steps.

Thanks to supporters like you, families are not left to face these conversations and decisions alone. Your generosity helps them prepare for what lies ahead. In our next letter, we'll share how that support continues through the final days of life. Helping patients and families understand what to expect, creating space for meaningful goodbyes, and providing compassionate care during and after death.