

What People Wish They Had Known Earlier

Starting a palliative care journey - whether as a patient, a family member, or a carer - often brings uncertainty, questions, and emotional overwhelm.

Below are four key takeaways for navigating the palliative care journey, whether you are at the very start or already caring for someone you love:

1. UNDERSTANDING THE JOURNEY

Palliative care is about living well - not just dying. It can begin at or near diagnosis, running alongside treatment rather than replacing it. The journey is not always linear - there are good days and bad days - and knowing what to expect, including natural symptoms like fatigue and loss of appetite, can make a real difference. You don't have to wait until things are urgent to reach out for support.

2. UNDERSTANDING PLANNING

Talking about wishes and preferences is one of the most important things you can do - and it is far easier to have those conversations calmly and early, rather than in a moment of crisis. Planning ahead - including an Advance Care Directive, Will, Enduring Power of Attorney, and having key documents organised and accessible - can bring real peace of mind and reduce the burden on loved ones later. Planning is not giving up hope. It is making sure your hopes and wishes are known.

3. UNDERSTANDING SUPPORTS AVAILABLE

There is more support available than most people realise - and much of it is free. Palliative care teams support not just the person who is ill, but the whole family - including emotional, spiritual, and practical support, and bereavement care after death. Community nurses can come to the home, including after hours. Volunteer services can provide companionship and give carers a much-needed break. Your GP is also a central and often underutilised source of coordination and support. Please do ask - and keep asking.

4. UNDERSTANDING WHAT IS IMPORTANT

Many carers worry about doing everything perfectly. What people at the end of life most often say they value is simply presence - someone being there, listening, holding a hand. Connection and compassion matter far more than perfect words or technique. Anticipatory grief - grieving losses before they happen - is also completely normal and recognising it can help carers feel less alone and more supported. If you are showing up with love, you are doing it right.

Helpful resources

We encourage you to explore the following resources. They are full of practical information, guidance, and support:

- **KARUNA HOSPICE SERVICES**

<https://karuna.org.au/>

Our home - find out about our services, how we can support you, and how to get in touch. And our upcoming peer support groups for carers and bereaved.

- **UNDERSTANDING PALLIATIVE CARE - CARESEARCH BOOKLET**

<https://www.caresearch.com.au/Palliative-Care-Booklet.pdf>

A clear and compassionate guide to understanding palliative care.

- **CARERHELP**

<https://www.carerhelp.com.au>

A comprehensive resource for carers navigating the end-of-life journey.

- **QUESTION PROMPT LIST FOR HEALTH PROFESSIONAL CONVERSATIONS**

<https://www.carerhelp.com.au/Question-prompt-list>

A practical list of questions to help you get the most from appointments with doctors and health professionals - we highly recommend this one.

- **PALASSIST**

<https://www.palassist.org.au>

A free telephone and online support service for anyone living with a life-limiting illness, and their families and carers. Please note: PalAssist is free to access (subject to any costs your telephone provider may apply to 1800 number calls).

- **PALASSIST GUIDE TO PALLIATIVE CARE**

<https://resources.palassist.org.au/products/guide-to-palliative-care>

A helpful guide to understanding and navigating palliative care services.