

Living well with advanced cancer

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While many of us may benefit from the extraordinary advances being made in cancer care, there are still about 45,000 Australians each year whose cancer cannot be cured.

This large group of people deserves the same level of attention and

investment in improving their lives as is directed towards treatment for cancer itself.

Controlling symptoms such as pain, providing access to good information, and knowing what to do if problems arise all contribute to better health outcomes. As does providing people with an opportunity to explore their values and make decisions to ensure the care they receive reflects those ideals.

Palliative care focuses on all these things. And it works.

There are now six [meta-analyses](#)—large studies combining data from many other studies—that suggest earlier access to palliative care improves a patient's quality of life, lowering their levels of anxiety and depression. Four of these analyses also showed that people lived longer.

Yet, timely access to palliative care in Australia is patchy at best, meaning most people miss out on these benefits.

Why the delay?

[Our research](#) has shown about 69% of people who die from cancer in Victoria access hospital-delivered palliative care a median average of 20 days before death.

Twenty days simply isn't enough time to build confidence in community care networks. It's too late to think through what might be important when considering a life well lived, and then set about realizing those things.

Several factors contribute to this gap between best evidence and practice, including the structure of existing [palliative care services](#)—which are often focused on inpatient or home-based care—and

uncertainty about when and who to refer to palliative care.

A significant additional barrier is people's perceptions of what palliative care is and a fear of what it means to be referred.

Palliative care's 'image problem'

My research team has conducted a series of interviews to better understand how people perceive palliative care.

The responses we received suggest many patients are hesitant to access palliative care because they think of it as being "put in a bed somewhere," or "hooked up to a morphine drip for the last few hours of life."

This (mis)perception means palliative care is often associated with imminent death, making it difficult for [clinicians](#) to introduce the concept to patients, for fear of destroying their sense of hope.

As this difficult conversation is delayed, we risk losing the comfort and creative opportunities available for living well in this important phase of life—however long that might be.

Offering an extra layer of support

Our research team has created an early integrated palliative care model called [Care Plus](#), designed to explicitly address these barriers and form a routine part of the treatment pathway for people with cancer.

Care Plus is designed to be introduced at an agreed trigger point in a person's illness, whereby everyone reaching that trigger receives access.

A team of palliative care doctors and nurses then provide care adapted to the patient. This may include: relieving symptoms (which could be physical, emotional, spiritual or social); providing support for the [family](#); connecting patients to extra information and [support services](#); and helping patients think through decisions and plans for the future.

Configuring palliative care as a standard aspect of best quality care, or "part of what we do at this time," normalizes it.

We describe Care Plus as an extra layer of support integrated within the oncology treatment team, rather than a separate "add-on" service. This means seamless care for patients and families, and embedded collegiate relationships between clinicians, further enhancing the coordination of care.

To ensure ease of adoption we have developed a series of resources designed to support clinicians to offer Care Plus. These include guidance about introducing the service whereby clinicians are encouraged to describe the activities that Care Plus provides before telling the patients that palliative care teams are the experts in this area and will deliver this support.

This gives patients the opportunity to hear of and consider the benefits before hearing the words "palliative care."

Our [recent implementation study](#), supported by the Medical Research Future Fund, showed Care Plus is both feasible and acceptable. Families reported that they felt supported by the service, which provides coping strategies to people close to the patient, and clinicians found the introduction process to be seamless.

Ultimately, the aim of Care Plus is to ensure people with advanced illness and their families have the support they need to live well and plan

for their future.

As one patient summed up, "I thought [[palliative care](#)] was just caring for those who are dying. But this is much bigger than that—this is caring for those on the journey."

Provided by University of Melbourne

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