Myeloma Australia

LIVING WELL INFOSHEET

Palliative care in myeloma

Palliative care helps you to live as comfortably as possible with myeloma. It is not only for the end of life – many people benefit from receiving palliative care from the time of diagnosis and throughout treatment. Palliative care focuses on your whole wellbeing by supporting your physical, emotional, cultural, spiritual and social needs, as well as the needs of your family and carers. This infosheet is for people living with myeloma and those who support them. It explains how palliative care can help you manage symptoms and side effects, support you to live well with myeloma, and provide support for your family and carers.

Things to remember

- **Palliative care aims to help you live as well as possible with myeloma.** A wide range of healthcare professionals may be involved to support your physical, emotional, spiritual, social and cultural needs.
- **Palliative care is not only for the end of life.** It can begin at any stage of living with myeloma – from diagnosis, during treatment and remission or stable disease, or after treatment has ended.
- **Accessing palliative care earlier can make a big difference.** It can improve symptom management, help coordinate your care, and support your overall wellbeing.
- **Palliative care is tailored to you.** The services you receive will depend on your individual needs. This infosheet offers an overview of what may be available.
- **Palliative care through the public health system is free.** You may only need to pay if you use private services, specialised equipment, or certain medicines.
- **Palliative care also supports your family and carers.** They are considered part of your care team, and can receive guidance and support for their own wellbeing as well as yours.

If you're reading a printed version of this infosheet, a magnifying glass symbol shows where you can search for more information in the **'Learn more'** section at the end.

Palliative care in myeloma

What is palliative care?

Palliative care helps you to live well and as comfortably as possible with myeloma, aiming to improve your quality of life.

It focuses on relieving the symptoms and side effects of your myeloma and its treatment. Palliative care also supports your emotional, social and spiritual needs, as well as those of your family and carers.

Palliative care includes a wide range of services and supportive care tailored to your individual needs, helping you, your family and your carers navigate challenges beyond physical symptoms.

There are many benefits to accessing timely palliative care. You may receive palliative care at any time during your experience of myeloma, including:

- when you are first diagnosed
- during your treatment
- during remission or stable disease
- towards the end of life.

What is the difference between palliative and end-of-life care?

Palliative care and end-of-life care share common goals: to support comfort, manage symptoms, and improve quality of life.

Palliative care can be provided at any stage of myeloma, including alongside treatments aimed at remission. It supports the physical, emotional, and practical needs of both the person and their family.

End-of-life care is a part of palliative care. It is provided when a person is approaching the final stage of life, with a focus on comfort, dignity, and support.

Learn more

- End-of-life care specifically supports you in the final stages of life. If you would like to know more, read our *End-of-life care in myeloma* infosheet.

Who is part of the palliative care team?

The palliative care team is made up of different healthcare professionals who work as a team, known as a *multidisciplinary team*. Depending on your individual needs you may see:

- your general practitioner (GP)
- specialist palliative care doctors and nurses
- social workers
- psychologists
- pharmacists
- physiotherapists
- occupational therapists
- speech therapists
- dietitians
- spiritual or pastoral care practitioners
- volunteers trained in palliative care.

If you already receive, or are eligible for My Aged Care, NDIS or Aboriginal and Torres Strait Islander health worker support, then these will continue as part of your palliative care team.

Palliative care is an approach to care, not just a specialist service. This means you may receive palliative care from your primary health service, with specialist palliative care involved when needed or for additional support. Everyone involved in your care contributes to supporting your comfort, wellbeing and quality of life.

How do my treating team and palliative care team work together?

Your haematologist and treating team focus on treating your myeloma and helping you manage symptoms and side effects related to treatment.

The palliative care team works alongside your treating team to support your overall wellbeing and quality of life. They also help manage symptoms, but their role extends further. They support your physical, emotional, social, cultural and spiritual needs, as well as helping coordinate your care.

Rather than working separately, these teams work in partnership. Together, they care for you as a whole person, not just your myeloma. This is why you may see a wider range of healthcare professionals involved in your care over time.

> ***I had severe bone pain from crushed vertebrae caused by myeloma bone disease. My haematologist suggested a referral to the palliative care team. At first, I was concerned because I thought palliative care was for end-of-life. Now I understand that that they are the experts in managing myeloma symptoms and side effects, and can help at any time. The palliative care doctors were able to prescribe a combination of pain medicines that really worked. I also saw a physio to help strengthen my back. I am now able to do my everyday activities without severe pain.***
>
> **Georgios, Northern Territory**

What services does palliative care provide?

Palliative care is person-centred, meaning it's based on your individual needs. Services will differ for each person. This table outlines the types of palliative care services available so you know what you may ask for.

SERVICE	WHAT'S INVOLVED?
Symptom and side effect management (sometimes called palliative treatment)	Managing symptoms caused by myeloma and its treatments, such as pain, shortness of breath, fatigue, confusion, anxiety, depression and bone disease. This may include medicines, radiotherapy or other supportive treatments to keep you comfortable.
Medicine management	Reviewing your current medicines, adjusting doses or prescribing new medicines to better manage your symptoms and reduce side effects.
Equipment and aids	Organising equipment to support you at home, such as hospital beds, medicine storage, waste disposal units and mobility aids like frames or walkers.
Emotional support	Arranging psychologists, counsellors or social workers to support you, your family and carers in managing the emotional impact of myeloma.
Food and nutrition advice and support	Advice to help you manage appetite changes, nausea, constipation or swallowing issues, and help you to keep up strength and energy.
Support to meet cultural needs	Helps ensure that your care respects your culture, background, beliefs and values.
Spiritual support	Helps you explore meaning, beliefs and values, and connect you with faith leaders if you wish.
Social support	Assists with practical needs such as living arrangements, transport, meals, financial advice and setting up a support network.

> ***When I was diagnosed with myeloma, I was still working full-time as a teacher, and was a single mum with three young children. I was very stressed about finances and how my children would cope with the news. The social worker and psychologist from the palliative care team were amazing. The social worker was able to help me access financial support and negotiate flexible work-from-home arrangements with my employer. The psychologist helped me talk to my children about my diagnosis and linked them in with support that was suitable for their age through Canteen and Camp Quality.***
>
> **Xin, Queensland**

When should I be referred to palliative care?

You can be referred to the palliative care team at any time, which may even be when you are first diagnosed with myeloma. It is important to know that palliative care services can be offered together with your myeloma treatments. This is sometimes called supportive palliative care.

Palliative care can also be offered when myeloma treatments with the goal of remission have ended: whether that is when treatments have stopped working, or if you have chosen to stop treatment yourself.

You may receive palliative care services continuously or start and stop them as needed over a period of weeks, months or years.

Your haematologist, nurse consultant or general practitioner (GP) can refer you to palliative care services. Talk to your treating team about whether a referral to palliative care may benefit you.

Where can I receive palliative care?

Depending on your needs, the palliative care team can see you:

- as an inpatient (when you've been admitted to hospital)
- in an outpatient clinic (when you receive treatment in hospital or a healthcare facility without being admitted)
- where you live (through home visits from your local community palliative care service)
- in a hospice or respite care facility.

> ***I was referred to the palliative care team at my hospital when I was first diagnosed with myeloma, so they have been part of my treating team since the very beginning. I have needed their help on and off with different side effects throughout my different myeloma treatments. Being introduced to the palliative care team from diagnosis meant my side effects have been controlled very early on, rather than waiting until things got really bad and were harder to manage.***
>
> **Erik, South Australia**

Why is it important for me to access palliative care earlier?

Palliative care supports more than just your myeloma symptoms and side effects – it supports your whole wellbeing. That is why starting earlier can be very helpful.

Accessing palliative care sooner rather than later can improve:

- your symptom and side effect management
- your quality of life
- the coordination of your care
- your health outcomes
- support for your family and carers.

Accessing palliative care early may also allow you to put plans in place about how you would like to manage your future care through a process called *advance care planning*, if you have not already done this.

Advance care planning (ACP) involves discussing and making decisions about your future healthcare needs.

Learn more

- Read more in our *Advance care planning quick guide*.

Supporting your support network

No matter the level of care you need and receive, your family and carers will be impacted by your myeloma and need support too.

Having someone close to you diagnosed with myeloma is stressful and creates extra demands. It is important that your family and carers also receive the education and resources they need to support both you and themselves. Self-care helps them maintain their own wellbeing.

Your family members and carers may wish to create a self-care plan that identifies their own physical and emotional needs, and how these needs can be supported. A major benefit of palliative care services is that they extend to your support network, including your family members and carers.

Through palliative care services, your family and carers may be able to access:

- education about managing your myeloma symptoms and side effects at home
- emotional support
- financial support, such as a carer's allowance
- workplace support, including flexible working hours and leave arrangements
- information and support for your substitute decision-maker(s)
- in-home support, such as services and equipment
- planned and emergency respite services.

Who is considered family?

Who you call your family is up to you. It could include biological relatives, kinship networks, or your chosen family, including your friends or your pets. You also may choose not to have your family involved in your care. This choice is yours.

There are many resources available for carers, including:

- Carer Gateway
- Our webinar, *Caring for the carer*
- Our infosheet, *When myeloma returns*, includes helpful information on communicating with your support network and practical tips about asking for and coordinating help from others.

When Angelo was diagnosed with myeloma, I stopped doing all the things I loved that I know are good for me: like catching up with friends and going to Pilates. I would feel guilty doing these things for myself; life had become all about making sure Angelo was okay. But I also felt flat and isolated.

The pastoral carer at the hospital explained that these feelings are common with carers and talked to me about the importance of self-care. It took me a while to feel comfortable leaving Angelo at home, but I have managed to go back to my Pilates a couple of times a week and have coffee with a friend afterwards. I come home feeling revitalised and now make this a priority in my week.

Reyna, New South Wales

Will I need to pay for palliative care services?

Medicare will cover most of your palliative care costs through the **public** health system. There may be some out-of-pocket costs for services you receive at home or outside of a hospital or hospice.

You may need to pay for **private** palliative care services that you access through private hospitals, private palliative care services or private allied healthcare professionals, such as psychologists or physiotherapists.

Private health insurance may cover some of the costs. Your general practitioner (GP) can also organise a Chronic Disease Management Plan for you to reduce the costs of some private services through Medicare.

There may also be a cost if you need to hire specialised equipment to use at home, if you choose to have complementary therapies such as acupuncture, or for certain medicines and medical devices.

Ask your GP, treating team or palliative care team what out-of-pocket costs you may need to pay.

Learn more

Find more information in these Myeloma Australia resources available from myeloma.org.au.

RESOURCE	NAME	LINK
INFOSHEETS	→ *Managing myeloma pain* living well infosheet → *Nutrition and myeloma* living well infosheet → *Managing myeloma bone disease* living well infosheet → *Managing peripheral neuropathy* living well infosheet → *Fatigue and myeloma* living well infosheet → *Complementary therapies and myeloma* living well infosheet → *End-of-life care in myeloma* living well infosheet → *When myeloma returns* condition infosheet	Go to: myeloma.org.au Search for the document using the name after the icons
QUICK GUIDES	→ *Advance care planning* quick guide → *Managing symptoms during end of life* quick guide	Go to: myeloma.org.au Search for the document using the name after the icons
WEBINAR	→ *Caring for the carer* webinar	Go to: myeloma.org.au Search for the webinar using the name after the icons

Thank you to Palliative Care Australia for their information and assistance in preparing and reviewing this Myeloma Australia infosheet.

More information and support

- **Visit** Palliative Care Australia's **website** palliativecare.org.au to access a range of helpful resources for patients and carers, including a directory to help you find palliative and end-of-life care providers in your area, information to connect with your local palliative care member organisation, and links to advance care planning services.
- **Palliative Care Australia offers discussion starter guides** designed to help people think about what matters most as they approach end of life.
- **Read Cancer Council's booklet**, *Understanding Palliative Care*, for a more detailed overview of what you, your family and carers can expect when accessing palliative care.
  - Visit cancer.org.au and type 'Understanding Palliative Care booklet' into the search bar.
- **Visit Camp Quality** at campquality.org.au for more resources on supporting kids impacted by cancer.
- **Canteen** — canteen.org.au — also provides information to help support youth impacted by cancer.
  - Visit palliativecare.org.au/campaign/discussion-starters/ to explore the three available guides.
- **Go to Carer Gateway's website** at carergateway.gov.au for information and resources to support family members and carers.
- **Our Specialist Myeloma Nurses** are available on our Telephone Support Line to talk with you about your myeloma treatment and tests, and any questions you may have.

  To book a 30- or 60-minute call with a Specialist Myeloma Nurse:

  call **1800 MYELOMA** (1800 693 566)
  Monday–Friday, 9am–5pm AEST/AEDT, or

  go to **myeloma.org.au** and click on the 'Book a call' button.

  email nurses@myeloma.org.au to contact a Specialist Myeloma Nurse at any time.

We hope this infosheet has helped you understand more about palliative care in myeloma.

Your treating team can tell you more about the palliative care services and support that is available for you.

While the information in this sheet has been reviewed and endorsed by Myeloma Australia's Medical and Scientific Advisory Group (MSAG) and Myeloma Community Advisory Board (MCAB), it does not replace the care or advice of your treating team or palliative care team.

Please talk to your team about the best time to begin palliative care for your needs.

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