

End-of-Life Care Planning



— **END-OF-LIFE CARE PLANNING** is about making sure your care at the end of life reflects what matters most to you.

What is end-of-life care?

End-of-life care provides comfort and support to you and your loved ones when treatment options are no longer working or wanted.

End-of-life care can help by:

- Relieving pain and other symptoms
- Supporting emotional and spiritual needs
- Helping with practical planning and decision-making

The goal of end-of-life care is to help you feel as comfortable, supported, and at peace as possible.

Talking openly about end-of-life care

Myeloma patients at all stages of the disease often have questions about what the future may hold and want to understand their options.

If you haven't already, you may find it helpful to begin conversations with your loved ones and care team about your wishes related to end-of-life, including:

- Treatment preferences
- Care settings
- Emotional and spiritual needs

It's never too soon to talk about end-of-life care. Having these conversations sooner rather than later can help you feel prepared and supported, no matter where you are on your journey.



Advance directives make your wishes known

Advance directives are legal forms that ensure your care preferences are understood if you can't speak for yourself.

The 2 most common types of advance directives are:

- **Living will:** states what kind of medical care you do or do not want
- **Healthcare proxy:** allows a person you choose to make healthcare decisions for you if you're not able to make them for yourself

Your care team or social worker can help you complete and sign these forms.

Make copies of your advance directives. Give them to your family members, your care team, and your hospital medical records department. This will ensure that everyone knows your decisions and can carry out your wishes.

Understanding the role of hospice care

Hospice is a specialized type of care for people who are nearing the end of life. The goal of hospice care is to provide comfort and support to you and your loved ones.

Hospice offers many services, including:

- Nursing care
- Medications for symptom control
- Medical equipment
- Counseling
- Spiritual support

Hospice is:

- Usually provided at home, but may also be provided in nursing facilities, assisted living, or inpatient hospice centers
- Covered by Medicare, Medicaid, and most private insurance plans for patients who are expected to live six months or less

Hospice is not the same as palliative care. While palliative care also focuses on reducing symptoms, it can be provided at any stage of the disease — even alongside active treatment.

Support for you and your loved one

Many types of support are available to help you and those close to you cope, including:

- **Counseling or social work services** for emotional or family support
- **Support groups** to connect with others living with myeloma
- **Spiritual care** from chaplains or faith leaders
- **End-of-life doulas** for compassionate, non-medical, holistic support at the end of life

You do not have to go through this time alone. Your care team can help you find the support that best meets your needs.



Tell your care team about any changes you experience

People nearing the end of life may experience physical, mental, emotional and spiritual changes. Many symptoms can be managed with the help of hospice or palliative care teams, medicines, and other supportive therapies.



Supporting the caregiver

Caregivers play an important role at the end of life by providing love, comfort, and help with daily needs. While this role can be meaningful, it can also be physically and emotionally demanding.

Accepting help, taking breaks, and reaching out to family, friends, or your care team can help support caregivers as they care for their loved one.



What can I expect in the time ahead?

It's natural to think about the future and want time to prepare and make plans, but it's important to keep in mind that no one can predict exactly how much time you have.

Your doctor can give a general idea, but every situation is different. Many factors, including your health and how your myeloma progresses affect what happens next.

Your care team is here to support you every step of the way.



Have more questions about how to manage end-of-life care?

The MMRF Patient Navigation Center is available to answer your questions and provide additional support. Give us a call at 1-888-841-6673, Monday-Friday, 9AM-7PM ET, or visit us online at themmr.org/support/patient-navigation-center/