

You matter

When it comes to realistic care, we all matter



**Here's what you can do
to improve care for people
at the end of their lives.**



Care and support
through terminal illness

People who need palliative care matter

If you're living with a terminal illness, your personal goals and the things that are important to you should form the basis of your care.

The people who matter most in your life should also have the opportunity to be involved, in the way you choose.

The people who provide your health and social care should encourage and support meaningful conversations between you, your family and your carers.

You should have clear, easy-to-understand information about your care. And you should be supported and given enough time to make decisions that feel right for you.



Layton Thompson/Marie Curie

Actions you can take now:

- Talk to your loved ones about the type of care you want – now and in the future.
- Prepare a Power of Attorney, giving someone the authority to take actions or make decisions on your behalf if you're not able to.
- Make an Anticipatory Care Plan to help you record the type of care you want, and where you want to receive it.

Family and carers matter

It's very difficult when someone you care about becomes terminally ill. But what you want, what you think your loved one wants and what they actually want aren't always the same.

That's why it's important to talk to them, listen to what they want and respect their decisions and wishes, even if they're different from what you would choose.

Sometimes when a person is dying, they won't want to talk about the end of their life. That's okay, too – and you shouldn't force them to talk if they're not ready. Instead just let them know you're there for them.



Ben Gold/Marie Curie

Actions you can take now:

- Support the person who is ill to make decisions that feel right for them.
- Be involved in the person's care in the ways they want.
- Get support for your own health and wellbeing if you need it.

Health and social care professionals matter

It's not just those working in palliative care who need to think about supporting people at the end of their lives. Every health and social care professional has a part to play.

If someone you're working with is diagnosed with a terminal illness, it's important that you feel comfortable talking to them about it. Just being yourself is the best way to start.

Kindness, compassion and empathy are what really matters. Let the person know you're there for them, talk to them and listen to what they're telling you.



Kieran Dodds/Marie Curie

Actions you can take now:

- Make sure you have enough time to talk to the person about their illness and care – go at their pace and make sure you're not distracted.
- Set out all the options available and respect the person's decisions.
- Once you know what their priorities and wishes are, make sure you and other professionals working with that person act on them.

The Scottish Government and public bodies matter

Health and social care partnerships need to be able to embed realistic medicine (see page 7) in the care people with a terminal illness get. To do this, we need to improve people's understanding of palliative care, their choices, death and dying. This will require cultural and systemic changes.

Health and social care professionals need more training and support around realistic medicine. They should be empowered not to fear a potential backlash about not providing treatment, if this is what a person wants.



Ben Gold/Marie Curie

Actions you can take now:

- Engage with specialists and other departments in NHS boards and local authorities to embrace the principles of realistic medicine, using palliative care as an example.
- Establish a baseline and undertake benchmarking of services.
- Increase investment in the health and social care workforce and examine how existing services are organised and delivered.

Public perception matters

Death is a normal part of everyone's life. And sometimes, your quality of life can be more important than how long you have left to live. These are messages we need the public to understand better.

The media plays an important role in creating, spreading and reinforcing information about our health. We need to address the way death and dying is viewed by the public, so that unrealistic expectations can be managed and death is not seen as a failure.

Ben Gold/Marie Curie



Actions you can take now:

- Challenge misinformation and commonly accepted myths about death and dying.
- Share positive messages about patient choice, dignity, respect and empowerment.
- Be mindful of the language you use to talk to and about people at the end of their lives – sometimes ‘fighting’ to survive isn’t the only approach or doesn’t reflect the reality of their situation.

Talk to us about what you can do to support realistic palliative care

These are reflections from an ‘in conversation’ event on how we can achieve realistic palliative care with the Chief Medical Officer for Scotland, Dr Catherine Calderwood, on 14 September 2017.

Read Catherine’s reports on *Realistic Medicine* and *Realising Realistic Medicine*.

Now tell us your thoughts:

Richard Meade

Head of Policy and Public Affairs, Marie Curie Scotland

Phone: 0131 561 3904

email: richard.meade@mariecurie.org.uk

@RichardMeade13

Susan Lowes

Policy and Public Affairs Manager, Marie Curie Scotland

Phone: 0131 561 3902

email: susan.lowes@mariecurie.org.uk

@SusanLowes3

What is realistic medicine?

Realistic medicine puts the person receiving health and social care at the centre of decisions made about their care. It encourages health and care workers to find out what matters most to you so that the care of your condition fits your needs and situation.

For more information, visit **nhsinform.scot** and search “realistic medicine”

Need support?

If you're affected by terminal illness, you can contact the Marie Curie Support Line on 0800 090 2309 (8am – 6pm, Monday to Friday and 11am – 5pm, Saturday) or visit our website for lots of information and resources.

mariecurie.org.uk/help

Thank you to everyone who supports us and makes our work possible. To find out how we can help or to make a donation, visit **mariecurie.org.uk**



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