

Mostly Evidence Based

End-of-life care - why we need a roadmap, not just explanation

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...too much medical and not enough care.



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The moment that a loved one gets a terminal diagnosis, life changes for everyone. There's the shock, the fear and the stress - and as a family member you have to deal with your own distress while supporting somebody you love at the end of their life.

As soon as the diagnosis hits, many family members shift from being just relatives to carers, advocates, decision makers, appointment coordinators, and even benefits advisers. How do they navigate this while dealing with the emotional fallout - when most of the information they'll be given relates to the physical illness and not the practicalities?

One of the biggest communication challenges in end-of-life care may be that we focus on

explaining the illness, while paying less attention to everything around it.

A recent conversation with somebody who had worked in palliative medicine for many years brought this sharply into focus - it's clear that even the language used around palliative and end-of-life care can be confusing to people who aren't healthcare professionals. If experts can't agree on a definition for 'palliative', how can we expect patients and their families to understand the implications of end-of-life care, especially at a time in their lives that's so stressful and confusing?

It's much easier to focus on the medical details



This isn't about blaming doctors and consultants. They're trained to diagnose and treat illness. They're not trained to be counsellors, social workers, benefits advisers or experts in navigating the practical realities of caring for someone at home. The information supplied in hospitals and GP surgeries, or available online, is also aimed at explaining the medical problems, not the practical ones.

People need this information too, and to be fair, it's much easier to explain how an illness might progress, and how you can treat its symptoms, than it is to deal with complicated emotions, or the practical arrangements that might be needed to care for an individual patient.

Families will naturally have a lot of questions - and they aren't usually about what's happening physically. They want to know how they - and their loved one - will be able to cope with what's happening to them. **Research shows** that family caregivers need to know so much more than just how an illness is going to progress. What they need will also be different depending on their personal situation, they'll change over time and will need to be considered when healthcare professionals are trying to offer the right support.

NICE guidelines say that carers need information about financial, legal and practical issues too.



NICE guidance says that carers of people at the end of their life should be given:

> "up-to-date and accurate information and advice about financial, legal and logistical issues" when preparing for or following the death of the person they care for."

So, NICE clearly agree that there's more to good end-of-life communication than just medical care and prognosis.

Marie Curie's 2024 Better End of Life Report also found that many people at the end of their life - and their carers - either didn't know how to access coordinated support and community services or struggled to get the help they needed.

Another study, this time from the UK, asked carers and hospice staff what was missing, and they picked up on three major needs for caregivers that weren't being met.

1. knowledge and competence
2. being prepared
3. confidence in their caring role

It's not just support they were crying out for, it's the information and tools to take on the important role of looking after someone at the end of their life. Family members are being thrown into a situation that they aren't prepared for, and they don't just need answers to their questions; they need to know what questions they should be asking in the first place.

Questions like:

- Can I take care of my relative at home?
- What help is available for us?
- Can I get any financial support?
- How can I care for them overnight?
- Who do I call if things get worse?
- What happens when they die?

Being a carer is likely to be a role that family members have had zero training for and are being expected to take on at an impossibly difficult time. The study suggested two things: giving carers a practical information pack and making sure that healthcare professionals actively check in with them, acknowledge their role and offer them the support they need.

Families need to know where to find information and they also need the confidence to ask important questions - and for help.

What information do carers need most?



People who are facing a terminal illness, whether the patient or their carers, can be frightened, exhausted and overwhelmed. Any information they're given to help needs to be compassionate, easy to understand and easy to 'chunk' into manageable parts. A wall of long words and legislation is just going to confuse them, and will make things worse.

NICE recommends that the information healthcare professionals - and people writing advice leaflets - give to carers should be.

- **plainly worded**
- **presented clearly**

- **jargon free**
- **delivered in manageable chunks.**

They also need honest and straightforward information, not vague, evasive or euphemistic explanations which don’t help.

People need practical support, not just clinical updates





There’s no shortage of information available about conditions, symptoms and treatments - and this isn’t the problem. What’s missing is the information people need about how and when to consider hospice support, what they can expect from palliative care at home, and whether they can access any support for nighttime or respite care.

They also need advice about what support they can ask for to look after their loved one at home - practically and financially, any benefits they can apply for, and help with adaptations to their home.

And really, really important things like - who to call in an emergency.

People won’t automatically think to ask these questions when they’ve just been given devastating news. But they shouldn’t have to search for information about benefits, hospice services and other practical help on Google in the middle of the night - and risk out of date or disjointed information.

If creating reliable, up-to-date and understandable information can reassure people that they aren’t alone, then providing the information they need isn’t just effective communication, it’s also good healthcare.

Where can families find help?

Marie Curie – practical information, hospice and end-of-life support

Hospice UK – finding and understanding hospice services

Carers UK – support for unpaid carers

Citizens Advice – benefits and financial advice

NHS – end-of-life and palliative care information

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