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What are the options for end of life care?

Death and dying can be difficult subjects to speak about. But if you've received a terminal diagnosis, or are caring for someone who is nearing the end of their life, it's important to understand the options available for care.

While patients and their loved-ones can sometimes be reluctant to explore services, having the right care at the right time can make all the difference during end of life.

Who provides end of life care?

As well as carers and family members, many individuals may be involved in providing end of life care, including a patient's GP, hospital staff, nurses, nurse specialists, hospice staff, other health professionals, and counsellors. The level of care afforded by each of these professionals will vary depending on the needs and desires of the patient.

Understanding palliative care

Although the words '[palliative care](#)' are usually associated with death and dying, they should instead be associated with quality of life. 'Palliative' simply describes physical, psychological, and social care that is designed to alleviate symptoms during life-limiting illness. The aim is to help patients to live life to their fullest, despite their challenges.

Palliative care is usually offered to patients when doctors feel they have probably entered the last 12 months of their lives. But it is also available for those still receiving treatment, to help support and manage their pain and other aspects of their condition. And this care may go on for a year or more.

"Someone who has, say, a neurological condition like [motor neurone disease](#) may well live 2-3 years more," explains Julie Pearce, [Marie Curie](#) Chief Nurse, Executive Director of Quality & Caring Services. "But there will still be support available from the palliative care team."

The positives of early intervention

Understandably not everybody with a terminal diagnosis feels ready to explore their care options at first. "People are reluctant sometimes to access palliative care, or may not feel ready to [talk about it](#)," agrees [Dr Ann Donnelly](#), who has worked in end of life care at both hospitals and hospices. "But having those conversations early on can be extremely beneficial."

"It really depends how someone is and how they're feeling as to the information they can take on board," agrees Ms Pearce. "Palliative care is about trying to talk with a person about what's important to them, what matters, what they would like to know, what things they might be worried about or that they might need more information about."

Having access to palliative care services will also mean that specialists can forward plan for your treatment and condition, in your specific circumstances. "This could include prescribing medications or equipment that you may need further down the line, so that they are available quickly if needed," explains Dr Donnelly. "You'll also usually get put on a special palliative care list at your GP's surgery meaning any call will be fast-tracked, including out-of-hours."

There are other practical ways the palliative team will be able to support patients - for example, by advising about financial aid that may be available. "If a patient's condition suggests they are in the last three months of life, they may be able to access financial support," explains Ms Pearce.

Palliative care teams will also be able to discuss or provide information on where to get help with important decisions such as Do Not Resuscitate orders, Wills, and Power of Attorney, and may be able to help patients and their families plan for eventualities they may not have considered.

In short, all the services provided by the palliative care team are there to make a patient's life as easy and enjoyable as possible and to ensure that their wishes are respected.

Where can I find out about palliative care?

Palliative care will often be something that is raised by your specialist or GP. But if you are unsure about where to seek help, the GP (or specialist nurse if you have one) is a good first port of call. They will be able to let you know of the services available in your area, as the exact nature and availability of services may vary.

The care available may also vary due to a patient's condition - different specialists such as occupational therapists or physiotherapists may be involved to ensure that a patient is provided with all they need to support them.

The [Marie Curie](#) Information and Support line (0800 090 2309) can help with information about all aspects of end of life or grieving, whether you have practical, emotional or financial questions or concerns, or if you just want someone to talk to. Nurses are also available to talk to on the line.

End of life options

In the final days or weeks of life when a patient may need more intensive support, it's important to think about and discuss where a patient would feel most comfortable to spend their final days. This may be in a hospital, a hospice or at home.

While difficult, it's a good idea to have a conversation about this choice early on when a patient is able to express what they would prefer. Depending on medical need, the palliative care team will work hard to meet patients' wishes.

End of life care in the home

Many patients express a preference to spend their final days in their home. A team of health professionals may need to assess a patient's need and suitability, and do their best to make this a practical option for patients. End of life care may be facilitated by a hospice, or via community nurses and your GP.

Nurse specialists will usually be overseeing a patient in their home and they will communicate with the wider team looking after the patient's care, including the GP and district nurse. They provide specialist advice where complex needs exist.

Hospice

As a hospice is especially designed to support people at end of life, it can offer many services that help patients with their care. "Hospices often offer day hospice for ongoing nursing, medical and complementary healthcare support. This may involve inpatient stays for symptom management, respite or end of life care. The care provided includes support not only for the patient but their loved-ones too," explains Dr Donnelly.

Hospital

Sometimes end of life care will have to be administered in a hospital environment. "Normally hospitals are reserved for acute care, but you will find that all staff members will endeavour to provide compassionate symptom management and end of life care where it is needed," says Dr Donnelly.

Difficult conversations

It's important for those with a terminal diagnosis to feel respected, and they may not wish to access or speak about palliative care initially. Some people like to have all the facts at their disposal, others may prefer to wait a little while until needs arise.

Some patients may feel reticent about having difficult conversations with their loved ones. The important thing is to prepare what you wish to say so that the facts are discussed even when emotions arise. This journey is not an easy one for everyone concerned, but when faced together the burden is eased for everyone.

COVID-19

The current pandemic may mean that certain services have to be managed in a different way, or new protocol is in place for some hospitals and hospices.

When it comes to visiting a patient in a hospital or hospice, individual organisations will have different policies. This is often due to the varied risks of viral exposure. However, staff will endeavour to bring people together when possible. This includes the use of i-phones, and iPad, as well as face-to-face visiting with appropriate PPE.

"Although communication is more challenging, we are learning all the time to make this a better experience for patients and loved-ones," explains Dr Donnelly.

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Authored by:	Peer Reviewed by: Dr Sarah Jarvis MBE, FRCGP	
Originally Published: 20/11/2023	Next review date: 19/01/2021	Document ID: doc_31448

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