

Carers' guides – caring for the dying and dealing with death

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Contents

Caring for the dying and dealing with death	3
Terminal cancer	3
Palliative care	3
Making plans	3
Advance decision and advance statements	3
Power of attorney	3
Talking about dying.....	4
What to do when someone dies	4
Practical obligations	4
Other things to organise	5
Bereavement benefits	5
Moving on	5
Meta description	6
Keywords	6
Copyscape	6

Caring for the dying and dealing with death

Terminal cancer

When a person enters the final stages of cancer, and has a limited time left to live, this is called terminal cancer. Caring for someone who is dying can be an exceptionally difficult time for both you and the patient, but as ever, there is a wide network of support services to help you through.

In this guide we will look at how to be a carer for someone who is dying, and what to do when someone dies.

Palliative care

In some ways, caring for a person who is dying can be a little easier, because their cancer treatments become far less aggressive and the focus changes to making sure they are as comfortable and as pain free as possible. This is called palliative care, and normally involves an agreed personal care plan. In the past, there has been a set protocol, called the Liverpool Care Pathway, but this is no longer used as it was found that a single plan was not flexible enough for everyone.

Palliative care can be delivered by a wide variety of medical professionals, including GPs, community nurses, Macmillan nurses and hospital or hospice staff.

Making plans

If the person who is dying has come to terms with the fact, then they may want to have a say in how they are treated at the end and where they would prefer to die. As a carer, you can help them to talk about these issues, as long as you both feel emotionally able to.

Advance decision and advance statements

A dying patient can formalise their wishes in documents called advance decisions and advance statements. An advance decision is a legally binding document that states what treatment they want or do not want to have. This may include a do not resuscitate order, although it is unlikely that someone with terminal cancer would be resuscitated. An advance statement is a more general document outlining the patient's wishes and cultural beliefs. Although this is not legally binding, it should still be respected by their medical team.

You can help the patient to think about the issues involved in these documents and there is a document called Preferred Priorities of Care document to help you. This contains questions to guide your thinking and will make it easier to talk about these difficult subjects.

Power of attorney

If the patient is concerned about not being able to make decisions for themselves towards the end, they can give you power of attorney, as a carer, to make those decisions on their behalf. There are two kinds of power, a lasting power of attorney, which covers legal and financial matters, and a health and welfare lasting power of attorney, which allows you to make medical decisions. Despite the name, lasting powers of attorney do not last beyond the death of the patient, and decisions are made differently at that point according to their will or probate law.

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Talking about dying

Talking about dying can be one of the hardest parts of being a carer, and you might be tempted to pretend that it isn't happening, but this will not help anyone.

Some patients remain in denial about their situation right to the end, while others accept their prognosis and find that it helps them to talk about it. Some people want to know how long they have left, while others prefer to take things one day at a time. There is no right or wrong way, but as a carer it can be very difficult to deal with the many practical issues if the person concerned remains resolutely denial. You cannot force someone to talk about dying, but you could ask their medical team to talk to them to make sure that they understand the full implications of their condition.

If the person you are caring for accepts the fact that they are dying, it can make it easier to make some of the important decisions. For example you can work together to make decisions about their care as discussed above, or talk about their preference concerning where they would prefer to die. It is important to remember that, despite your best efforts, these plans may not work out for them, and that this is common and unlikely to be your fault. Of the 82% of people who die from cancer that express a wish to end their lives at home, only around 29% actually get to do so.

Talking about dying will also help you to help the person you are caring for to get their affairs in order, so that you know how to deal with their finances and insurance policies. You may even want to talk to them about their funeral, so that you are sure you are doing what they would have wanted when the time comes.

What to do when someone dies

When the person passes away, you may feel a wide range of emotions, but at first you will probably feel numb. Even if you have known it was coming for a long time, death of someone close to you, that you have cared for for so long, can be hard to take in. Many people also feel relief, especially if the cancer has gone on for a long time and the person has been suffering. This is perfectly normal and nothing to feel guilty about.

Practical obligations

There are lots of things that need doing when someone dies, but that does not mean that as their carer you have to do them all. Some people find that it helps to keep busy, but you should ask for help from family and friends and spread the load if you need to.

There are three things you are obliged to do when someone dies:

- **Call their GP** - to have the death certified. Do not move the body or remove any medical equipment until this has been done.
- **Call an undertaker** – you can do this straight away, or wait until you are ready. Some people find it soothing to wash and dress the body before it is taken by the undertaker, as their last act of caring, but you can ask the undertaker to do this for you.
- **Register the death** – you must register a death with the local registrar within five working days. You should get several copies of the death certificate when you do this so that you have them ready when you sort out the person's affairs.

Once you have taken care of these immediate responsibilities, you will need to inform a wide range of organisations, from banks and building societies to insurance companies. Fortunately, most local councils operate a Tell Us Once scheme that allows you to inform HMRC, DWP, DVLA, the Passport Office and the local council in one go, so you don't have the trauma of repeating the sad news over and over again.

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Other things to organise

As well as the business of informing various official bodies and organisations, there are a number of other things that will need to be done following someone's death. As their carer, these responsibilities may fall to you, or other family members may make the arrangements for you. This includes things like:

- **Arranging the funeral**
- **Sorting out their will**
- **Dealing with their personal effects**
- **Selling their home**

Remember that you don't have to do all of this on your own, nor do you have to do it all straight away. Take your time, do things when you feel ready and ask for help if you need it.

Bereavement benefits

If you have lost your spouse, you may be entitled to various benefits from the government to help you through the first weeks and months. These benefits depend on your age and how much National Insurance the deceased paid. The two main benefits are:

- **Bereavement payment** – a one off payment of £2000 if your partner is under state pension age when they die.
- **Bereavement allowance** – formerly known as a widow's pension, this is a weekly benefit paid for a year following the death of a spouse. The amount of benefit varies depending on your age, rising to a maximum of £11 per week for people over 45.

Moving on

If you have been caring for someone with cancer for a long time, it can feel very strange to no longer have that responsibility. Not only will you miss the person, but you will also have a hole in your life that used to be filled with the demands of caring. This can take a while to get used to, and you may experience a range of emotions as you come to terms with your new life. Many people feel relief, and then feel guilty for these feelings. Some people feel guilty for being the one who survived, or feel bad for looking towards a future without the constant work of caring. These are all normal feelings, and you should console yourself with the fact that your efforts made the patient's time better and know that they would want you to move on.

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Meta description

Caring for someone who is dying can be especially challenging, and you will have a number of responsibilities following their death.

Keywords

Terminal cancer, palliative care, advance decision, advance statement, power of attorney, bereavement payment, bereavement benefit, register a death, death certificate, Tell Us Once

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