Preparing for the future

Practicalities to think about when someone is dying

If someone is dying at home, the experience will be different to that of dying in an institution. As a carer, you are more in control of what is happening to your relative and for taking care of your own comforts too.

You will have the support of community palliative care nurses (who may also be called hospice community nurses or Macmillan Nurses). These are clinical nurse specialists, skilled in pain and symptom control. They can provide emotional support and practical advice to patients and their families. They do not usually provide hands-on care, but give advice to the primary healthcare team. They can also link with the hospital or hospice. District and other community nurses who provide hands-on nursing care and practical advice in the home. They can usually be contacted through a GP's surgery or directly at their office.

Coping mechanisms when someone is dying

- First of all, prepare to put your normal life on hold. When someone is dying you will probably find it impossible to do or to think of anything else apart from being with them or preparing for their death. And when you are not with them, you will be on red alert every time the telephone goes.
- You may feel as if you are walking around in a bubble, unable to relate to 'normal' life. Everyday conversations may seem trivial and irrelevant. You may find loud places like supermarkets or restaurants intolerable.
- Explain clearly to your children and other family members what you are going through. Additional stresses and strains can feel hard to bear. Tempers can easily fray.
- Get someone to stock-up the fridge and cupboards with ready-made meals and soups. You probably won't feel like cooking when you come home. But do make sure you have something hot and nourishing to eat every day - you will need to keep up your health and strength.
- Tell friends what is happening. People are often amazing in situations like this and very happy to provide support and help.
- Some dying people may want to see friends and extended family, but others may not. This can change from day to day. Always check with them before inviting people to visit. Nearer the end, it may be okay to offer people the opportunity to come and say their farewells. Some will gladly do this. Others may not, preferring to remember the dying person as they were. Try not to take this personally.
- Make sure you have plenty of credit for your mobile, and remember to charge it regularly. You will find yourself making and taking lots of calls from family and friends. In a hospital, this usually has to be done in an echoing corridor with trolleys and people clattering by.
- Hospitals generally charge for parking, so make sure you have plenty of change for the car park. Some machines only take coins**.** Some hospitals offer discounts for people who need to come in regularly or for extended periods of time. Ask at the hospital information desk about this.
- Be very careful when you drive as you may well be preoccupied with what's going on.

Planning ahead

Planning ahead is important for people who are dying and for their relatives and friends. It means thinking and talking about how you wish to be cared for in the final months of your life.

Why plan ahead?

It's important to plan ahead so that you can put your mind at ease, and say those important goodbyes. By planning ahead you will also make the financial, legal and practical consequences of illness and death much easier for your family to deal with.

Here's a checklist of things that you might like to consider, whether you are facing the end of life now, or you want to plan for your future end of life care.

Checklist of five important things to think about.

- Legal and financial matters
- Organ donation
- End of life care
- How you would like to be remembered
- Funeral plans

1. Consider legal and financial matters

Don't leave chaos behind for others to clear up. This can cause disputes and arguments between family members.

So make a will as soon as possible, taking legal advice if necessary.

2. Organ donation

You can donate any organ or tissue you choose, including your brain, to medical science. If this is what you want to do, make sure you write it down (or make an Advance Decision) and tell your family and your GP

3. Make a plan for what you want when you die

It's important to consider the kind of care you would like towards the end of your life. This includes where you would like to die whether you have any particular worries that you would like to discuss, and whether you wish to continue with any life-prolonging treatment. It's important to do this earlier rather than later just in case you are unable to make decisions for yourself in the future. You can do this by making an Advance Decision. This can be made by anyone of sound mind over 18 years old (16 in Scotland).

4. Consider how you would like to be remembered

What would you like people to know before you die? Are there any messages you would like to leave for those you love? Perhaps you would like to create a "memory box" or a video for your loved ones. The time to do this is while you are still able.

5. Plan your funeral arrangements:

Have you thought about whether you would prefer to be buried or cremated? Perhaps you would like a green funeral rather than a more traditional one. Think about what kind of service you would like, and whether you want it to be more of a celebration of your life than a conventional ceremony. What hymns, readings or music would you like to have, and who would you like to be there? Write this down and give it to someone whom you trust, or put it in your will. Dying Matters has a free and simple form, My Funeral Wishes, to set down what you want for your funeral.

Talking about death and dying

What to say, how to say it and where to find help.

It's not always easy to know how to talk about dying. Awkwardness, embarrassment and fear means we tend to shy away from connecting with those who are dying or those who are grieving. But when we don't talk about what matters it can increase feelings of isolation, loneliness and distress. In this section you will find practical guidance, information and resources on: how to say goodbye; the importance of good listening skills; and what the dying may experience as death approaches. There is also guidance on talking to children and young adults, and practical guidance on how to break bad news.

- Fear of talking
- Starting the conversation
- Saying goodbye
- How to open up difficult conversations
- How to listen well
- Spiritual support
- Talking to people with dementia

Fear of talking

It’s not only relatives and friends who might find it difficult to talk about what’s happening. The dying themselves often find it very hard to express what they are feeling or what they would like.

Why relatives and friends won’t talk about it

Reasons may include:

- Fear of saying the wrong thing and making matters worse
- Fear of loss
- Cure collusion (refusing to face the truth, or pretending everything’s alright) with relatives,doctors and carers
- Fear of what other relatives might say
- The notion that professionals know best, so nothing is addressed
- Fear of own mortality
- Guilt/shame about what has happened in the past
- Denial - I can’t face the truth of what’s happening

Why people who are dying won’t talk about it

The ability or willingness of someone who is dying to talk openly about what they're going through may be affected by some or all of the following:

- Fear of being burden to family and friends
- Lack of privacy, particularly in hospital wards
- Inner conflict and unfinished business
- Fractured, strife-ridden families
- Secrets that have never been shared
- Denial – I don’t want to face the truth
- Fear of upsetting relatives
- Never been a talker, and don’t want to start now
- Trusting the right person (a dying person may chose who they want to talk to, and this might not be a relative, trained nurse or doctor).

The most important thing is not to push anyone into talking if they don’t want to. Just make sure they know you are willing to listen if and when the time is right.

Starting the conversation

The following guidelines are aimed at relatives, friends and carers. But they may also be of help to anyone who is facing the end of life and doesn’t know how to reach out.

Saying goodbye

Of course, dying people need appropriate physical pain control. But they also have what might be termed 'soul needs' – to feel heard, cared-for, connected and emotionally safe. Dying people want to be understood and accepted like anyone else.

Some people are fortunate in being able to approach their dying process at peace with themselves and with those they love. But that’s not always the case. People can be frightened, confused, unable to express what they’re feeling or what they need.

- They may be afraid to die.
- They may feel they’re a burden to their friends, family or society.
- They may be raging at the thought of being cheated of life.
- They may feel lost and alone, and desperate for someone to ask how they truly feel.
- They may feel angry and let down by their God.
- They may be clinging onto hope for a miracle cure.
- They may feel as if they have wasted their life and are grieving missed opportunities.
- They may be desperate to die.

- They may want to make contact with ex-partners or estranged family or friends.
- They may want to confess to things that have happened in the past, or to ask for forgiveness. This can be painful and upsetting for relatives, but it can also be powerfully healing.
- They may also become irrationally angry, blaming and resentful towards you, or the medical and nursing staff, or the world at large.
- They may be missing relatives and friends who are unable to be with them.

If your relative or friend is becoming anxious or upset and you feel unable to deal with it, do talk to the nursing staff. The person may not be able to tell you exactly what's going on for them. Indeed, they may find it difficult to understand themselves. But they may be willing to talk to a nurse, pastoral carer, volunteer visitor, or particular friend.

Do your best to be there for the person who is dying, in any way that you can, but make sure you take care of yourself too. You may feel okay about being alone with the dying person. You may want and need company. But be aware that some close family members may find the thought of sitting with their dying relative too upsetting.

Saying goodbye in person is an important process for everyone. With gentle encouragement and support, anxious or frightened relatives can often overcome their alarm and find comfort in having done so.

How to open up difficult conversations

People who are dying usually know what is happening to them. Nevertheless, when a dying person believes relatives and friends can't cope with the truth, it can be hard for them to talk about what they're experiencing or ask for what they want or need. This can leave them feeling isolated and lonely, not knowing how to reach out or say goodbye.

So, how can a meaningful conversation happen?

A dying person might sometimes help indirectly by throwing out 'tester questions' to check if you are willing to engage with them. They might, for example, ask you, 'What do you think happens to you after you die?' They might ask if you think there is life after death. They might ask, 'Do you think God really exists?'.

On the other hand, you yourself may want to broach the subject of death with your relative or friend, but don't quite know how, especially if death has never been mentioned before. One of the easiest ways of opening up the subject is to ask your relative or friend who they would like you to contact if they became very seriously ill. This conveys that you know they may not recover and are willing to talk about it. It also gives them the space to decide whether or not to respond.

If you don't feel quite ready to have this kind of conversation and you're in a hospital, hospice or care home setting, talk with the nursing staff so they can offer appropriate support.

How to listen well

The most important gift you can give to a dying person is to listen. Here are a few golden rules of good listening which can help you open up communication:

- Be respectful: none of us truly knows what is going to happen after death, whatever our religious or spiritual beliefs. So it's important not to force our viewpoint onto the person. This is their experience.
- Be honest: often in difficult situations we tend to search for the 'right' or clever thing to say. Or we deny what's happening, or make a joke of it. While such reactions are very understandable – humour has an important place too, even in death – dying is a profound process that just needs us to be there, and perhaps hold a hand. The act of sharing ourselves openly and honestly can be very liberating and soothing for the dying person.
- Use engaged body language: don't be afraid to look your relative or friend in the eye. Be alert and attentive to what they are telling you, and the way they are saying it. Listen to their tone of voice and be aware of changes to their facial colour; their willingness to engage with you; their willingness to meet your eyes.
- Watch their body language: is what they are saying really what they mean? Are they asking you something with their body language that they are not expressing with words? If so, invite them to tell you what they really want to say.
- Stay calm: you may also feel embarrassed by this kind of emotional intimacy, or fearful of seeing your relative or friend cry or become helpless and vulnerable. Breathe slowly to calm yourself.
- Keep grounded: ground yourself by physically feeling your feet firmly on the floor. This will help you to be present and accepting of what is happening.
- Try indirect questions, such as 'I wonder whether there's anything you want to talk to me about?' or 'Perhaps there's something bothering you which you want to tell me about?' or 'What can I do to help you at the moment?' This gives your relative or friend the choice to respond, or to say no. Providing choice is empowering. They may decline initially, but will

know the door is open if they want to talk about it later. Indirect, exploring questions give the signal that you are safe to talk to, and that you care.

- Try leading questions: you can also gently ask leading questions to find out how they are feeling, such as, 'If you become really ill, would you like me to sit with you?' or 'If you become ill, what medical care would you like?' or 'Have you ever thought about what you want to do with your belongings?' or 'Have you thought about what kind of service you would like at your funeral?' Again, this provides the dying person with the choice to respond or not.
- Use short statements: these can also provide comfort. You might say, 'If there ever comes a time when you want to talk about something or you feel frightened, please do tell me'. This gives your relative or friend permission to talk in his or her own time, without expectation.
- Don't fear tears: it's okay to cry; crying is a natural response to emotionally charged situations. Being brave enough to express your grief can have a powerful healing effect on your relationship, as well as giving your relative or friend permission to grieve for the life he or she is leaving behind.
- Be quiet! Don't feel you have to talk all the time. Just being there quietly at the bedside is important, and can often be surprisingly peaceful.

Spiritual support

Spiritual care at the end of life is now recognised as part of good palliative care. Many people die without a religious or spiritual belief and this must be respected. But research shows that the nearer we come to the end of life, the more questions can arise about the meaning and purpose of our existence.

Don't be afraid to knock on the hospital chaplain's door. They are there to provide help and support whether it's for your dying relative, or you need to talk about things that are distressing you. You can also ask for pastoral support to be organised for the dying person by hospice and care-home staff. Chaplains will arrange for prayers to be said, and last rites to be administered if the dying person is a Christian. They will also arrange for other faith ministers, priests or rabbis to visit or talk with the dying person.

Other practical things to think about

Choosing where to die: advice for relatives

At home

The GP and district nurse will be the main source of support for people at home. Support is also provided by visiting community palliative care professionals and Hospice at Home services.

Hospice professionals work closely with GPs and community nurses to plan and deliver care.

Hospice at Home services allow people to receive hospice care in their own home. This may be care when someone is getting near to the end of their life, respite care (to give carers a break), or it may just be care during a difficult time. Some teams can offer nursing care 24-hours a day.

Hospices and palliative care teams will provide support for carers in the community – for example, through a support and information group or by offering them advice.

Although rewarding, caring for someone at home can be physically and emotionally demanding. You need to think about your own needs. So it is important to find extra help to give you support, and time for breaks and sleep. You can search for these on Dying Matters' Find Me Help see below.

Hospice

Most hospice care is provided by charitable hospices. There are also a number of hospices that operate in the NHS.

As leading providers of end of life care for many years, hospices have developed specialist knowledge which is accessible to patients, their families, professionals and other carers through a variety of services.

The range of care may include:

- Pain and symptom control
- Psychological and social support
- Palliative rehabilitation – helping patients to stay independent and continue to live their lives as they have done before

- Complementary therapies, such as massage and aromatherapy
- Spiritual care
- Practical and financial advice
- Support in bereavement.

Hospices provide care in a number of different places including people's own homes, day care and inpatient units.

Daycare support

Daycare gives people the chance to spend time in a hospice and get the care and support they need without being admitted as an inpatient.

Inpatient care

Some people are admitted to a hospice or palliative care inpatient unit at an early stage of their illness for a short period of intensive care, for example 10 to 14 days, and they will then go home or to another care setting. It could be for rehabilitation after treatment, or to control their symptoms (for example, pain, nausea or vomiting). People may also be admitted to a hospice during the final stages of their illness. There may be room for relatives to rest or stay overnight.

Outpatient services

Increasing numbers of hospices offer outpatient services to patients including consultation appointments with health professionals, access to information and drop in services and rehabilitation opportunities.

See above for home care support.

Hospices work closely with colleagues in other settings such as primary care, care homes and hospitals to identify people who could benefit from their care and to plan and provide it accordingly.

Most patients are referred for hospice care by their GP or hospital doctor. A district nurse may also make a referral. Some patients are able to self-refer, although the hospice may wish to discuss the referral with the patient's GP or another health professional.

Care home

Care (or nursing) homes, which are either privately owned or run by the NHS, cater for long-term elderly residents who are no longer able to cope on their own. Care home staff usually encourage regular visits from relatives and, supported by the GP, are happy to consult relatives on continuing treatment and care of the elderly person, especially when their health is failing. They do not usually provide rooms for relatives to stay overnight, but are normally happy for you to spend as much time as possible with the person who is dying.

Hospital

More than half of us die in hospitals. Hospitals are busy, noisy places which deal in helping people to get well. There are minimal facilities for relatives who want to spend extended periods of time with a dying person. You may be lucky enough for your relative to be put into a side-room. Insist on this if you can. Otherwise, your relative will be in the main part of the ward, which can add to an already distressing situation.

That said, a hospital may be the best place for your relative or friend to die, especially if they require specialised nursing care. Consequently, it is important not to feel guilty if, for example, the dying person cannot be taken home. If your relative is in a side-ward you will usually be allowed to visit or remain at the beside for as long as you wish. This may be more difficult if they are in a main ward.

Choosing how to die

- Assisted dying or voluntary euthanasia
- Refusing life-prolonging treatment
- Refusing life-prolonging treatment – a guide for relatives
- Making a legal will
- Organising lasting power of attorney

Assisted dying or voluntary euthanasia

Some people want to die if their quality of life has become intolerable. At the present time, assisted dying or voluntary euthanasia is illegal in the UK. For Dying Matters' stance on assisted dying, visit their FAQs.

Refusing life-prolonged treatments

However, it is possible to refuse life-prolonging treatments. This is done by making an Advance Decision (living will) and giving it to your doctor and to your next of kin. If you have not made an Advance Decision, and become so ill that you are unable to make decisions for yourself about your end of life care, your next of kin will be consulted by medical staff.

Refusing life-prolonging treatment – a guide for relatives

Many people make it known that they would not wish to be resuscitated or to receive life-prolonging treatment if their quality of life was to suffer due to a debilitating illness. For other patients, when it is clear to the medical team that treatment is not helping their condition and that they are beginning to die, the doctors will decide to begin to stop, or withdraw, these treatments.

In the case of an emergency admission to hospital, for example after a major stroke or heart attack, you may feel it necessary to inform medical staff about the wishes of your relative. However, it is important to understand that any decision about continuing or stopping life-prolonging treatment is the responsibility of doctors. They will respect the family's thoughts and feelings, but they are not asking next of kin for permission to withdraw life-prolonging treatments.

It can be very upsetting to be involved in such discussions on behalf of a relative who is unable to make their wishes known for themselves. So, take your time to talk through any concerns you may have with medical staff, and also with other relatives and the GP.

Making a legal will

This differs from an Advance Decision as it concerns how you may want to allocate your money, property, or possessions after your death. A will is a legally binding document.

Organising lasting power of attorney

Organising this is essential. It means nominating a next of kin, a close friend or your solicitor to take care of your personal finances, property and other assets should you become too ill to do it yourself.

Signs that death is near

There are certain signs in the last few weeks, days and sometimes hours of life that indicate when someone is preparing to die. Recognising what these are will help you to say those important goodbyes, and prepare yourself for what is to come.

When someone starts to die, these are the signs that indicate death is nearing:

- **Physical changes:** in older people, skin can become paper-thin and pale, with dark liver spots appearing on hands, feet and face. Hair can also thin and the person may shrink in stature. Teeth can discolour or develop dark stains.

- **Their external world begins to diminish** until the dying person no longer wants to leave the house or their bed and may not want to talk very much. Their mood, character and behaviour may change. For example, some may become uncharacteristically anxious. Others who have held atheist views may suddenly want to explore religious or spiritual teachings.

- **Increased sleep:** the person begins to sleep for long periods. This can be distressing for relatives, but it's important to understand that even the mildest physical exertion for someone approaching death can be exhausting, and for the moment all effort is being put into staying alive. Nearer the end, the dying person may increasingly drift in and out of consciousness.

- **Appetite reduces:** the body knows it no longer needs fuel to keep it going so those who are dying often lose their desire to eat or drink. They can begin to lose weight, sometimes rapidly. It's important not to force food or drink onto someone who no longer wants it. But do take guidance from the nursing staff.

● **Changes of expression:** the person may start to talk about ‘leaving’,‘flying’, ‘going home’, ‘being taken home’, ‘being collected’, ‘going on holiday’ or making some kind of journey. They may also begin to express heart-felt gratitude to their carers and to their family as a preparation to say their farewells.

● **Special requests:** the dying person may want something special such as to visit a particular place, or to be surrounded by their favourite flowers. They may want to hear certain music, to have family photographs nearby or to make contact with someone who has been important in their lives.

This content has been written by Dying Matters and Macmillan Cancer Support. It was commissioned as part of Find Me Help, Dying Matters' new online search tool which gives access to a comprehensive database of national and local organisations providing support and advice for people coping with death, dying and bereavement.

To find more information visit the following websites www.dyingmatters.org or www.macmillan.org.uk