

Thinking Ahead: Preparing for End of Life

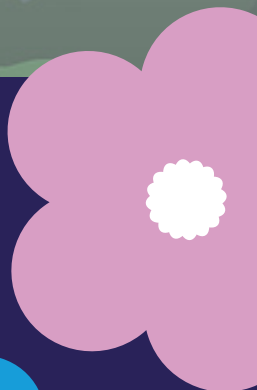
A guide for people with mesothelioma,
their families and carers



MESOTHELIOMA UK

www.mesothelioma.uk.com

0800 169 2409



Contents

Introduction	1
Talking about it	3
Practical matters	6
Your healthcare team	7
Home adaptations	8
Wills	8
Planning your own funeral	9
Lasting power of attorney	9
Palliative care	10
Advanced decisions	11
Resuscitation	12
Further resources	14
For carers	14
Getting the right support	16
Preparing yourself	17
Final weeks and days	17
After death	21
The role of the coroner (or the procurator fiscal in Scotland)	21
Further resources	23

Introduction

It can be difficult to think about dying, and you may not feel ready, but starting to prepare and talk about what you want can be helpful. This booklet aims to help guide you, and the people caring for you, through some of the things you might want to consider.

We've split it up into sections:

Talking about it

This part aims to spark initial conversations between you and your friends and family, such as thinking about what you want in terms of your care.

Practical matters

This section looks at financial and legal matters like making a will. It also talks about ensuring you have the right support in place. For example making home alterations or thinking about palliative care.

For carers

This is aimed at carers, specifically those who are intending to care for someone at home. It covers how to prepare both practically and emotionally, as well as making sure you'll have enough help from others.

Please be aware that this last section discusses

what happens to someone nearing the end of their life, which you may not feel ready to read straight away.

It also talks about what happens after someone with mesothelioma dies, such as the likely involvement of a coroner.

Questions?

If you need support or information don't hesitate to contact your healthcare team.

You can also contact the Mesothelioma UK support line, which offers a call back service from a mesothelioma clinical

nurse specialist on 0800 169 2409 or email:

support@mesothelioma.uk.com

The Mesothelioma UK website also has useful information about living with mesothelioma:

www.mesothelioma.uk.com

Talking about it

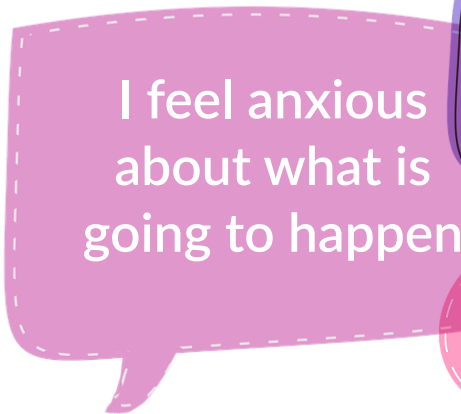
Talking about it

Talking about death and dying is not easy. But doing so can help you and those you care about. Doing so early helps everyone know what you want and what needs to happen to achieve it.

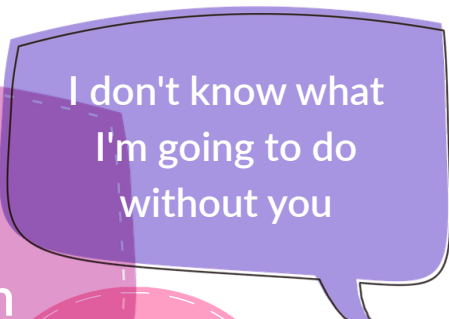
It can be good to sit down and think about who you'd like to talk to and why.

Perhaps you want to discuss making a living will so those caring for you know what medical interventions you do and don't want. Or perhaps you'd like to start talking about the type of funeral you want.

Even if it's something you think others will find trivial, if it's important to you, talk about it.



I feel anxious about what is going to happen



I don't know what I'm going to do without you



I don't want chemotherapy

This includes your family and friends. They will have their own questions and concerns.

For many, talking to friends and family is enough, but for some, talking to someone outside of their immediate circle is easier and feels safer.

There are lots of people you could talk to including nurses, counsellors or allied health professionals such as occupational therapists. You can also contact the Mesothelioma UK support line.

Professionals often have experience that is helpful as well as being

able to explain unfamiliar processes and terminology.

“ My mum has made sure everything is sorted so we don't have to make any decisions, right down to who she wants at her funeral and what reading she wants done.

- Gemma

Practical matters

Practical matters

When you feel ready, you can start thinking about any practical matters you'd like to address. This includes home adaptations, making your wishes known regarding your care and treatment, as well as financial matters and making a will. Don't feel like you have to do this all on your own, ask for support if you need it.

Your healthcare team

Your healthcare team will be one of your main sources of care and support. There will be a number of different healthcare professionals involved in your care,

and they will all have different areas of expertise. For example, occupational therapists will be able to see if any adaptive equipment can help. Whereas your GP, community nursing team and palliative care teams will be able to monitor things such as pain relief.

It can be difficult to keep track. Don't hesitate to ask if you don't understand what somebody's professional role is, and how often they are likely to come.

Mesothelioma or other clinical nurse specialists can provide clinical expertise and also be a source of continuity

during this time. It is likely that you will have one involved in your care. You can also seek expert advice and support from a Mesothelioma UK clinical nurse specialist via our support line 0800 169 2409.

Home adaptations

Your local council provides equipment to support people in their own homes. Most equipment can be loaned for free and there are grants available for major adaptations.

You will need to have an assessment of your needs by a professional such as an occupational therapist

or a district nurse before any equipment or adaptations are approved. You can ask your nurse specialist, GP, or district nurse to refer you for an assessment or you can refer yourself by contacting your local council.

Wills

A will lets people know what you want to happen to your money, property, and possessions (known as your 'estate') after your death and is legally binding. You may have talked about your wishes with your family, but if you do not have a will, the law decides what happens to your estate.

Dying without a will is called 'intestacy' and the law sets out how your estate should be allocated which may not be in accordance with your wishes. Even if you are OK with how the law would allocate your estate, it will be easier for your family to manage your affairs if you have left a will.

It is especially important to have a will if you are not married nor in a civil partnership with your partner, as there is no automatic right of inheritance for an unmarried partner.

Mesothelioma UK have a free will writing service.

Contact us for further information.

Planning your own funeral

You may want to make a very detailed funeral plan or simply want to decide some aspects of it. For example, what music you'd like to be played and whether you would like to be buried or cremated. Starting the conversation with those close to you will help them know your wishes.

www.mariecurie.org.uk/help/support/terminal-illness/planning-ahead/planning-your-own-funeral

Lasting power of attorney

A lasting power of attorney (LPA) is a legal document that lets you appoint one or more people (known as ‘attorneys’) to help you make decisions or make decisions on your behalf. This document gives you more control over what happens if you are unable to make your own decisions at some point in the future.

There are two types of LPA, one for health and welfare decisions and one for property and financial decisions. You can choose to have only one or both types of LPA.

You can make an LPA online at www.gov.uk or use paper forms. You do not need to use a solicitor to make an LPA if you prefer not to. An LPA must be registered with the Office of the Public Guardian, or your attorney will not be able to make decisions for you.

It currently takes up to 20 weeks to register an LPA.

LPA's end automatically when a person dies. From that point a person's affairs will be looked after by their executors or personal representatives.

Palliative care

People sometimes feel uncomfortable with the term palliative care because of associations with end of life. However palliative care is far wider than this, it is about living well. It can help people manage their symptoms (physical, psychological, emotional, and social), as well as their information and communication needs. Families and carers may also have palliative care needs.

Don't be afraid to bring the topic up with your healthcare team.

Advanced decision

An advanced decision (sometimes known as an advanced decision to decline treatment, an ADRT or a living will) lets family, carers and the healthcare team know what treatment(s) a person does not want if they lose the capacity to make or communicate decisions in the future. The advance decision needs to be:

- written down
- signed by the person
- signed by a witness

The charity Compassion in Dying has an advance decision form you can fill in with suggestions for things

to think about.

www.compassionindying.org.uk

For further information, a number of charities provide information on their websites.

www.mariecurie.org.uk/help/support/terminal-illness/planning-ahead/advance-care-planning

www.ageuk.org.uk/information-advice/money-legal/legal-issues/advance-decisions

Resuscitation

Resuscitation can be very difficult to think about.

If you are in hospital, the team looking after you may discuss cardiopulmonary resuscitation (CPR) and will try to help you understand if and why CPR might not be advisable or appropriate.

A Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)

is when a doctor looking after someone has made the decision that CPR would not be in their best interests. This decision will usually be recorded on a special form and kept in the medical notes.

Please note that a DNACPR is not the same as an Advanced Decision.

An Advanced Decision can be used to refuse any treatment, whereas a DNAR form only applies to CPR. Whilst only doctors can issue a DNACPR, it is advisable to talk about it with your healthcare team.

It is important to know if this decision has been made as it can guide health professionals about what to do in an emergency situation. Resuscitation Council UK has some useful information regarding CPR decisions and how these are made:

www.resus.org.uk/library/additional-guidance/guidance-dnacpr-and-cpr-decisions

Keep in mind that in most cases people with an illness such as advanced cancer do not die because their heart stops suddenly (a cardiac arrest). Instead their heart stops after a gradual period of becoming frailer and more unwell. When this is the case it is not usually possible or advisable to try and reverse this.

Performing CPR will not prevent death if the heart stops as part of the natural process of dying.

Further resources

Marie Curie produces a checklist that you may find helpful. It talks about some of the things we have already covered, as well as who will look after any pets, what will happen to your online accounts, and making a list of important documents (such as bank accounts, pension, insurance):

[www.mariecurie.org.uk/
help/support/terminal-
illness/planning-ahead/
start-planning-ahead](http://www.mariecurie.org.uk/help/support/terminal-illness/planning-ahead/start-planning-ahead)

For carers

For carers

This section talks about caring for someone who is nearing the end of their life.

If the person you are caring for would like to prepare themselves, Macmillan provide some good information:

www.macmillan.org.uk/cancer-information-and-support

Caring for someone at end of life can be a very rewarding experience.

Getting the right support

Caring for someone at end of life can be a very rewarding experience. But it is exhausting both physically and emotionally. You need to consider how much caring responsibility you can realistically take on. Try to share the care with other people when possible, and remember it is OK to leave the person's side to have a break. Try to accept any help that is offered.

Many people find that having some professional caring help enables them to spend time with their loved one in a non-carer capacity and stops them from burning out.

Your nurse specialist, GP, or district nurse can tell you how to get help from health and social care professionals and voluntary organisations.

It is also important to realise that a situation can change. You may have intended to care for someone at home until they die, but sometimes this is not possible.

It is OK if this happens, it is about ensuring that the person receives the best possible care – wherever that may be.

Preparing yourself

It is important to prepare yourself both practically and emotionally for this time.

Reading about what to expect and asking others who have been in the same situation, for example, by attending a support group, can help.

You can find out about support groups from our website:

www.mesothelioma.uk.com/for-carers

In addition, keep an open dialogue with the healthcare team. They

will be able to advise and adjust medications right up until the end to ensure the person you are caring for is as comfortable as possible.

Final weeks and days

We know from what carers have told us that knowing what to expect when a person is nearing the end of their life is really helpful.

However, we realise this might not be something you feel ready to read about yet, so just make a mental note and come back to it later.

Consciousness

When approaching the end of life, people often

sleep more and may drift in and out of consciousness. Provide familiar sounds and sensations. For example, a piece of music. Keep the environment calm by not having too many people in the room at once and avoid bright lighting.

Changes to medicines

When approaching the end of life, there may be changes to existing medication in terms of what is taken as well as how it is given. For example, if someone is no longer able to swallow medicines may need to be given via patches, injections or a small battery-operated pump

called a syringe driver. Your healthcare team should keep you informed, but ask if you have any questions.

Pain

If the person is less conscious, they may grimace or groan to show pain. Always check their position in bed to see if this can help. They may be too weak to move and lying in one position for a long time can cause stiffness. Consider if they have any areas that are known to hurt, for example back pain, and remember this when positioning them. Sometimes using something like a warm wheat pack can help. It can

be difficult to determine the cause. If in doubt consult the healthcare team. There are medicines that can help.

Breathlessness and cough

Sit the person up if possible and support them with pillows. Opening a window to allow fresh air in may help as can a handheld or electric fan. There are also medicines that can relieve these symptoms. However oxygen does not always help. Ask the healthcare team for advice.

Noisy breathing

Before someone dies, their breathing may become more noisy. This is due to extra mucous

that can build up. This is often referred to as noisy breathing. It tends to be more traumatic for friends and family. There is no evidence the person you are caring for finds it distressing, as they are often very sleepy and unaware.

Agitation or restlessness

Practical causes such as wet bedding or constipation should be considered first. Sometimes though, there may not be an obvious cause. Try reassuring the person by remaining calm, sitting with them and talking quietly. Touch can be effective. Do not hesitate to contact your

healthcare team – they can assess for things such as constipation as well as prescribe medicines that can help settle and relax someone.

When you feel ready, you can access more comprehensive information on the Marie Curie website www.mariecurie.org.uk/help/support/publications such as the booklet 'What to expect at the end of someone's life'.

After death

When the person you are caring for dies you may experience a range of emotions. There is no 'right' way to feel but talking about it can help. Try talking about your feelings to a friend, family member, health professional or counsellor. You could also contact a support organisation such as Cruse Bereavement Care:

www.cruse.org.uk

Below is some information about the likely involvement of a coroner. It is worth being aware of this so that it doesn't come as a shock.

The role of the coroner (or the procurator fiscal in Scotland)

Mesothelioma is classed as an industrial disease, and in England and Wales all deaths from industrial disease must be referred to the local coroner's office.

Because of this, we recommend speaking to your palliative care team and GP about happens when a person with an industrial disease dies at home in your local area.

In some cases, this could involve the police attending. Please try not to be alarmed, this is standard procedure in some parts

of the UK and the police are there to act as the coroners representatives.

You will be contacted by a coroner's officer as soon as possible after the referral and they will explain the process and what will happen next.

It is helpful to have information to hand that confirms the diagnosis of mesothelioma.

In some cases, a post-mortem examination may be necessary. This will be discussed with you before taking place. If an examination is required, it will usually take place within a couple of days of the death.

Once the examination is complete the coroner will give consent for the funeral to go ahead. If the coroner needs to wait for test results or further information to confirm the cause of death, an interim death certificate will be issued. This can be used for the same purposes as a standard death certificate unless confirmation of the cause of death is required.

The procurator fiscal carries out a similar role in Scotland. However there is a legal procedure in Scotland that can mitigate the need for the involvement of the procurator fiscal. Please contact our support line

if you would like further information about this.

You can also read the Mesothelioma UK booklet Mesothelioma and the Coroner's Role:

www.mesothelioma.uk.com/downloadable-resources

Further resources

There's a lot to take in when someone dies, and we haven't gone into everything you might want to know here. When you are ready you can find more information in the Marie Curie booklet When Someone Dies:

www.mariecurie.org.uk/help/support/publications/all/when-someone-dies

Mesothelioma UK

The team at Mesothelioma UK are also available to offer you support, advice as well as signposting to additional services.

Freephone
0800 169 2409

Or email:
info@mesothelioma.uk.com

Mesothelioma UK

provides specialist, impartial, up to date support and information.



To sponsor or donate contact: Mesothelioma UK
CIO Registered Charity Number 1177039
Email | info@mesothelioma.uk.com

Freephone | 0800 169 2409

Website | www.mesothelioma.uk.com

Reviewed: Sep 2022 | Review due: Sep 2024 | MED-18-02
This title was previously called End of Life Tool

Download information from
www.mesothelioma.uk.com

To request a copy, freephone 0800 169 2409
or email info@mesothelioma.uk.com