

Mesothelioma UK

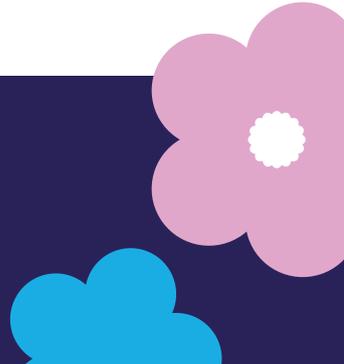
End of Life Tool



MESOTHELIOMA UK

www.mesothelioma.uk.com

0800 169 2409



It is important to be aware of what to expect at the end of life and how to make the experience as comfortable as possible. Your healthcare team, including your Mesothelioma nurse, will advise you on medications that can help with controlling symptoms at the end of life. Your Mesothelioma nurse will also advise you on how to get the assistance you may require to help you care for someone at home.

It is important that the community nursing and palliative care teams work closely together. GP surgeries often keep lists of people who require this sort of care so that concerns can be addressed promptly when the practice is contacted. It may be helpful to check with the surgery that the person is included on this list.

For some people, this time period may be a number of weeks, for others, it may only be final days or hours of life. Many people die very peacefully. The ReSPECT process helps with person-centred decision making and helps to ensure that everyone is given the opportunity to discuss their preferences and goals at the end of life. More information about this can be found at www.compassionindying.org.uk

Forward planning (if possible) can help and the information in this toolkit may be useful if the end of life is occurring at home or in a hospital, hospice or nursing home.

If you need support or you would like to discuss future care, don't hesitate to contact your Mesothelioma nurse or other key worker. You can contact the Mesothelioma UK information line on 0800 169 2409 or email info@mesothelioma.uk.com

The Mesothelioma UK website also has useful information about symptom management at www.mesothelioma.uk.com

Advanced Decision Living Will

An advanced decision to refuse treatment lets your healthcare team know your wishes if you are not able to communicate them.

An advanced decision (sometimes known as an advanced decision to decline treatment, an ADRT or a living will) is a decision that you can make to decline a specific type of treatment at some time in the future.

The treatments you decide to decline must be named in the document and it is helpful to have a copy at home, in your hospital notes and with your GP.

Find out more about planning ahead from:

- Age UK: advance decisions and advance statements
- Cancer Research UK: advance care planning
- Compassion in Dying: making decisions and planning your care
- Macmillan Cancer Support: advance care planning

Professional Health and Social Care Support

The person may have many different needs and you may meet many different healthcare professionals. These may include:

- The Mesothelioma Clinical Team including the Mesothelioma or other Nurse Specialist
- A General Practitioner
- District Nurses
- Social Workers
- Physiotherapists
- Occupational Therapists
- Dietician
- Palliative Care/Macmillan Team/Marie Curie

Changes to medicines

When approaching the end of life, it is often necessary to anticipate that someone may not be able to swallow medicines in the near future.

Medicines may be difficult to take by mouth due to the person not being able to swallow or absorb medicines, and also as consciousness is likely to be reduced or lost. Some medicines may no longer be necessary as the body undergoes changes. Examples of these are medicines such as statins, blood pressure medications and in some cases, medicines for diabetes. Some of these medicines are no longer required as the person stops eating, loses weight or becomes less active. Always ask your healthcare team for advice about which medicines take priority and which can be paused or stopped.

The route of taking medicines may also change from taking them by mouth to patches, injections or to a small battery-operated pump called a syringe driver. If the person is dying at home, it may be necessary to have some medicines in case they are needed at short notice and a nurse or doctor can give them straight away. These are usually injections for pain, sickness, restlessness and noisy breathing. Changes to medicines may be required frequently and your healthcare team will advise about this and usually the District Nurse will be visiting every day.

Communication and environment

When approaching the end of life, people often sleep more than they are awake and may drift in and out of consciousness.

Try to imagine what the person you are caring for would want. Provide familiar sounds and sensations, a favourite blanket, for example, or a piece of music. Keep the environment calm by not having too many people in the room at once and avoid bright lighting. This can reduce anxiety, even when someone is unconscious. Even when they cannot respond, it is important to keep talking to them as they can most probably hear right up until they die.

Pain

Some people may be in pain when they are dying. There may be many different causes of pain. Your healthcare team can help to identify this. If the person is less conscious, they may grimace or groan to show this.

Always check their position in bed to see if this can help. They may be too weak to move and this can cause discomfort. 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. There are medicines that can be given to help relieve pain.

Feeling sick

Sometimes people can feel nauseated or sick when they are dying.

If vomiting and you are unable to sit the person up, turn the person onto their side to protect their airway. There are medicines that can be given to help relieve this. Sometimes medicines can be given by mouth or by injection and sometimes via a small battery-operated pump that will be used to gently administer medicines under the skin.

Breathlessness and cough

Breathlessness and cough can lead to agitation, distress and make it difficult to communicate. Reassurance is required as these symptoms can increase anxiety.

Talk calmly and try to reduce anxiety. Sit the person up if possible and support with pillows, rather than lying flat. Opening a window to allow fresh air in may help or the use of a handheld or electric fan. Medicines can also help to relieve breathlessness and cough. The use of oxygen does not always help and you should ask a healthcare team about this. Before someone dies, their breathing may become noisy due to extra secretions accumulating and the muscles at the back of the throat relaxing.

When this occurs, it tends to be more traumatic to relatives than to the person experiencing it as they are unaware due to being very sleepy and reducing consciousness. Medicines can be used to help with this and can be given by an injection or via a syringe driver.

Agitation or restlessness

Some people become agitated and distressed when they are dying. It can be frightening to look after someone like this. It is important to check for reversible causes like having a full bladder or constipation. Your healthcare team can assess this if necessary.

Check if their pad or bedding is wet to see if they are incontinent. If this is not the problem, there are a number of things that you can do to help. Reassure the person by remaining calm, sitting with them and talking quietly. Touch can be effective. There are medicines that can be given to help settle and relax someone.

Moving

The person will require washing at least once per day and regular turning every 2-4 hours to protect their skin from developing pressure sores.

Alternate their position from lying on their back to each side. You can use pillows or rolled up towels to support them and also support under their arms, between and under their legs. When you are washing the person, look for signs of redness or changes in the skin. Check the back of the head and ears, the shoulder blades and elbows, and the base of the spine, hips and buttocks, ankles, heels and between the knees.

If the person is at home, the District Nurse can assess whether there is a need for pressure care aids and they can arrange for these to be delivered such as cushions, special mattresses for beds and also for equipment to help to move someone in bed.

Washing

Sometimes, it may be too disruptive for the person to have a full wash. Just washing their hands, face and bottom can be refreshing.

To give a bed bath, use two separate flannels, one for the face and top half of the body and one for the lower half. Start by washing their face, arms, back, chest and tummy. Next wash the feet and legs. Finally, wash the area between their bottom. Dry their skin gently but thoroughly. Only expose the parts of the body that are being washed at a time – you can cover the rest of the body with a towel. This helps to keep them warm and maintains dignity.

Going to the toilet

Towards the end of life, a person may lose control of their bladder or bowel. We expect someone to go to the toilet less as they eat and drink less. Contact the healthcare team looking after them if they have not passed urine for 12 hours or more as it can be uncomfortable.

Keep the person comfortable by regularly washing them and changing pads if they are wet or soiled. It may be that a urinary catheter is helpful. Your healthcare team will advise on this.

Mouth care

While people rarely complain of thirst at the end of life, a dry mouth can be a problem. This may be due to breathing mostly through the mouth.

It is important to keep lips moist with a small amount of un-perfumed lip balm to prevent cracking. Regularly wet inside their mouth and around their teeth with a moistened toothbrush. Check for sore areas and white patches on the tongue, gums and inside the cheek which can be sore. If this happens, tell the person's healthcare professionals as thrush (candida - a fungal infection) may have developed. This can be easily treated.

Eating

Sometimes, it may be too disruptive to eat for as the body shuts down, it no longer needs the food and fluid to keep it going. The person often loses the desire to eat and drink, and finally their ability to swallow. They can lose weight rapidly. This is often difficult to accept as we often associate feeding with health and an act of love. However, hunger and thirst are rarely a problem at the end of life.

Continue to offer a variety of soft foods and sips of water with teaspoon or straw as long as the person is conscious. Remember to sit them up to avoid choking. Don't force food and drink onto someone who no longer wants it.

When no longer able to swallow, some people want them to have fluids via a drip but at the end of life, this offers very little benefit. The body cannot process fluid like a healthy body and it can be harmful to artificially feed and hydrate. Risks include fluid overloading, resulting in swelling or even breathing problems.

The role of the Coroner (or the Procurator Fiscal in Scotland)

Mesothelioma is usually caused when someone has been exposed to asbestos which is considered as an unnatural cause of death.

When someone dies with mesothelioma, the Coroner has to conduct an investigation to establish if the death was due to an industrial disease which is considered an unnatural cause of death. Whether the death is sudden or expected, regardless of where the death occurred, the death has to be referred to the Coroner. The doctor who confirms the death is required by law to inform the Coroner.

In some cases, arrangements may need to be made for a post mortem examination to be conducted. After the post mortem, the Coroner will decide if an inquest is required. An inquest will be opened in the Coroner's Court. In most cases, the family are not required to attend the opening of the inquest.

At the same time, the Coroner will issue a document for the cremation or burial to go ahead. The Coroner's Officer works under the direction of the Coroner and is a point of contact for bereaved families. Advice can be found on www.mesothelioma.uk.com, listed under leaflets.

Looking after yourself

Caring for a dying person can be exhausting both physically and emotionally. Take time to eat, rest and sleep.

Sometimes a Marie Curie Nurse can be arranged to stay the night allowing you to get some sleep. Hospice at home services are also becoming more available. 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 as you can always rescind and / or review this. Nominating one member of the family to keep the wider circle of family and friends informed may be helpful.

This tool kit has been developed with the assistance of
<https://helixcentre.com/project-end-of-life-toolkit>

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

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Website | www.mesothelioma.uk.com

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