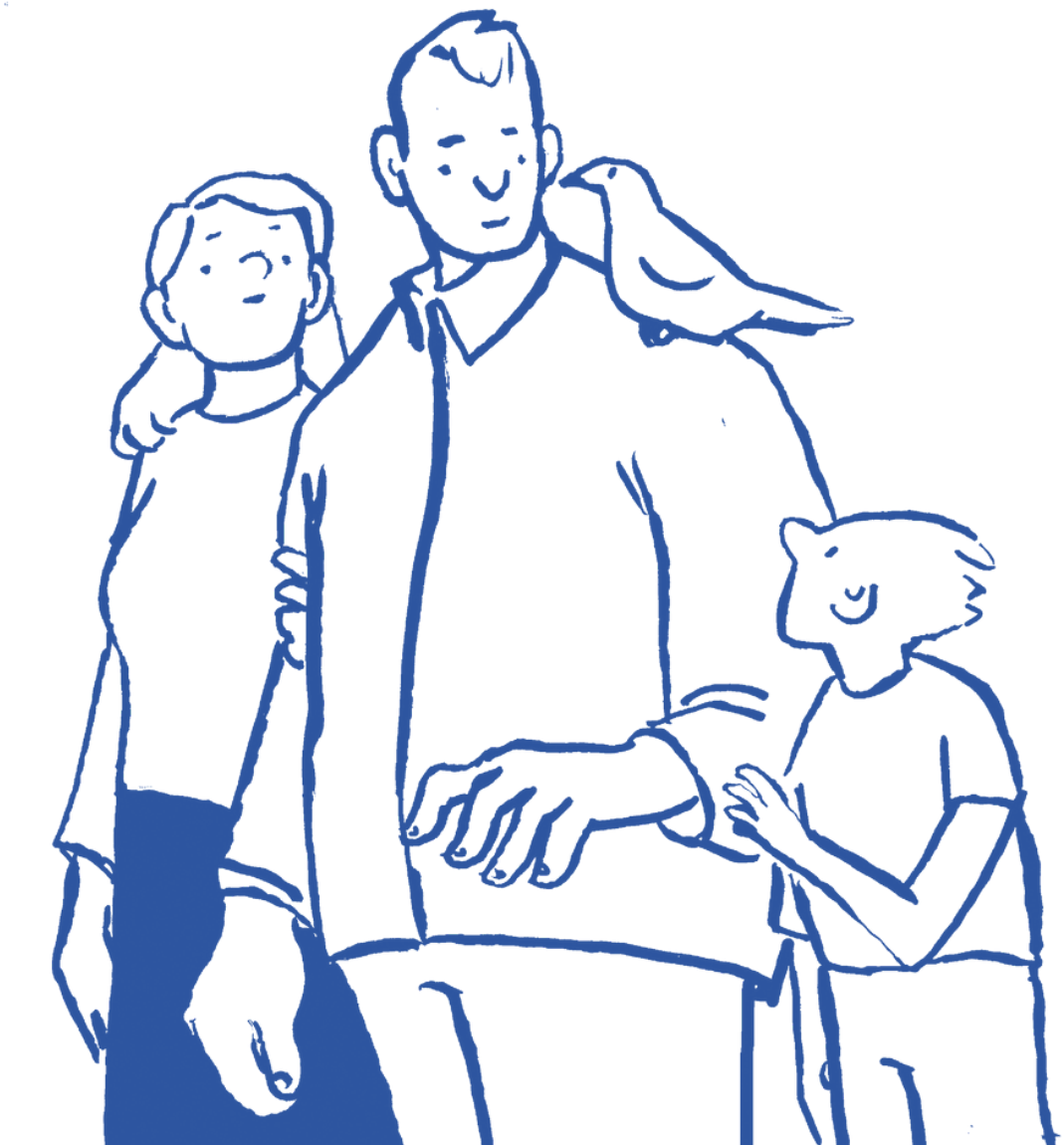
St Columba's Hospice Care

What we can expect when someone is dying



Introduction

Finding out that we or someone we love is in the last days or hours of life can be difficult, and it can take time to come to terms with this. Some people find it helpful to know a bit about what to expect in advance.

The process of dying is unique to each person. However, there are some things that tend to happen to most dying people. As far as you are able, and want to, you can remain in control of what happens as you are dying. However, as these symptoms increase you are likely to be less aware and less able to make decisions. Your care team will look to keep those around you involved in your care.

This booklet is about the process of dying whether you are at home, in a care home, in the hospital or at the Hospice, and covers the changes that can generally be expected when someone is in the last days and hours of life.

Most people can expect a calm and peaceful death. However, your disease may bring additional challenges not covered here. It is always best to speak to your care team about what might happen for you. It's also important to say that sometimes things don't go as expected—at this time it's really important to speak to your care team.

Dying is something that comes to us all and in the sections that follow we talk about 'us' – because we will all face this at some point. This guide is designed to help you, and those around you, have peace of mind about the kinds of things to expect and to provide some reassurance that you are not alone.

For each section we will explain what is likely to happen, why this happens, and offer some support to you and those around you about what might help.

Changes to eating and drinking

As we near the end of life, we will typically have less appetite as our body's need for food and drink naturally reduces. We might find it takes too much effort to eat and drink—or swallow.

Why this happens:

This happens because our metabolism slows down and we require less energy to function. Our body is redirecting its resources and conserving energy for essential functions. Having a dry mouth doesn't necessarily mean we are dehydrated; it's part of our body's natural process as it prepares for the end of life.

What might help:

- Having small sips of water or drinks we enjoy (while we can swallow)
- Having our mouths moistened with a moist soft toothbrush or ice chips
- Lip balm to prevent dryness

It's normal to eventually stop eating and drinking completely. It's important for those around us to know that this is a natural part of dying and doesn't mean we are hungry, suffering or uncomfortable.

Changes to medication

As we approach the end of life, our medication needs are likely to change. Our care team will discuss what this means for us and explain the changes to those around us.

Why this happens:

Some medications that were essential, when we were fit and well, may no longer be helpful, and new medications may be needed to manage symptoms that arise during the dying process. As we become less able to eat/drink and swallow, we may need to have our medications administered in a different way.

What might help:

- Our doctors and nurses may stop medications that are no longer beneficial to simplify what our body needs to process
- New or different medications might be introduced to manage pain, nausea, anxiety, or other symptoms mentioned in this booklet

Sometimes a small pump is used to deliver medications under the skin – this is often called a syringe driver, and it allows us to receive a consistent dose of the medications we are prescribed without us having to swallow or even be awake.

Comfort is the priority, and the medical team will focus on ensuring we are as free from distressing symptoms as possible. This can sometimes feel worrying to us and those around us, and it is best to ask the care team if there are any concerns. They will go through everything with us; care teams do not want changes to medication to add stress and worry at an already difficult time.

Changes to breathing

It is normal for breathing patterns to change in our final days and hours. We may take shallower breaths, experience long pauses between breaths, yawn frequently as our body naturally tries to draw in more oxygen, or make noises while breathing because of fluid in our chest or throat.

Why this happens:

As we become less active, our body needs less oxygen. And as our systems shut down our lungs stop working.

A rattling sound can occur when we are no longer able to properly reabsorb or clear fluid in our chest or throat. This sound doesn't mean we are in distress or suffering, even though it might be upsetting for loved ones to hear—it's similar to snoring and, like snoring, it affects those who hear it more than the person making the sound.

What might help:

Understanding what is happening to us, and those around us being able to talk to the care team about what they are seeing and hearing can be extremely helpful. In addition:

- Sometimes it may be helpful to have our position changed so that we are on our side, and our care team can help with this
- The doctor or nurse may also suggest medication to reduce the fluid in the chest or throat. This is not always needed, and it does not always make a difference
- Anxiety can sometimes cause our breathing rate to increase. Having someone sit with us can help reduce anxiety and ease our breathing

In our very last moments, our breathing may become much slower and quieter before stopping altogether. Some of us may stop breathing and then take one or two final breaths as our system stops.

Changes to bladder and bowels

As our system slows down, the muscles in our bladder and bowels relax. We may have fewer bowel movements, pass less urine (which may be darker in colour) and we may lose control. This is a natural process as our muscles and systems begin to shut down.

Why this happens:

The muscle relaxation occurs because our nervous system is gradually getting weaker. We lose the ability to consciously control these functions, and because of this weakness the muscles don't work as they did. Our urine can become darker as we drink less and our body finds it harder to process fluids.

This is a natural part of the dying process and not something we should feel embarrassed about.

What might help:

- Having a supply of incontinence pads
- A catheter (a thin tube placed into the bladder) inserted to drain urine can make us more comfortable
- Having someone to help keep us and our bedding clean and dry

Our care team can help manage these changes to keep us clean and comfortable. Some of us, and our family members, may choose to manage personal hygiene ourselves, while others prefer assistance from care professionals.

Changes to skin and body

When we are close to death, our skin may feel cooler or hotter and our hands, feet, ears, and nose may feel cold to touch. We may look a bit mottled and blue or patchy in colour and dark purple patches may appear, particularly at the base of our spine.

Occasionally, our hands or other body parts may swell slightly. Our breath, skin, and body fluids may develop a distinctive smell (similar to nail polish remover). Our eyes may remain partially open, even when we are sleep.

Why this happens:

These changes happen because our heart becomes less efficient at pumping blood to our extremities Our body prioritises blood flow to vital organs and we are less able to regulate our temperature. The distinctive smell comes from changes in our metabolism. The mottled appearance occurs as blood isn't moving around as efficiently, and the muscles controlling our eyelids relax so they don't always close.

Changes to sleep and rest

As we approach the end of our life we will spend more time sleeping; we may be drowsy even when awake. We might drift in and out of consciousness or become completely unconscious for periods before death; these periods could last for hours or several days.

Why this happens:

As our body conserves energy for essential functions, our brain reduces its activity in non-critical areas. This is why we become less aware of our surroundings and spend more time in sleep-like states.

What might help:

We are all different, and it's important to remember that we won't all be comforted by the same thing. However some things that might help are;

- Gentle touch, like holding our hand/arm might be soothing for us and for those around us
- Having someone read to us or tell us news about family and friends
- Hearing our favourite music can be calming
- Being spoken to in a normal voice, even if we appear unconscious, can be reassuring

Even when we appear to be sleeping or unconscious, we may still be able to hear the voices of our loved ones and sounds around us. This connection can be deeply comforting even when we can no longer respond verbally.

Supporting our emotional and spiritual needs

Our emotional and spiritual needs are just as important as our physical ones. During this time, we may experience a range of emotions including fear, sadness, anger, peace, or even moments of unexpected joy and meaning.

Why this happens:

The end of life is not just a physical process but also an emotional and spiritual experience. Having emotional support can significantly improve our comfort and quality of life in our final days.

What might help:

We are all different, and it is hard to predict how we will feel. Some of us find it helpful to talk about how we are feeling, and sharing feelings with people close to us can bring comfort and relief. Others don't. There's no right or wrong way to approach this. However, some of us might find it helpful to:

- Reflect on our life and share memories, or hear those around us remember stories and their memories
- Discuss our funeral wishes, or make a will if we've not already done so. This is something we can do to carry on caring for the people we are leaving behind
- Connect with people who share our faith or beliefs, or have special texts/poems, music or customs around us—we might need to think about what we might like in advance

At this point, we are unlikely to find counselling support accessible or helpful, but it might help those around us to have someone to talk to about what's happening and how they feel about it all.

Changes to restlessness and confusion

It's common for us to become restless in our last few days. Some times there are clear reasons for this-like needing to use the bathroom or being uncomfortable, but often there may not be an obvious cause. We might appear to be confused and not recognise familiar faces. We may see or hear people or things that aren't actually there-including pets or people who have died, drift in and out of sleep, become less aware of what is real, pull at bedding or clothing, or try to get out of bed.

Why this happens:

This kind of confusion or restlessness can happen because of changes in the chemistry of our brain and living with reduced oxygen to the brain as we move less and our breathing changes. This can also be due to:

- Organ failure, particularly of the liver or kidneys, which cause our bodies to be less efficient
- Sometimes this can be because of unresolved physical discomfort (constipation, full bladder), and our care teams will be looking out for this to help minimise any discomfort

What might help:

- Having a loved one sit with us quietly to help calm our anxiety
- Gentle reminders of who is present (and being patient if we need repeated reminders)
- Keeping our surroundings calm with minimal changes in noise or lighting
- Not correcting us if we say something wrong/see things that aren't there
- Speaking clearly and letting us know the time of day
- Medication prescribed by our doctor, if needed, to ease severe agitation
- Spending time with pets/animals

These symptoms can be managed and will often settle down, as our bodies adjust and we often become calm again before death. It can be distressing for those around us to see us confused or restless. It is always better to talk to the care team around us about what they are seeing, and share worries and concerns.

Thinking about the people around us

As we've seen, dying is a physical process, and an emotional and spiritual one. For the majority of us, it is also social. Our families, friends, and pets, may be in our minds, and we may want to see and spend time with them. They are also likely to want to see us. While this can be comforting, having several visitors at once might be exhausting for us.

We may struggle to rest if there's a lot of noise. There may also be multiple people that want to know how we are and those closest to us may have enquiries from multiple people asking for news. It can be exhausting, difficult and time consuming to manage this while someone they love and care for is dying and they might rather spend their time and energy with us, or resting.

What might help:

- Planning visits to allow us periods of rest
- Having one person to coordinate visitors to avoid us being overwhelmed, and talking about this beforehand
- Having a group chat to connect with the people wanting to know about how we are can help manage expectations
- Those around us understanding that some days we may want company, while other days we may prefer quiet or just close family
- Acknowledging that it may not be possible for everyone that wants to see us, and who we want to see, to be there, and including them in what is happening to us

It can be helpful if our loved ones understand that what feels right will be different for each person and may change from day to day. It may also help to remember that what matters is the life we've shared together over years; it isn't just the last days and hours that count.

Considering the children in our lives is important. Our instinct is to protect children from what is happening. However, we know from research that including children, and letting them know what is happening to us as it's happening, is really important for them to make sense of it and to help their recovery from grief. There is more information available on the Hospice website about talking to children about dying and death on the family support pages, and we can also talk to our care teams.

We hope that you have found the information in this booklet helpful and reassuring.

Please remember...

This is not easy and it may feel unfamiliar or unsettling. Be kind to yourself and others. It's not uncommon for people to feel overwhelmed, and it can be helpful to remember that everyone is doing the best they can.

You can make your wishes known in advance and/or appoint someone to speak on your behalf through doing some future care planning. Your care team will always be led by your wishes and wherever possible will include you and those around you (whether appointed or not) in decisions that need to be made to keep you as comfortable as possible.

You are not alone; your care teams are there to support you and the people around you. Please ask them about any questions or concerns you may have, particularly if you are likely to face additional challenges because of your disease. No matter how small your questions may seem; your team would much prefer to talk things through and have the opportunity to support you all.

For further understanding of the dying process, Dr. Kathryn Mannix's short animation is available here: bit.ly/dyingforbeginners.

You might also like to find out more about your options for future care planning and writing things down in advance. Please visit the website for help, support and resources.

The Hospice produces a practical guide about what to do after a death which is available on the Family Support Team page of the website: here or by scanning the QR code below.

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