

Difficulty swallowing

Information for people living
with a terminal illness, and
their family and friends



* Calls are free from landlines and mobiles. Your call may be recorded for training and monitoring purposes.

Introduction

This booklet is for people living with a terminal illness, and their family and friends. It may be helpful if you or someone you know is having difficulty swallowing. It may also be useful if you have a condition that may cause difficulty swallowing in the future, to help you understand what to expect.

Difficulty swallowing is a common problem for people living with a terminal illness. It can affect your ability to eat, drink and take medication, and this may be worrying for you and your family and friends. However, there are things that your health and social care professionals can do to help you, and there are also things you can do yourself.

If you have any questions or concerns about finding it difficult to swallow, speak to your health and social care professionals who will be able to support you. You can also call our free Support Line to speak to a nurse or trained staff member on **0800 090 2309*** or visit mariecurie.org.uk/support

Health and social care professionals

In this booklet we use the term ‘health and social care professionals’ to talk about the people involved in your care. This might be your doctor, nurse, professional carers or a speech and language therapist (SALT). If you live at home and you’re not sure who to speak to about difficulty swallowing, contact your GP.

Contents

What is difficulty swallowing?	3
What are the signs and symptoms?	4
What problems can it cause?	5
What causes difficulty swallowing?	7
What can help with difficulty swallowing?	8
Choosing food and drink	11
How your hospice can help	16
Eating and drinking at the end of life	18
How Marie Curie can help	22
Useful organisations	24
About this information	27

What is difficulty swallowing?

Difficulty swallowing is when you have problems taking food, drink, medication or saliva from your mouth, down your throat and into your stomach. Swallowing is something that we normally do without thinking, but it's quite a complex process and many things can affect it.

Difficulties with swallowing are called dysphagia (pronounced 'dis-fey-jee-uh'). This might be a new problem for you, or it might be something you've had for a while. Swallowing problems can happen gradually, so you might not have realised you were having difficulty straight away.

Swallowing problems are different for everyone. They might get better or worse over time. For some people, swallowing problems can get better or be treated. If this is not possible, there might be things that can help you cope with swallowing difficulties and reduce the risk of having other problems.

Philip Hardman/Marie Curie



What are the signs and symptoms?

Symptoms of swallowing problems include:

- coughing or spluttering, particularly when you eat or drink
- choking
- feeling like food is stuck in your throat
- having more saliva in your mouth, which can cause drooling or problems talking
- bringing food back up through your mouth or nose.

If you have any of these symptoms, speak to your health or social care professionals as soon as possible.



iStock

What problems can it cause?

Finding it hard to swallow can cause a range of problems and you might become nervous about eating, drinking or taking medication. Your health and social care professionals can help you with any problems you have and talk to you about your concerns.

Your difficulties with swallowing might stop you from being able to swallow at all, or you might have difficulty with certain food, drink or medication.

Some people find that they eat and drink less, which can cause weight loss or dehydration. You might be malnourished – this is when you're not getting enough nutrients from your food. This can mean that your body is not able to repair damage, fight infection and have energy.

Swallowing problems can sometimes cause choking, where food blocks your airways. This can be frightening, especially if you're unable to clear your airways by coughing. It can stop you breathing and be very serious. If you feel like you are choking, call for help and try to alert someone immediately. If you can, keep calm and try to cough up whatever is stuck. If you're worried about choking, you could ask someone to be with you while you eat if possible. If you have one, you could keep a medical alert button nearby.

Swallowing problems can also cause particles of food or drink to go into your lungs (sometimes called 'aspiration'). This can sometimes cause pneumonia (a severe chest infection), which can be serious and difficult to treat.

Difficulty swallowing

You may feel nervous about trying to swallow and may feel upset or worried that you're now finding it difficult. Problems eating and drinking may also stop you from enjoying meals and socialising with family and friends. This can have a big impact on how you feel about life in general and might make you feel low (depressed), worried or stressed.



iStock

What causes difficulty swallowing?

Many things can cause difficulty swallowing when you have a terminal illness, including:

- stroke
- motor neurone disease (MND)
- dementia
- Parkinson's disease
- multiple sclerosis (MS)
- other conditions that affect the brain, nerves and muscles
- cancer, especially cancer in the head, mouth, neck, throat or oesophagus (the tube between your mouth and stomach)
- cancer treatment such as surgery and radiotherapy
- some medication
- other health conditions or illnesses, such as reflux, thrush infection, inflammation, oesophageal ulcers and stomach ulcers
- older age, as people's muscles get weaker.

What can help with difficulty swallowing?

Practical tips

There are many things that you can do to help with your eating and drinking:

- Sit in an upright position when you eat or drink if possible – this can make it easier to swallow.
- Keep your mouth clean (see page 9) – this can make it more comfortable to chew and less likely that you'll get an infection.
- Have small, regular meals rather than three large meals a day.
- Do not rush when you're eating or drinking – allow yourself plenty of time.
- Chew your food thoroughly before you swallow.
- Choose food and drink that you like.
- Tell your health and social care professionals what's important to you – for example, whether you want to try to eat and drink by yourself if possible.
- Ask for help whenever you need support to eat, drink or take medication.

Your health and social care professionals can give you advice and talk to you about what might be best for you.

Mouth care

Mouth dryness, sore mouth, ulcers, bad breath, infections, changes in taste and drooling are all common problems for people living with a terminal illness. Talk to your doctor or nurse if you have any new symptoms or any symptoms that get worse.

There are lots of things that you can do to keep your mouth clean and comfortable. These general tips might help:

- Brush your teeth twice a day for at least two minutes.
- Use a toothbrush and small amount of fluoride toothpaste.
- A soft toothbrush is best if your mouth is sore.
- An electric toothbrush can be very effective and may be less tiring to use.
- If you wear dentures, clean them at least once a day and rinse them after you eat.



For more information about mouth care, including what can help with a dry or sore mouth, visit mariecurie.org.uk/mouth-care or call our free Support Line on **0800 090 2309***.

How your health and social care professionals can help

Talk to your health and social care professionals if you have problems with swallowing or if your symptoms change. If you live at home or in a care home, make sure your GP knows about any problems you have.

Difficulty swallowing

Your health and social care professionals can look at the problems you're having and talk with you about what they can do to help. They will look at what could be causing your swallowing difficulties or making them worse. They may recommend things that could help, such as stopping or reducing medication. They might involve other professionals in your care, such as a speech and language therapist (SALT) or a dietitian. These professionals can do things to help you, including teaching you exercises to help you swallow more safely or recommending certain food or drink.

Your health and social care professionals may be able to help you to eat and drink during mealtimes if you need this support.

They can also talk with you about what you want from your future care – for example, if your ability to swallow gets worse. This is sometimes called advance care planning or, in Scotland, anticipatory care planning. Your wishes can then be followed if you are not able to make decisions in the future.

Questions about eating or drinking?

Your health and social care professionals are there to help you be as comfortable as possible. It's common to have questions about any problems you have with swallowing, eating, drinking and taking medication. If you or your family or friends have any concerns or questions, do not hesitate to speak to your health and social care professionals.

Choosing food and drink

Your health and social care professionals might recommend certain kinds of food or drink to make it easier for you to swallow them safely. For example, soft foods chopped into small pieces may be easier to swallow than dry foods or hard foods in large pieces. Thicker liquids may be easier for you to swallow than thin liquids (for example, water). Your health and social care professionals might also change the thickness (consistency) of your food and drink using liquids, gels or powders.

Your health and social care professionals might also recommend using high calorie drinks, so that you do not have to eat as much.

If your family or friends want to make or bring you food or drink, they should check the advice you've been given about what might be best for you.

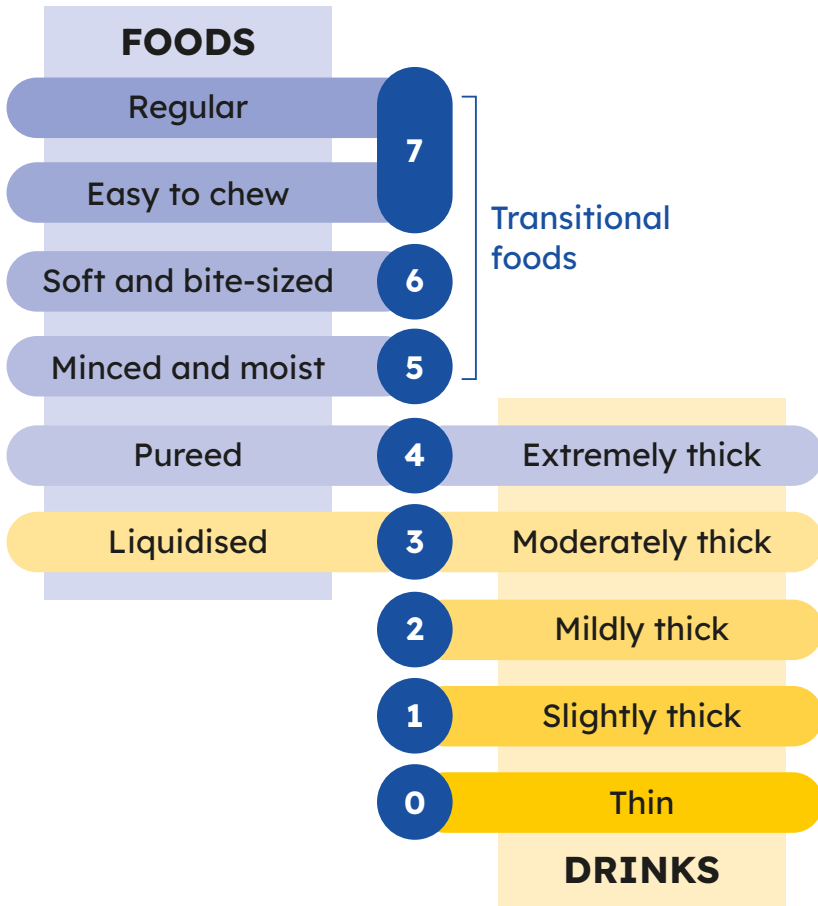
Different thicknesses of food and drink

The diagram on page 12 shows the different thickness levels of food and drink – this is the measurement system that your health and social care professionals should use to work out what you should be eating and drinking. They can measure the thickness level of food and drink by looking at how easily it flows – for example, whether it can be sucked through a straw or how quickly it flows through a syringe.

Difficulty swallowing

Your health and social care professionals will usually organise this for you, but it might be useful for you to understand what they're doing. They can tell you what levels of food and drink are right for you and explain what this means. Anyone preparing your food or drink should follow this guide and it may be written in your care plan, if you have one.

Guide to different thickness levels of food and drink



Source: The International Dysphagia Diet Standardisation Initiative 2019. <https://iddsi.org/framework/>

If your health and social care professionals use other words to describe these levels, ask them what they mean.

Foods

Foods are measured in levels 3-7. If you're unable to swallow regular food (level 7), your health and social care professionals will look at what level of food might be best for you. If you're in a hospital or hospice, they should either give you food that is already the right level for you, or they will change food to make it suitable. For example, they may chop it up into smaller pieces or add liquid to make it softer.

Drinks

Drinks are measured in levels 0-4. If you're unable to swallow a thinner (lower level) drink, your health and social care professionals might suggest having a thicker (higher level) drink. They might use thickening powder or gel to make this, or there may be drinks available that already have the right thickness for you.

Examples of food and drinks

You can find more information about the different levels of foods on the International Dysphagia Diet Standardisation Initiative website (see page 24).

Choosing food and drink safely

Make sure that you:

- follow the advice from your health and social care professionals
- follow any instructions about how a product (for example, thickening gel) should be stored and used
- talk to your health and social care professionals before using any new products
- tell your health and social care professionals if things change and you think you might need food or drink of a different thickness level.



iStock

Getting extra fluids and food

Patients, or their family and friends, often ask if they can have food and drink through a tube or drip. This is sometimes called ‘clinically assisted nutrition and hydration’ or ‘artificial nutrition and hydration’. This can help some people – for example, if you have a long-term condition such as dementia, motor neurone disease (MND) or cancer and you find it difficult to eat enough food. But it is not always a suitable option. For example, it may not be suitable in the last days of someone’s life if it’s unlikely to make them feel better or live longer. Talk to your health and social care professionals about this or see page 19 for more information.

Taking medication

If you need to take medication but cannot swallow tablets, there may be other options. You may be able to have the same medication as a liquid, injection or patch rather than tablets. Or your health and social care professionals may suggest you have a patch or a syringe driver. A syringe driver (sometimes called a ‘syringe pump’) is a small, battery-powered pump that delivers medication at a constant rate through a small tube under your skin. Ask your health and social care professionals for more information or visit mariecurie.org.uk/syringe-drivers.

Some people crush or melt tablets to make them easier to swallow. But this could affect whether they work properly. If you want to do this, check with your pharmacist or health and social care professionals first.

How your hospice can help

Your local hospice may be able to help you with eating and drinking, whether you are staying in the hospice, at home or in a care home. Speak to your local hospice or your GP about getting support. You can find your local hospice on the Hospice UK website (see page 25).

If you're staying in a Marie Curie Hospice

Our staff are here to help you to be as comfortable as possible and answer any questions or concerns you may have. There are some things we'll do as part of your general care and support:

- When you arrive at the hospice, we'll look at your ability to eat and drink, and what support you might need.
- We'll talk to you about what food and drink you like and do not like, as well as any cultural or religious food requirements you have. If you need support eating, drinking or taking medicines, our staff will help you with this or talk to your family and friends about how they can help you.
- We can help you choose food, drink and medication that you can swallow more easily.
- If you need more support, we might involve other professionals in your care, such as a speech and language therapist (SALT) or a dietitian.

How your hospice can help

- If your family and friends want to bring you food and drink, ask them to check what might be suitable with your health and social care professionals.
- If you're leaving the hospice and have difficulty swallowing, ask your health and social care professionals about what can be put in place to support you.
- If you need any support to eat or drink when you're in the hospice, use your call bell.

If you're staying in a different hospice or a hospital, they might have similar care in place. You can ask them what to expect from their care and how they can help you with eating and drinking.



Philip Hardman/Marie Curie

Eating and drinking at the end of life

During the last days or hours of life, it's normal for people to eat and drink less than usual or not at all. This is because the body slows down and needs less energy. Some people are unable to process food and drink at this stage. People may also be too sleepy or weak to swallow. Your family and friends can support you to eat and drink if you want to and are able to, but you should not be forced to.

How to know if someone is dying

It's very hard to tell when someone is approaching the end of their life and when they might die. This is because we are all different – there's not one pattern people follow.

In the last weeks and days, people might experience:

- feeling too weak and tired to go to the toilet or dress themselves
- being drowsy or sleeping more
- eating and drinking less
- some physical symptoms might get worse, such as breathlessness, pain or nausea
- weight loss
- difficulty swallowing
- talking or communicating less.

Not everyone will experience these changes. And these changes can be caused by other things. Check with your health and social care professional if you are worried about any of these symptoms.



Find out more in our free booklet, **What to expect at the end of someone's life**, or call our Support Line on **0800 090 2309***.

If someone is not eating, drinking or taking medication at the end of life

It's normal for people to stop eating and drinking at the end of life. Family and friends might worry that the doctors have 'given up' if the person is not eating or drinking. But how much they eat at this stage will not change how long they live.

People sometimes ask about having food and drink through a tube. If someone is expected to die within hours or days, this is unlikely to help them live longer or make them feel better, and it can cause other problems. You can talk to your health and social care professionals about your wishes in advance and they can help answer any questions you have. Your health and social care professionals will look at your medication and how to manage any symptoms. If you have problems swallowing medicines, they might use a patch to give medicines or set up a syringe driver (see page 15).

There are other things that your family and friends can do to help you eat, drink and feel as comfortable as possible (see page 20). If you do not have family or friends who can help with this, you may be able to get help from your health and social care professionals. Speak to your GP or social services about what support is available.

How family and friends can help towards the end of life

If you're a family member or friend of someone who might be in the last weeks or days of life, there are many ways you can support them. Here are some ways that you can help them to eat or drink:

- Follow their lead – they will let you know if they want to eat or drink.
- Offer small amounts of a favourite food or drink without pushing.
- Try to accept that your loved one may not want or need to eat or drink. If the person cannot speak, they might tell you that they do not want to eat by closing their mouth, turning their head away or biting the spoon.
- Small chips of ice or frozen juice might be refreshing in their mouth.
- If the person can swallow, you could give them small amounts of fluid through a syringe (without a needle) or dropper.
- If they want to, help them to take regular sips of drinks.
- If their mouth is dry, ask their doctor or pharmacist about saliva substitute sprays and gels.
- Moisturise their lips with a petroleum-based or water-based jelly (do not use Vaseline® if they are having oxygen therapy as this is a fire hazard).

Eating and drinking at the end of life

Health and social care professionals will make sure that your family member or friend is as comfortable as possible. Ask them if you have any questions about their care. They will also provide care and support for you as their close family and friends – let them know if you have any concerns or questions.

We know that this can be a really difficult time for family and friends. Support is available. Speak to your health and social care professionals or call our Support Line for free on **0800 090 2309***.



Philip Hardman/Marie Curie

How Marie Curie can help

Marie Curie is here for anyone with an illness they're likely to die from, and those close to them. Whatever the illness, wherever you are, we're with you to the end.

Marie Curie Support Line

0800 090 2309*

Our free Support Line is for anyone with an illness they're likely to die from and those close to them. Our team, including nurses and specialist Energy Support Officers, offers practical and emotional support on everything from symptom management and day-to-day care to financial information and bereavement support. Our Support Line is available in over 200 languages, or via webchat at mariecurie.org.uk/support. Open between 8am to 6pm from Monday to Friday, and 11am to 5pm on Saturday.

Marie Curie Companions

Companion volunteers focus on what's important to you and those close to you. It might be accompanying you to appointments, being there to listen to how you're feeling without judgment, or stepping in so family or carers can take a break. Companions provide the emotional and practical support you want – at home, in hospital or over the phone.

mariecurie.org.uk/companions

Marie Curie Telephone Bereavement Service

Get ongoing bereavement support over the phone from the same volunteer. You can access up to six sessions of 45 minutes. We can help if your bereavement was expected, happened recently or was some time ago.

mariecurie.org.uk/bereavement

* Your call may be recorded for training and monitoring purposes.

Marie Curie Online Community

Our Online Community is a space for you to share thoughts, feelings and experiences. It's moderated by the Marie Curie Support Line team, who can also help answer your questions.

community.mariecurie.org.uk

Marie Curie Hospice care where it's needed

Our hospices

Our hospices help people with any illness they're likely to die from, and the people close to them, receive the support they need. From medical and physical support to psychological and emotional care, whatever your illness, at whatever stage of the journey, we help you to live the best life possible, right to the end.

mariecurie.org.uk/hospices

Hospice care at home

Our nurses, healthcare assistants and other healthcare professionals bring the clinical, practical and emotional help you need to you, in the comfort of your own home. And we offer support to the people close to you too – from reassurance and practical information to letting them take a break.

mariecurie.org.uk/nurses

Looking for more information?

If you found this booklet useful, we have free information available online at mariecurie.org.uk/support or to order at mariecurie.org.uk/publications

Useful organisations

Alzheimer's Society

0333 150 3456

alzheimers.org.uk

Provides information and support for people affected by dementia, including information about the later stages of dementia.

Alzheimer Scotland

0808 808 3000

alzscot.org

Provides a wide range of specialist services for people with dementia and their carers. Offers personalised support services, community activities, information and advice at every stage of the dementia journey.

Dementia UK

0800 888 6678

dementiauk.org

Committed to improving quality of life for all people affected by dementia. Its website includes information about the condition and where carers can get support.

International Dysphagia Diet Standardisation Initiative (IDDSI)

iddsi.org

An organisation that works on naming and describing different levels of food and drink for people with difficulty swallowing. Its website includes examples of different levels of food and drink, how to test the level and foods to avoid.

Hospice UK

020 7520 8200

hospiceuk.org

A UK and international directory of hospice and palliative care, plus other information for people with a terminal illness.

Macmillan Cancer Support

0808 808 00 00

macmillan.org.uk

Provides practical, medical and financial support for people affected by cancer.

Motor Neurone Disease (MND) Association

0808 802 6262

mndassociation.org

Care, research, campaigning and information about motor neurone disease in England, Wales and Northern Ireland. Its website includes the latest research, as well as guidance on getting support.

Motor Neurone Disease (MND) Scotland

0141 332 3903

mndscotland.org.uk

Provides care and support to people affected by motor neurone disease in Scotland. It also provides information and education services to healthcare professionals and funds research.

Multiple Sclerosis (MS) Society

0808 800 8000

mssociety.org.uk

Gives grants and provides information and support to people affected by multiple sclerosis.

Stroke Association

0303 3033 100

stroke.org.uk

Up-to-date information for people who have had a stroke, and their families and carers. It also has a directory of local services on its website.

Parkinson's UK

0808 800 0303

(textphone **18001 0808 800 0303**)

parkinsons.org.uk

Gives information and support to people living with Parkinson's disease through its website and helpline.

About this information

This booklet was produced by Marie Curie's Information and Support team. It has been developed with people affected by terminal illness, and health and social care professionals.

If you'd like the list of sources used to create this information, please email review@mariecurie.org.uk or call the free Marie Curie Support Line on **0800 090 2309***.

Notice

The information in this publication is provided for the benefit and personal use of people with a terminal illness, their families and carers.

This information is provided as general guidance for information purposes only. It should not be considered as medical or clinical advice, or used as a substitute for personalised or specific advice from a qualified medical practitioner. In respect of legal, financial or other matters covered by this information, you should also consider seeking specific professional advice about your personal circumstances.

While we try to ensure that this information is accurate, we do not accept any liability arising from its use. Please refer to our website for our full terms and conditions.

Did you find this information useful?

If you have feedback about this booklet, please email us at review@mariecurie.org.uk or call the free Marie Curie Support Line on **0800 090 2309***.

Your notes

[illegible]

Marie Curie

Marie Curie is the UK's leading end of life charity. Whatever the illness, wherever you are, we're with you to the end.



0800 090 2309*

Marie Curie provides free support over the phone in over 200 languages, and via webchat, to anyone with an illness they're likely to die from and those close to them.

Our team, including nurses and specialist Energy Support Officers, offers practical and emotional support on everything from symptom management and day-to-day care to financial information and bereavement support. Visit mariecurie.org.uk/support

We also have an Online Community where you can share thoughts, feelings and experiences at community.mariecurie.org.uk

We can't do it without you

Our free information and support services are entirely funded by your generous donations. Thanks to you, we can continue to offer people what they need, when they need it.

To donate, visit mariecurie.org.uk/donate

* Calls are free from landlines and mobiles. Your call may be recorded for training and monitoring purposes.

