

Delirium when someone has a terminal illness

A guide to sudden changes
in thoughts and behaviour



**Marie
Curie**

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

Introduction

Delirium is a serious condition, which may affect people living with a terminal illness. It causes a sudden change in how someone thinks and behaves. Delirium can have a big impact on someone's life and the people around them. But there are ways to help.

This booklet is for carers, family members and friends of someone living with a terminal illness. It explains what delirium is, how it is treated and how you can support someone with delirium. It may also be useful for people living with a terminal illness.



If you have questions or concerns about delirium, speak to a healthcare professional. To speak with someone about how you're feeling, call our free Support Line on **0800 090 2309***, email **support@mariecurie.org.uk** or contact us by webchat.



We have more information about delirium online and in video. Visit **mariecurie.org.uk/delirium** or scan the QR code below.



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What is delirium?

Delirium is a serious condition that develops quickly over a few hours or days. It causes a sudden change in a person's mental state, which can affect how they think and behave. Delirium is usually caused by medical problems, serious injuries or side effects of medication (see page 6).

People can develop delirium wherever they live or are cared for. It may be a sign there is something making the person more unwell and can cause more health problems.

It can be distressing for the person with delirium, as well as the people close to them.

Diagnosing delirium early helps healthcare professionals to give the person the right care. With the right support, it can often be treated or the person's symptoms managed.



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Delirium and dementia

Delirium and dementia are different conditions. But they can be mistaken for each other. They both cause changes in a person's mental state, but in different ways:

- Delirium usually develops quickly, over hours or days. Dementia develops more slowly, over months or years.
- Someone with delirium may recover, if the underlying cause is treated. Dementia is incurable and gets worse over time.

What to do if you think someone has delirium

If you are worried about a recent change in someone you're caring for, contact their doctor or nurse as soon as possible. Let the healthcare professional know the changes you've noticed. They will assess if the person has delirium and help plan their care.

Symptoms of delirium

Confusion

Someone with delirium may often feel confused.

They may:

- not know where they are or recognise familiar people around them
- have difficulty talking or understanding others
- have memory problems or find it difficult to concentrate
- believe things that are not true.

Behaviour changes

Their behaviour might change. They may:

- say or do things that are out of character
- hear or see things that are not real (hallucinate)
- distrust people caring for them or believe they are in danger, without reason
- have disturbed sleep and vivid dreams
- suddenly become quieter or sleep more.

Other symptoms

Someone with delirium may also:

- be drowsy, seem sad and withdrawn
- be restless or agitated, anxious or frightened.

Delirium symptoms may come and go. They sometimes get worse at night.

Causes of delirium

Delirium can have many causes, including:

- not drinking enough fluids (becoming dehydrated)
- side effects of medication
- being in pain
- having an infection (for example, a urinary tract infection)
- being constipated
- being unable to pee
- having a stroke
- kidney or liver problems
- having surgery
- a serious injury, like a hip fracture or head injury
- moving to a new or unfamiliar place, like a hospital, hospice or care home.

People at risk of delirium

Anyone can develop delirium, but some things can increase someone's risk:

- Age – if they are aged over 65.
- Having several health conditions.
- Hearing or sight loss.
- Having dementia.
- Having depression.
- Having had delirium before.
- Nearing the end of their life.



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How delirium is treated

Healthcare professionals will try to find and treat what is causing someone's delirium. They may give antibiotics for an infection or encourage someone to drink more fluids if they are dehydrated.

Many people will recover from delirium if the underlying cause is treated. Recovery usually takes a few days. But it can take longer.

Delirium can usually be treated wherever someone is staying, such as their home, care home or hospice. But some people may need to go to hospital if they need more care.

As well as treating the underlying cause of the delirium, there are other ways to help someone with delirium feel less distressed. You may be able to help with some of these.

Help them to feel calm and safe

- People can find it reassuring to have someone they know with them, if possible. This might be a family member, friend, or a carer they know and recognise.
- Make sure they are wearing their glasses and hearing aids, if they need them.
- If they find it difficult to talk, ask simple questions where they can give 'yes' or 'no' answers.
- If they are distressed, try to address what is causing this – for example, are they in pain, thirsty or worried?
- If they believe things that are not true, be kind and reassuring.
- If they think somebody is trying to harm them, let them know they are safe.

Help them to stay aware of what's happening around them

- Talk in simple sentences about familiar things.
- Gently remind them where they are and what's happening around them.
- Have a clock nearby. This can help them to know what time of day it is.
- Use familiar photos or favourite items to help engage with the person.
- Play familiar music or sounds.
- Try to avoid loud noises or too many visitors.



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Help support their daily routines

- Help the person to drink, eat and take their prescribed medicines, if it's safe to do so.
- Support them to keep as active as they can. You could help them to sit up in bed or in a chair. Or encourage them to move around, if they are able.
- If they cannot go outside, offer to take them near a window to get some daylight.
- Encourage them to sleep at night. Avoid giving caffeinated drinks after lunchtime – offer decaffeinated drinks instead. Try to keep the room quiet and the lights dimmed at night.



We have more information about practical ways to help someone to eat and drink on our website.

Visit [**mariecurie.org.uk/eating-drinking**](https://mariecurie.org.uk/eating-drinking)

Medicines to reduce distress

If someone becomes distressed because of their delirium, they can usually be comforted by healthcare professionals, family, friends and carers. But sometimes this is not enough, and medicines might be used to help them feel calm.

Healthcare professionals will only use calming or sedating medicines if the person with delirium is very distressed and other things have not helped. This is because they may make the person's delirium worse, and sometimes cause other unwanted effects.

Delirium and making decisions

Delirium may cause someone to temporarily lose the ability to make decisions about their medical care. If this happens, their healthcare team will make decisions in their best interest and in discussion with the people close to them.

Someone may have an **advance care plan** (also called a **future care plan** or **anticipatory care plan**) or shared their wishes in another way. If they have, you and their healthcare team should consider this when making decisions.

If you want to know more about decision making and mental capacity, speak to the person's doctor or nurse. They can explain the laws around making decisions and support the person to make plans.



For more information about planning ahead and understanding someone's wishes, visit mariecurie.org.uk/planning-ahead, call our free Support Line on **0800 090 2309*** or email support@mariecurie.org.uk.

Delirium in the last days and hours of life

Delirium becomes more common as someone approaches the end of their life. Up to three in four people with a terminal illness (75%) may develop delirium towards the end of their life.

It's hard to know exactly how long someone will live for. Everyone is different and will have different symptoms. If you have questions, speak to their doctor or nurse.

If someone develops delirium during their last days of their life, they may not have time to recover from it. Healthcare professionals will focus on the person's comfort. They may support them by:

- helping them to feel calm and safe
- managing pain and other symptoms
- helping with mouthcare
- supporting them to drink, if it's safe to do so
- encouraging them to sleep at night.

You can also help to support someone with delirium in some of the ways listed on pages 8 to 10.

Terminal agitation

In the last hours or days of life, people with delirium usually feel tired and sleepy.

But sometimes they may become agitated, distressed, restless, and groan or talk in a confused way. This can be called **terminal agitation** or **terminal delirium**.

If someone is agitated or distressed, healthcare professionals will try to address what's causing this. They can help to manage any symptoms and keep the person as comfortable as possible. They may need to use medicines to help the person feel calm and relaxed. If you're worried about this, or would like more information about what to expect towards the end of life, speak to their doctor or nurse.



We have more information about what to expect at the end of life on our website and in our free booklet, **What to expect at the end of life**. Visit [**mariecurie.org.uk/what-to-expect**](https://mariecurie.org.uk/what-to-expect) or contact our free Support Line on **0800 090 2309*** or at [**support@mariecurie.org.uk**](mailto:support@mariecurie.org.uk).

Support for families and carers

It can be distressing to see someone close to you with delirium. Caring for them can be hard, both physically and emotionally.

You might find that behaviour changes have a big impact on you. Try to remember these changes are caused by the delirium. They are not anyone's fault.

It's important to look after yourself too. Take breaks if you can and try to find some time for things you enjoy.

If you have questions about delirium or need support, speak to the person's healthcare team. This could include their GP, care home staff, district nurse or social worker.



For information and emotional support, call our free Support Line on **0800 090 2309***, use our webchat, or email **support@mariecurie.org.uk**.

Or, to give and get support from people who may be in a similar situation, join our Online Community at **community.mariecurie.org.uk**

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*

support@mariecurie.org.uk

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-line**

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

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 online at mariecurie.org.uk/information or to order at mariecurie.org.uk/publications

Useful resources and organisations

We have more information about delirium online and in video. Visit mariecurie.org.uk/delirium or scan the QR code below.



Carers UK

0808 808 7777

carersuk.org

Provides expert advice, information and support to carers. There are links to its national services from the website homepage.

Carers Trust

0300 772 9600

carers.org

Carers Trust offers information, advice and support for carers, including care in the home by support workers who help carers to have a break.

Dementia UK

0800 888 6678

dementiauk.org

Provides information about dementia, including practical and emotional matters, as well as phone and face-to-face support from Admiral Nurses.

Sue Ryder

0808 164 4572

[sueryder.org](https://www.sueryder.org)

Sue Ryder runs hospices and care centres in the UK for people with many different disabilities and diseases. Services include long-term care, respite care, symptom control, rehabilitation, day care and home care.



Philip Hardman/Marie Curie

About this information

This booklet was produced by Marie Curie's Information and Support team, alongside researchers at the Marie Curie Edinburgh Hospice. 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

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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**](https://mariecurie.org.uk/support)

We also have an Online Community where you can share thoughts, feelings and experiences at [**community.mariecurie.org.uk**](https://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 support us, visit [**mariecurie.org.uk/get-involved**](https://mariecurie.org.uk/get-involved) or use the QR code.



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