

Supporting a child or young person when someone has a terminal illness



Marie
Curie

Practical and emotional help

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

Introduction

This booklet is for an adult supporting a child or young person when someone they know has been diagnosed with a terminal illness.

You might be the person living with the terminal illness, or you might be a member of their family or a friend.

It includes information about:

- how to talk to a child or young person about the illness and treatment
- tips for managing day-to-day life
- how you can prepare them for when someone will die
- the people and organisations that can provide support.

We know that this can be a very difficult time. We are here for you. For practical information and emotional support, call the free Marie Curie Support Line on **0800 090 2309***, use the online chat on our website, email support@mariecurie.org.uk or visit mariecurie.org.uk/information

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Should I tell a child or young person that someone has a terminal illness?

You might be unsure if telling a child or young person about a diagnosis is the right thing to do.

This might be because:

- you want to protect them
- you do not want to get upset in front of them
- you're worried about how you will cope with their emotions
- you're concerned you do not have enough information to answer their questions.

It's natural to feel like this. But being open and honest can help children and young people understand what is happening and feel supported.



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Why being open and honest can support a child or young person

We explain here why talking openly and honestly about someone's illness can support a child or young person.

So they get the correct information

If you do not tell them they might not understand things they see or hear. They might try to find out themselves by looking online or on social media.

So they have someone they can trust

If they're told by someone they trust, it can help them to feel included and less alone.

If they find out that you were not open with them, it could affect how they process the death. It could also affect their relationship with you. Talking honestly and openly can help create closer bonds that can support their wellbeing in the longer term.

So they have more control

It gives them the information they need to make decisions about things that affect them. For example, they can decide if they want to visit someone. It also means they can have control over how much they want to know – because they can keep talking to you.

It can help them feel more in control at a time when they cannot control someone's illness. This may help reduce feelings of anxiety and help support their wellbeing.

How to talk to a child or young person about the illness

It's usually best if they are told by someone they know well like their mum, dad, guardian or a family friend.

If you're worried you do not know enough about the illness or treatment, ask the doctor or a healthcare professional to explain anything you're not sure about. You might want to ask if you can have a health or social care professional to support you. It could be a doctor, nurse, social worker or counsellor. The child may also want to speak to them.

You could ask about getting support from a counsellor or from your local hospice, including Marie Curie Hospices. Some hospices have counsellors for families, children and young people. Or they may have an art therapist who could help support the child. They can usually only help if the person who's ill is known to the hospice, but you can contact your local hospice to find out.



You can read about services at Marie Curie Hospices at mariecurie.org.uk/hospices. Or search for your local hospice on the Hospice UK website at hospiceuk.org/hospice-care-finder

When and where to talk to them

There's no set way to talk to the child – because every family and every situation is different.

It's usually better to talk to them soon after the diagnosis or when the illness becomes more serious. Otherwise, they may notice that something is different.

Make enough time so it does not feel rushed. A weekend may give you more time to support them. And doing it in the daytime, rather than before bedtime, may be better also. Try to find somewhere comfortable, safe and private (like at home) so that it's OK if they get upset.

If you need to tell more than one child, you might want to speak to them together first. They will then not get upset that you've told one before the other or worry that you've told them different things. It may also help them to support each other.

Having the conversation

These things may help you talk to them:

- You could begin by asking them what they know already or if they've noticed anything. They might say something like: "Grandpa's too tired to play with me."
- If they know something, you can pick up on that. You could say: "You know that I have been ill for a long time."
- Ask them how much they want to know. Some children want detail while others want to know the basics.

How to talk to a child or young person about the illness

- Try to use clear and simple language. Saying things like the person is ‘feeling under the weather’ can be confusing. And if you’re not clear, they might think they will get better.
- Let them know they can ask you questions. You can also ask if they might feel more comfortable writing them down. They might not have any questions at first and need time to process things. Read about how you can prepare for their questions on page 8.
- It might be easier to give information in small chunks and to gently check that they understand. You can go back to it later.

You might be surprised at how they react. It might seem as though they’re not upset or like they have not understood. But they may just need time to process it. Keep checking in with them and reassure them that they can ask you anything.

We know this can be a difficult conversation. You might want to ask your doctor or social worker for support or ask if you can speak to a counsellor.



You can also call the free Marie Curie Support Line on **0800 090 2309***, email **support@mariecurie.org.uk**, or speak to one of our trained team via web chat.

How to answer their questions

You might worry about answering questions about the person's illness or treatments. Or you might not know what you'll say if they ask you about dying or death.

The most important thing you can do is to try to be honest. If you do not know the answer then you can say that. Let them know that you will try to find out for them. Remember that every child or young person is different, and you know them best.


How you answer will depend on how old the child is, their stage of development and if they've experienced someone being ill or dying before.



You can read about what children understand about illness at different ages on page 10.

It might help to talk to them using stories about someone being ill or dying. You may have traditions or rituals within your own family or community that can help to support you both when you are speaking to them. Looking at children's books together about feelings they might have when someone is ill can also be a good way of helping them express their feelings. You can ask a health or social care professional about books for their age – or you can ask at the library, at a bookshop, or look online. The charity Child Bereavement UK (childbereavementuk.org) also has a list of recommended books.

How to talk to a child or young person about the illness

 We have information about what children understand about death and how to answer questions about dying and death in our booklet **Supporting children and young people when someone dies**. You can order booklets for free by calling the free Marie Curie Support Line on **0800 090 2309*** or visit **mariecurie.org.uk/publications** to order online or download a copy.



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What a child or young person might understand at different ages

It's important that a child or young person has information that's right for their age and level of understanding. Children may be the same age but at different stages of development.

Magical thinking

This is when children or young people worry that their thoughts or behaviour could have caused the illness. Or that good behaviour, like tidying their room, could make the person get better. It can be a normal part of child development. Make sure that a child or young person knows that what's happening is not their fault and that anything they think or do cannot change the person's illness.

Children under three

Children under three struggle to understand things they cannot see or touch. Unless they see someone sneeze or cough, for example, it's hard for them to understand that someone's ill.

They could be upset by changes to their environment or routine. This could include missing someone's voice or being upset if they cannot spend as much time with them.

Children aged three to five

Children aged three to five may understand that something is wrong. But they may not understand that death is permanent.

They might notice physical changes. For example, if someone cannot pick them up or play with them. Try to make sure they know that this does not mean that they love them less.

At this age a child can accept someone else looking after them, especially if they can know before who it will be and when. Try and make sure they know they're loved and will be taken care of.

They might find it hard to explain how they're feeling and seeing you upset could upset them. They can use play as a way of communicating, so you could use play or art to help explain things.

Children aged six to eight

Children this age tend to understand that when someone dies that it's forever.

Give them simple but clear explanations about the illness. You could tell them what it's called and talk to them about the person's treatments and how their illness affects them. Make sure they know they can talk to you about their worries.

They might get upset if they cannot spend as much time with the person who's ill. It's important to reassure them that they are loved, and that the person still cares for them.

Children aged nine to eleven

A child this age might understand more about someone's illness. You could give them small amounts of information as the illness progresses.

It's important to make sure the child knows that the person's illness is not their fault.

Some children might want to visit or help with caring for the person. It could be small things, like making cups of tea or reading to them. This is OK, but make sure they're not doing too much.

They may find it easier to show their feelings at this age. They might get upset by things like changes in how someone looks, or by thinking about a future without them. But remember all children are different and some may be less willing to show how they are feeling.



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Teenagers

Most teenagers will understand what is happening and understand loss and what this might mean for them. It can be especially hard for a teenager when someone important to them is ill or dying. They can be vulnerable to feelings of anxiety and depression.

An important way that you can support them is to talk to them openly and honestly about the person's illness, their symptoms and treatments.

They may want to talk to someone their own age who is going through a similar situation. The charity Child Bereavement UK (childbereavementuk.org) have a helpline and an online chat to support young people. The charity Hope Support Services (hopesupport.org.uk) can support young people from 5 to 25 when someone has a serious illness.



Read more about things that can support a young person's day-to-day life on page 20.



Read more information on getting support on page 25.

Children, teenagers or young people with special educational needs or disabilities (SEND)

Children, teenagers or young people with special educational needs or disabilities (SEND) may be able to understand information about the person's illness and that it means they will die.

It's important to include the child or young person when you communicate about what's happening. Communicate with them in the way that works best for them. This might be talking, using picture cards, watching videos, drawing or looking at photos. Give them the facts in a way that's right for them. Use clear and simple language.

You might find it helpful to speak to a health or social care professional involved in the child's care, like a key worker or special educational needs coordinator, about how best to explain the illness to them.



You can read more information on how to tell a child with SEND that someone has died at

childbereavementuk.org/supporting-bereaved-children-with-send

How children or teenagers may react or behave

Learning that someone important to them is going to die can be very stressful for children and young people. You might start to notice changes in their behaviour.

Children

Children may have lots of different feelings including:

- shock – they may feel numb after hearing the news
- fear – they might be afraid of the person dying or that they or other people may die
- upset – they may find it upsetting if someone's appearance changes
- sadness – they might feel sad thinking about a future without the person
- worry – they might be worried about how someone will change as the illness progresses, or they may worry that they could get the illness
- anger – they may feel angry that the person became ill
- guilt – some children may feel guilty that they caused the illness in some way or feel guilty for having fun
- loneliness – they may become withdrawn or feel like they do not want to upset you by talking about it.

Some children may not show their feelings. Reassure them that however they're feeling is OK and that they can talk to you.

You may notice changes in their behaviour, like trouble sleeping or finding it harder to concentrate at school. Younger children may become clingy and want more physical contact.

A child may try to cope by spending time with the person. You might then support them to make special memories with the person. For example, by visiting a meaningful place or watching a film together. Or they may want to help care for them. Or a child or young person might try to distract themselves and not want to think about it.

It may be hard to know how a child is coping, especially if they will not talk about their feelings. Try not to worry about this but do not be afraid to ask. Make sure they know that talking about their feelings will not make it more upsetting for you or the person who's ill.

Teenagers

A teenager may have lots of different feelings when they are dealing with the illness of someone important to them. They may want to care for the person and comfort them. They may be angry because they think it's unfair. Or they may feel lonely, if they do not feel like they can share how they are feeling. They might worry about the future and be afraid of a future without the person. This might make it hard for them to talk about their emotions.

Some teenagers cope by trying to keep things normal by going to school or spending time with their friends. It might seem like they do not care but it can be a natural response and does not mean that they are not upset.

A teenager might also want to spend time alone or away from friends, to make sense of their feelings or to spend time with the adult who is ill. They might want to take on extra responsibilities such as being involved in the person's care or doing more at home.



Read about practical support for day-to-day life at home if you're supporting a child or teenager on page 20.

Children, teenagers or young people with special educational needs or disabilities (SEND)

A child, teenager or young person with special educational needs or disabilities (SEND) may find changes to their normal routine upsetting. They may also feel upset if the person cannot play or spend as much time with them.

Some children may not use words to communicate their feelings. Instead, you might notice changes in their behaviour, like problems sleeping.

Communicate with them in the way you usually do. This might be talking, using picture cards, watching videos, drawing or looking at photos. You might also want to ask for support from a health or social care professional involved in the child's care, like a key worker or special educational needs coordinator. Remember, you know them best, so support them in the way that you feel is right for them.

Hospital and hospice visits

Visiting someone in hospital or a hospice may help a child understand that the person is ill and that they cannot do usual activities together. It may also help if they're missing them. But some may find it upsetting. The person who's ill may also not want the child to see them in hospital, so check with them first.

You can then ask the child or young person if they'd like to visit. You can plan it together including how long they will stay. You might want to look at the hospital or hospice together online first and tell staff at the hospital or hospice that they're coming.

It can help to explain to the child or young person what the visit will be like. This can include:

- what the room looks like
- what equipment they'll see in the room
- how the person may look or how they may be.

For example, you could let them know that someone may be sleeping a lot or may talk in a whisper. Reassure them that even though someone might look different, they are still the same person.

If a child cannot or does not want to visit, make sure they know that it's OK and that the person who's ill will understand and still loves them. They might be able to have a phone or video call with them instead, or send them a video message. Or they could make a card to put up in their room. People's feelings about visits can change. So, the person who's ill or the child may need time to think about whether they want another visit.

Care at home

If someone is being cared for at home, you may want to discuss arrangements with them if there's a child or young person at home too. If it feels right, you could ask the child or young person to be part of this.

If possible, try to make sure the child or young person has their own space with their own things away from the person who's ill and from medical equipment. Make sure they also know about arrangements like when carers may visit so they are not surprised by seeing strangers in their home.



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Practical support for daily life when someone's ill

Below are some practical things for daily life that can help support a child or young person's wellbeing when someone has a terminal illness.

Reassurance

If you can, reassure them that they're always loved and cared for even if their own emotions may change while someone is ill.

Routine

Try to keep things at home as normal as possible by encouraging them to stick to their routines. Young people we've spoken with have said that being able to go to after school clubs or activities helped them to cope.

Activities or clubs can also mean they have time away from home. It gives them a chance to be with people they may have known for a long time. Or they might want to join a new club to increase their circle of support with new friends. Some clubs or organisations may also give them access to counselling.

Social life

Make sure they know that it's OK to still have fun.

Seeing friends and keeping up with their social life can be important. Young people have told us that age-appropriate activities and seeing their friends helped them when someone close to them was dying. If you're not able to do things like give lifts to and from activities, see if someone else can do this for you.

Organisation and planning

Being organised and explaining plans to a child or teenager can help their life feel more stable. This includes things like organising childcare or letting them know who will pick them up.

You could also consider making more long-term practical plans, like making a Will. This is so:

- it's not something that a teenager or young person needs to worry about
- the stress of someone not having made a Will does not affect their home life in the future.



You can find more information about making a Will if you're living with terminal illness at mariecurie.org.uk/wills

Plan for unexpected emergencies or changes to arrangements

Giving a child or young person an emergency contact can help them feel more secure. You could arrange for them to spend some time with them, so they are more familiar with them if they need to be looked after in an emergency.

You can also plan for things like who picks them up from school when you cannot or who has a spare key for the house – and share it with the child or young person.

You might want to have a ‘grab and go’ bag packed in case they need to stay over unexpectedly. Or you could speak to their school about keeping things like a spare jumper, PE kit or a box of snacks in case of an emergency.

Support at school or college

It’s usually best to talk to the school or college about what’s happening. They may have a wellbeing officer, school nurse or a specific teacher who they can go to for on-going support. You may need to follow-up with the school if your child or teenager needs support and you feel they’re not getting it.



You can find more information about support at school, college or university at mariecurie.org.uk/return-to-school

Preparing a child or young person for when someone dies

There may come a time when you have to tell them that someone's going to die.

They might have become more anxious as the person has become more ill. Or they may have started getting used to the idea they're getting more ill and will die. Whatever their reaction, it's important to understand that children and young people cope in different ways.

Helping them to say goodbye

Some children or young people want to be able to say goodbye, but others will not want to do this. Ask them how they feel and reassure them that it's OK whatever they decide.

If they want to say goodbye, try to prepare them for what the person might look like or be like. For example, if they will be very sleepy. If they're in hospital or a hospice, you could describe what that will be like too.

Sharing messages of love with the person who is dying can help them to have long-lasting, positive memories of their relationship. If it's too difficult for the person to talk, the child or young person might like to hug or hold their hand. Or they might want to draw or write something for them that can be kept in the person's room.

Supporting children and young people when someone dies

It might be helpful for the child or young person to speak to a faith leader, social worker, counsellor or bereavement support worker at an organisation like Child Bereavement UK. You could ask about this at the hospice or hospital, through your GP or social services. You could also contact a faith leader in your community.

If they cannot say goodbye, it's OK and it's no one's fault. It might still be possible for them to make something or record a message. Or they may want to write a letter or card to help them say goodbye in their own way.



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Getting support

Remember that you do not have to do this alone. You can ask for support for you as well as the child or young person.

You may need to ask for support from friends, family members or professionals. Family members and friends might be able to help you with practical things like making meals. They may be able to do lifts or take the child to school or clubs.


The child or young person may want to have someone else they can talk to as well as you. This could be a teacher, sibling, family friend, faith leader or other professional.

The charities Child Bereavement UK (childbereavementuk.org) and Hope Support (hopesupport.org.uk) have information and support for children and young people. They also have communities for children or young people to connect with others going through the same thing.

You may be able to speak to a counsellor, art therapist or other professional or get support from your local hospice, including Marie Curie Hospices. Some have counsellors or other professionals like a Patient Family Support Team who can support your family. These are usually only available if the person who is ill is known to the hospice, but this can vary.

Supporting a child or young person when someone has a terminal illness

Contact your local hospice to find out more. You can find a list of Marie Curie Hospices at mariecurie.org.uk/hospices or search for your local hospice on the Hospice UK website at hospiceuk.org/hospice-care-finder

 You can also contact our free Support Line on **0800 090 2309*** or at support@mariecurie.org.uk for practical information and emotional support.



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Looking after yourself

It can be hard to remember that you also need to look after yourself. Being there for a child, talking to them about the illness and supporting them emotionally can be challenging.

People supporting a child or young person when someone's seriously ill can find it hard to balance everyone's needs, including their own. This is especially true if you are caring for the person who is ill. You may find that you're putting your own needs aside to look after others.

Whether you are ill, or you're helping to care for someone, it's important to think about your own needs, and try to take some time to look after yourself.

Think about the people you have around you who could support you. Having a support network can help reassure the person who is ill that the child will be looked after, but it can also give you time to have a break.



There is more information on looking after yourself and respite care in our booklet, **Being there for someone with a terminal illness**. You can download it or order a free copy at mariecurie.org.uk/publications



You can also call our free Support Line to speak to someone about your feelings on **0800 090 2309***. Or you can contact them via web chat at 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*

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

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

Useful organisations

Barnardo's

[barnados.org.uk](https://www.barnados.org.uk)

A charity which supports children, young people, parents and carers.

Child Bereavement UK

0800 02 888 40

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

Supports families when a baby or child of any age dies or is dying, or when a child is facing bereavement.

Childhood Bereavement Network

[childhoodbereavementnetwork.org.uk](https://www.childhoodbereavementnetwork.org.uk)

Aims to improve the quality and range of bereavement support for children, young people, their families and other caregivers. Offers information about support services.

Childline

0800 1111

[childline.org.uk](https://www.childline.org.uk)

Confidential 24/7 helpline for children and young people in the UK up to age 19. Childline is free, confidential and available any time. Available by phone, by email or through 1-2-1 counsellor chat.

Children 1st

08000 28 22 33

[children1st.org.uk](https://www.children1st.org.uk)

Scotland's national children's society, which provides advice and support for parents and families.

Cruse Bereavement Support

0808 808 1677

cruse.org.uk

A charity which helps bereaved people in England, Wales and Northern Ireland.

Cruse Scotland Bereavement Support

0845 600 2227

crusescotland.org.uk

A charity which helps bereaved people in Scotland.

Grief Encounter

0808 802 0111

griefencounter.org.uk

Supports bereaved children and teenagers.

Hope Support Services

01989 566317

hopesupport.org.uk

Helps young people aged five to twenty five when a loved one has a serious illness.

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.

Mencap

0808 808 1111

mencap.org.uk

A charity which supports people with learning disabilities, their families, and their carers. It works across England, Wales and Northern Ireland.

Young Minds

youngminds.org.uk

A mental health charity for children and young people.

About this information

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

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.

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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***.

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 support us, visit mariecurie.org.uk/get-involved or use the QR code.



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Curie**



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