Supporting children and young people when someone has a terminal illness

Practical and emotional help

Marie Curie

Care and support through terminal illness

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

Introduction

This booklet is for any adult who is supporting a child or young person when someone close to them is living with a terminal illness. Whether you are a parent, another family member or close friend, we understand that it can feel difficult to know how to support children when someone is ill.

In this booklet, we talk about children and young people. This means anyone up to the age of 18, except for some sections where we mention specific ages.

This booklet contains information on how to support a child or young person when someone is ill. You may find it useful if you are the person who is ill, or if you are a family member or friend of someone who is ill. This booklet covers the questions children might ask, practical ways you can support them, preparing them for when someone dies and looking after yourself during this time.

Supporting children and young people when someone close to them is dying can be a difficult time. For practical information and emotional support, you can contact the Marie Curie Support Line on **0800 090 2309*** or visit **mariecurie.org.uk/support**

Contents

Should I tell a child that someone has a terminal illness?

Telling a child that someone close to them has a terminal illness and is going to die isn't easy. But it can help them if you do talk about it.

Some adults find it difficult to tell a child or young person that someone close to them is ill. You may still be processing the news yourself. It can be especially hard when you know the person won't get better.

How telling a child might help them

If children are told that someone close to them is ill, it can help them to understand what's happening better, and it might make them feel less lonely and worried about the situation.

If children notice that something is wrong, they may start to search for information themselves. This might lead to them getting the wrong information or misinterpreting the situation. For example, they could see something on the internet, or overhear information from someone else. It's better for information to come from someone they know and trust.

Talking openly and honestly about the person's illness may also help the child to speak about the things they're worried about. It can provide opportunities to spend time together as a family, and it gives you and the child the chance to share your feelings. It can also help them to be more prepared for when the person dies.

Telling a child that someone is ill might also help them to feel more in control, as it can give them the chance to be more involved

in making decisions. For example, whether they'd like to see the person if they go into hospital.

> We were always very honest with the children about what was going on when Erin was diagnosed and then when she was told it was terminal – her illness was part of their lives for a long time. They knew they could ask us anything and we would do our best to answer their questions.
>
> Chris, whose wife had a terminal illness

Ben Gold/Marie Curie

Things that make it difficult to tell them

You may find it difficult to talk to the child about the illness. This might be because you want to protect the child, or you worry they won't be able to cope or understand.

You might not know the best way to share the news, or worry you may get upset in front of them. Family circumstances might make it harder to find the right time to talk, like if parents live separately, if adults disagree on what to tell the child or if the child has experienced another loss.

Getting support can help you if you're finding it difficult to talk about the illness. A doctor, nurse, social worker or counsellor may be able to give you ideas on how to begin the conversation. They may also be able to give you more information about the illness, so you feel better prepared to talk about it.

You might feel like the child won't be able to cope or understand what is happening. But they may have noticed that something is different at home, and they may feel less worried if they know about the situation.

You could try telling them a little bit about the person's illness, and encourage them to ask questions if they want to. Remember that you don't need to know the answer to every question they have. When you tell them, you could make a list of any questions you can't answer and find out the answer together. You can find out more on questions children might ask on page 14.

> It's a conversation that I'm really glad we had because it meant we all knew at any point we could come back to talking openly and honestly about grandma. And we've always done that since.
> Tracy, whose mum had a terminal illness

Getting support with telling them

Telling a child or young person that someone is ill can be very emotional. It's important to take some time to think about what you'll say. You may be able to get support with telling them from a family member, friend, or a professional like a GP, social worker, counsellor or religious leader.

You could speak to a counsellor or get support from your local hospice, including Marie Curie Hospices. Some have counsellors for families, children and young people. These are usually only available if the person who is ill is known to the hospice, but this can vary. Contact your local hospice to find out more. You can find a list of Marie Curie Hospices at **mariecurie.org.uk/hospices**, or a list of hospices in the UK from Hospice UK (see page 45).

You could also contact the Marie Curie Support Line via web chat or by calling **0800 090 2309***, for practical information and emotional support.

Telling a child that someone is dying

Telling a child that someone is going to die can be very difficult. Often people find it difficult to know how to begin the conversation, or worry about which words to use.

Who should be involved in telling the child?

Conversations about someone being ill are usually best coming from someone who is close to the child and knows them well, like a parent, other relative or close family friend.

If you don't feel comfortable telling the child on your own, it's OK to have someone with you for support when you tell them, like a friend or family member.

You might want to have a health or social care professional in the room with you, like a doctor, nurse, social worker or counsellor. While the news is better coming from someone who knows the child, it can be reassuring for you to have someone there to support you. The child can also speak to the professional if they'd like to.

Where and when should I tell them?

There is no set way to tell a child or young person that someone is ill. Every family and every situation is different.

It's usually better to tell the child or young person soon after the person is diagnosed, or when the illness becomes more serious. Children may notice changes in the person who is ill or sense that something is different, and speaking openly can give them the chance to ask questions as the illness progresses.

You could try telling the child in a place where they feel comfortable and safe, like at home. Try not to tell them before bedtime, as they may have trouble sleeping, or go to sleep with unanswered questions. It might be best to tell them in a place which isn't too public, so they feel able to show their emotions if they want to.

You might want to tell them on the weekend or during the school holidays (but try not to delay the conversation if the holidays are quite far away). This means they can have family around if they have any questions or need support.

There may be more than one child or young person you need to tell. If they are different ages, you may want to tell them separately, in different ways. You could also tell them at the same time, but speak to them separately afterwards to make sure they feel supported. See page 18 for more information on what children may understand at different ages.

If you do tell the children separately, you may want to have a conversation all together afterwards.

> It doesn't matter where you're told, as long as you're surrounded by people you love.
>
> **Hannah, 14, whose father had a terminal illness**

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How do I begin the conversation?

It can be very difficult to know what to say or how to begin the conversation. Being too optimistic can give children false hope, but it can be hard to tell them about something serious.

You may find it helpful to start by asking the child or young person what they know already, or whether they've noticed anything different about the person who is unwell. Some adults find that the child knows more or less than they initially thought.

Ask them how much they want to know – some children might want more detailed information, while others may prefer to just know the basics.

Try to use clear and simple language. Using euphemisms, like saying the person is 'feeling under the weather', can be confusing, especially for younger children. If a child isn't given clear information, they might think the adult could get better.

As you're speaking to them, it can help to check the child understands what you've said. Giving information in small chunks is sometimes easier than telling them everything in one go. Remember that all the information doesn't have to come in one conversation – you can have a number of conversations where you build on what you've said before.

Here are some ideas for how you could start the conversation:

- If the child knows something already, you could acknowledge this. You could say: "You know that I have been ill for a long time, and the doctors have been trying to make me better." Their response may help you to understand how much they already know.
- You could ask what they've noticed about the person recently. They might say something like: "Grandpa's too tired to play with me." They might go on to say more about what they think is happening.
- Guided by what they say, you could say something like: "Mum's illness has gotten a lot worse and the doctors have tried everything they can. There isn't anything more they can do now to make her better, and that means mum won't live for much longer. This means that mum will die. We don't know when this will be, but the doctors think it could be soon."

You may be surprised at how the child or young person reacts. They might seem less affected or upset than you expected. Try not to worry if this happens – children may react differently to how you'd expect when they hear bad news. There is more information on how children or young people may react on page 23.

The child might ask questions which you find difficult to answer. It's OK if you don't know the answer to all of these – some children just want to know that they are being listened to. Some children

might not have any questions at first. There are examples of questions children might ask, and how you could answer them, on the next few pages.

Having this conversation can be emotionally difficult. You may find it helpful to speak to a counsellor, social worker or GP for further support.

You can also call the Marie Curie Support Line on **0800 090 2309*** or speak to one of our trained officers via web chat.

Questions children might ask

If you tell a child or young person that someone close to them is ill, they may have lots of questions. You might be worried that you won't be able to answer them.

If you are unsure about how to answer any of their questions, you could ask the person's doctor, nurse, a counsellor or social worker for support.

Remember that it's OK if you don't know how to answer their questions. Here are some examples of questions children or young people may ask and the answers you could give.

These are just suggestions. Remember that every child is individual, and you may need to adapt answers depending on the child, the situation, and your beliefs.

If possible, you might like to ask the child questions too, to find out how much they understand, and what they think. This may help you to understand exactly what the child means. It can also help them to know that they are being listened to.

How you answer questions will depend on how old the child is, their stage of development and whether they've had any experience of death before. You can find more information on what children might understand at different ages on page 18. We also have information on how children understand death in our booklet, ***Supporting children and young people when someone dies***.

Is the person going to die?
Yes, the person will die. I know it might not feel nice if you're not sure about what's going to happen. I feel that way sometimes too. What I do know for sure is that I love you very much. Is there anything you want to ask me about?

When will the person die?
This is a difficult question to answer. We don't know exactly when they will die but it could be in a few days/weeks/months.

Can I catch the illness?
No, you can't catch the illness.

(If it's relevant, like if the person had a genetic disease, you may also want to say something like this: Some diseases are genetic, meaning that a family member might be more likely to get it, but this is not usually the case).

Will the person be cured?
The doctors have tried really hard but there is nothing to cure the person's illness. But they may give the person some treatment which will help them with their pain.

Will the person look different?
The person might look a bit different, and they might not be able to do as many things as they used to, like play football with you or do the cooking. But they are still the same person on the inside, and they still love you very much. They will always be your (mum, dad, grandma, for example).

Why do people die?
Some people die because they are very old, or have an illness or an accident which the doctors can't make better.

Does dying hurt?
Having an illness might hurt, but the doctors might give the person medicines to help them with their pain. The person can't feel pain after they have died.

Is it like being asleep?
No, it is not like being asleep. When people are asleep, they wake up, but death lasts forever.

Why can't we stop people dying?
There are some illnesses we can fix and some we can't. Some people die because they are very old, and their body has worn out.

When will I/you die?
I don't know. Probably not for a long time yet.

The child or young person may have questions which aren't listed here. Here is some space to note down any other questions they may have. If they would feel more comfortable writing their questions rather than asking them out loud, you can also use this space for that. If you're not sure of any answers, you could make a note of the questions here and ask someone involved in the person's care at a later date.

What children might understand

How much a child or young person is able to understand about the person's illness and death may depend on how old they are, their stage of development and any previous experiences of illness or death they've had. Some children may be the same age but will be at different stages of development.

It's important to give them information which is appropriate to their age and level of understanding.

Children under three

Children under the age of three might not be able to understand the situation or the concept of death, but they may notice if the person isn't around as often. They may be upset by changes to their environment, like if the person can't spend as much time with them, and they may miss their voice and smell.

Children aged three to five

Children aged three to five may understand that something is wrong, but they might struggle to understand that death is permanent. They will be able to notice physical changes in the adult, like if they can't pick them up anymore.

They may struggle to explain how they're feeling, and they might find it upsetting when they see an adult is upset. Try to reassure the child that they are loved and will be taken care of.

You might find it best to explain things to them gradually. You can give them information across a number of conversations – it doesn't all have to be in one conversation.

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It can be helpful to explain that if the adult is acting differently, it doesn't mean they love them less. For example, if the adult can't play or speak as much anymore. Children this age often use play to communicate, so you could explain difficult things using play or art. If they aren't able to see the adult in person, they might like to make gifts, write note cards to them, or record a voice message on a phone for them.

Sharing stories about illness or death might be helpful, or you may find it useful to read children's books together about feelings you might have when someone is ill. There is a list of books you may find useful on page 41.

Children aged six to eight

Children this age tend to understand that death lasts forever and the adult won't come back when they die. They might worry that bad thoughts can be harmful, or worry that they in some way caused the illness. This is known as magical thinking. Magical thinking might include things like believing if they clean their room, the person could get better.

Try to give the child simple but clear explanations of the illness. For example, it might help them to know the name of the illness, how it affects the person and any treatments they may have. Explaining what is happening can help them to feel more comfortable with asking questions.

Children this age might become quite emotional, and they may get upset if they can't spend as much time with the adult. If they are worried that it's their fault, or worried that the adult doesn't love them as much, try to reassure them that they are loved and that the unwell adult still cares for them. Let them know that it's not their fault.

Some children feel like they need permission to ask questions as they're worried they might upset someone if they do, so reassure them that they can talk about their worries if they want to. You can also reassure them that it's OK to be happy and have fun, if that's how they feel.

> When children are young I think you need to give them basic truthful facts. One drop of truthful information at a time.
>
> **Sarah, who spoke to her two young children when their grandmother was ill**

Children aged nine to eleven

Children this age will generally be able to understand more about the illness, so you may need to give more detailed explanations. You could try giving them small amounts of information as the illness progresses.

They might want to visit the adult in hospital or help out with their care. This is OK, but make sure they're not doing too much. They might like to do small things, like making cups of tea for the person.

Some children this age may find it easier to show their feelings about the person's illness. They might find it upsetting to see the person's appearance change, and they may find it difficult to think about a future without them. It often depends on the child's personality – some may be less willing to show how they're feeling.

If they're worried they're to blame for the person's illness, try to reassure the child that the illness isn't their fault. If they feel up to it, it might help them to see their friends, or stay involved with any clubs or activities they normally do.

Adolescents

Being given information about the illness, symptoms and any treatments can help young people cope when an adult close to them is ill. Having open conversations and being kept up to date may help them understand what is happening better, and can reduce any feelings of uncertainty they have. If you find it difficult to talk about the illness, try giving them small amounts of information at a time.

You might find that teenagers struggle to talk about how they are feeling. They may worry about upsetting the person who is ill, or they might be struggling to come to terms with the fact that the person is dying.

You could ask them if they'd like to spend time with the person who is ill, if that's possible. Teenagers may also benefit from having support from someone else, like an adult at school who knows about the situation, or from the person's doctor or a counsellor.

Spending time with friends or going to school may help them to keep a sense of normality in their lives when lots of other things are different. However, they may also want to spend some time alone.

They might also want to speak to others who are in a similar situation. The charities Child Bereavement UK and Winston's Wish have helplines and online chats to support young people. See pages 44-46 for their contact details.

Children with learning disabilities

Children and young people with learning disabilities may be able to understand information about the person's illness and that they are dying. Talking to them might help them to cope with the situation better.

But you might find it helpful to speak to a health and 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.

Some may find it difficult to understand the concept of death. It can be helpful to use simple language, repeat information, and check they've understood what you've said. Spending time with the person, or playing a role in the person's care, if that's possible, might also help them to understand the illness.

The charity Mencap (see page 45) has information on children with learning disabilities and a learning disability helpline.

How might children react?

Different factors can affect how children and young people react to learning that someone close to them is ill. These could include their age, the relationship they have with the person, or if they've previously experienced someone close to them dying.

Learning that someone close to them is going to die can be very stressful for children and young people. You might start to notice changes in the child's behaviour. You might find it hard to know what to say or how to make them feel better. This is OK. Just try to make sure that they know you're there for them, if they need you. Having honest conversations might help them feel closer to you.

Children

Children may have lots of feelings when they find out an adult close to them is ill. These could include:

- shock – they may feel numb after hearing the news
- fear – they might be afraid of the person dying
- upset – they may find it upsetting if the person's appearance changes
- sadness – they might feel sad thinking about a future without the person
- worry – they might be worried about how the person will change as the illness progresses, or they may worry they could get the disease themselves
- 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 guilty that they shouldn't be having fun
- loneliness – they may become withdrawn, or feel like they can't talk about the situation or ask questions, in case they upset the person who is ill.

These feelings are normal. You may find some children don't seem to show these at all. Try to reassure them that it's OK to feel this way, and they can talk about their feelings if they'd like to.

They may also have problems with their behaviour, like trouble sleeping or finding it harder to concentrate at school. Younger children can become clingy, wanting more physical contact with their parents.

Children may try to cope by spending time with the ill person or helping to care for them. Or they might try to distract themselves from the situation, or not think about it. This can happen when they are at school for example, and away from the person who is ill.

Children may want to take on more responsibilities in the home, like helping with housework. This can help them feel like they are a useful part of the family.

Some adults find it hard to know how a child is coping, especially if the child doesn't talk about their feelings. Try not to worry if this happens. You might find it useful to encourage conversations with the child, to let them know they can talk about their feelings or ask questions if they want to.

Try not to be afraid of asking how they're doing. Reassure them that they won't make it more upsetting for the person who is ill, or others around them, if they talk about their feelings.

There is more information on practical tips for supporting children on page 28.

Teenagers

Teenagers may have lots of different feelings when they are dealing with the illness of someone close to them. They may want to care for the adult and comfort them. They may also be angry, because they find it unfair that the person has become ill. They may feel lonely, if they don't feel like they can share how they are feeling.

Teenagers might be worried about the future and be afraid of the person dying. This might make it hard for them to talk about their emotions.

Teenagers may try to cope by trying to maintain a sense of normality. They might like going to school or spending time with their friends. However, some teenagers might 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.

Ben Gold/Marie Curie

You might also feel like they're acting as if they don't care, by spending time away from home or going out more with friends. This is a normal response, and doesn't mean they don't care about the person's illness.

They may take on extra responsibilities around the home. They might want to be involved in the adult's care or do more household chores.

> Javen has been a star. She looked after Amelia quite a bit when Erin was ill - taking care of her, feeding her. She was only 16 and doing her GCSEs at the same time too. She has been incredible.
>
> **Chris, whose wife had a terminal illness**

Having support during this time can be really important for teenagers. It may help for them to have someone they can speak to, like a family member, someone at school, or a counsellor. They may have lots of questions, and might feel upset if these aren't answered. There is more information on practical tips for supporting teenagers on page 28.

The charities Child Bereavement UK, Winston's Wish and the website RipRap have support and information on coping with illness, including stories from other young people (see pages 44-46).

Children with learning disabilities

A child or young person with a learning disability may find big changes to their normal routine upsetting.

They may feel upset if the person isn't able to play or spend as much time with them anymore.

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

It can be helpful to talk to children about what they already know, and what they understand about what is happening. Try to use simple, clear language when explaining things. This can encourage them to ask questions and talk about their feelings. You might find that you'll have to have the conversation more than once. It may also be useful to use pictures or something visual to help explain what's happening.

For extra support, you could speak to a professional involved in the child's care.

Practical ways to support children and young people

There are lots of things you can do to support children or young people when someone close to them is ill.

Reassuring children

It's important to remember that children's emotions and reactions might change as the person's illness progresses, and that is normal. No matter how they seem to be coping, it can be helpful to reassure

them that they are loved and cared for. Being reminded that they are important and valuable in the family can help the child feel appreciated.

Children and young people may take comfort from spending time and having conversations with the person who is ill. Whether this is talking about their day, or hearing stories about the person's life, these conversations can help the child to create positive memories of them.

Family routine

Some people try and keep to a regular family routine as much as possible when someone is ill. This can give the child a chance to spend time with their friends and keep a sense of normality. It may also help reassure the person who is ill that the child will have support when they die.

But keeping the normal family routine isn't always possible. Sometimes, symptoms of the person's illness or hospital appointments mean the routine gets disrupted. Try not to worry if this happens. It can be helpful to have other people around who may be able to support you and the child, like friends and family members, if the routine does have to change.

Deciding where the person is cared for

Some people who are ill may want to stay at home if that's possible. Others may stay in a hospice when they get very ill. And some may stay in a care home or need to go to hospital.

You might be worried about the person being at home when there is a child or young person living at home too. Try talking about this, and if you feel it is appropriate, you may want to involve the child or young person in the discussion too.

If you have questions about looking after the person at home, speak to their nurse, doctor or someone else involved in their care.

You can also contact the Marie Curie Support Line via web chat or on **0800 090 2309*.**

Planning the child's care

Children and young people might have questions about who will take them to school or clubs, and who will look after them when the person is ill and when they die.

It's useful to have thought about who will look after the child while the person is ill, and who will be doing things like cooking and taking them to clubs or school. You can then answer them honestly, if they do ask questions. Knowing this information may reduce any feelings of uncertainty they might be having.

If you have told the child's school about the person's illness, you could explain to them that the school knows about the situation, and there is a certain teacher, nurse or wellbeing officer who they can speak to if they're worried while they're at school. There's more information about telling school below.

Telling school

School can be an important source of comfort for children and a way to keep a sense of routine. For some children and young people, they find school a good distraction from events at home. Having support from their friends and teachers can also give them someone to talk to outside of the family.

It's normally a good idea to tell the child's school that the person is ill. This can help the school understand any changes to the child's

behaviour. Schools may have wellbeing officers, a school nurse or a teacher the child can talk to. You might also want to speak to them, as they may be able to tell you about local support services.

If you are worried about telling the school, someone involved in the person's care may be able to help you do this.

Children and young people may be able to have some time off school when the person is very ill. It's best to speak to the school and find out if there are any policies on this.

Hospital and hospice visits

If the person goes into hospital or a hospice, the child or young person may want to visit them.

Seeing the person in hospital can help the child understand their illness and treatment better, and may comfort them if they're missing the person.

However, some children may find it upsetting, and some adults may not want the child to see them in hospital. If they can't go, or don't want to go, you might like to arrange for them to speak on the phone.

> Thomas came nearly every night to visit his nan. He'd come after school, and they'd have a sausage sandwich waiting for him so he could eat tea with his nan. It's those sorts of things that make all the difference.
>
> Carole, whose mum was cared for in Marie Curie's Bradford Hospice

Kate Stanworth/Marie Curie

They could write the person a letter, or send a voice or video message. Try to reassure them that even though the person might look different, they are still the same person.

Ask the child or young person whether they'd like to visit the person in the hospital or hospice. You could explain to them what the visit will be like, including what the room will look like, and how the person may look. It can also help to tell the hospital or hospice staff that the child will be visiting.

Some children can get bored at hospital, so you may want to encourage them to bring a game or activity which can involve the person who is ill. This could even be something simple, like a hairbrush or nail polish.

Making memories together

You might want to spend some quality time with the child and person who is ill. This can help create positive memories for them after the person has died. Using photos, videos, music, arts and crafts can be a good way to spend time together.

> The pillowcase activity is about solid memories. Family members paint each other's hands, including the person who is ill, and place them on the pillowcase. The emphasis is on the family unit and having fun together rather than the individual. It can help the child continue to feel close to their special person after their death.
>
> Ann, children and young person's counsellor

Activities you could try

Spending time with the person who is ill can help build positive memories for the child. You may want to try some of these activities:

- Make a photo album of the child and the person who is ill, or look through family photo albums together. This can be useful for starting a conversation about what the person was like before the child knew them.
- Make jewellery using beads with letters, which can be used to make up the child or adult's name.
- Make paintings to decorate the person's room. You can hang these wherever the person is being cared for, whether that's at home, or in a hospice or care home.
- Create a memory box, which could include photos and souvenirs from special days, with the person who is ill.
- Draw pictures of their favourite things to do together.
- Write a story about their favourite memories.
- Read stories together.
- The child might like to learn things about the person's life that they didn't know already. This could be things like their favourite food, what their first car was, or their favourite subjects at school.

You may find that doing some of these activities is upsetting for you. You could invite a close family friend or relative to join in as well, to provide some extra support.

Getting support

Trying to support children and young people when someone is ill can be difficult. It's important to remember that you don't have to do it alone.

You may find it helpful to get support from friends, family members or professionals. Family members and friends might be able to help

you with practical tasks around the house, like making meals or doing chores. They may be able to take the child to school or clubs.

It may also help the child to know that they have someone else they can talk to, as well as you. This could be a teacher, sibling, family friend or professional.

Ask a healthcare professional involved in the person's care about the support available for you and the child or young person.

You may also be able to speak to a counsellor or get support from your local hospice, including Marie Curie Hospices. Some have counsellors or other professionals who can support families, children and young people. These are usually only available if the person who is ill is known to the hospice, but this can vary. Contact your local hospice to find out more. You can find a list of Marie Curie Hospices at **mariecurie.org.uk/hospices**, or a list of hospices in the UK at Hospice UK (see page 45).

You can also call our Support Line on **0800 090 2309*** for practical information and emotional support.

> The girls started going to music therapy classes in the hospice's day therapy unit where they learnt to play the ukulele and thumb piano. After they'd learnt a song, they'd rush up to the ward to play it for granny. When she heard their singing she'd sit up in bed and smile and try to hum along.
>
> Rachel, whose mother-in-law was cared for in a Marie Curie Hospice

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Looking after yourself

It can be hard to remember to look after yourself when you have children to take care of. Being there for a child, talking to them about the illness and supporting them emotionally can be challenging.

Some adults find it hard to balance everyone's needs, especially if they are looking after the person who is ill. You may feel tempted to put your own needs aside to look after others.

Whether you are ill, or whether you're looking after someone who is, it's important to think about your own needs, and try to take some time to look after yourself. If possible, you might like to continue doing hobbies you've always enjoyed, or take a break to see friends or family.

It's useful to 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 read it online or order a hard copy at **mariecurie.org.uk/publications**

You can also call our 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/support**

Preparing a child for when someone dies

As the person gets more ill, children and young people might become more worried or anxious. Or, you may find that they have already started coming to terms with the idea that the person will die. Whatever their reaction, it is important to understand that children cope in different ways.

Helping them to say goodbye

Children and young people may want the chance to say goodbye to the person who is ill. For some children, this can bring relief and a sense of closure. Ask them if this is something they would like to do, as some children may not want to say goodbye to the person.

Sharing messages of love with the person who is dying can be important for children and young people, as it can help give them long-lasting, positive memories of their relationship. If they find it too difficult to talk, they might like to hug or hold hands. If it's not possible for the child or young person to see the person, they might like to make a gift or card for them, or record voice or video messages.

The child might find it helpful to speak to a religious leader or a chaplain, whether they are religious or not.

Speak to the child about whether they'd like to say goodbye to the person or not before they die. If they do, try to prepare them for what the person might look like. If they're in hospital or a hospice, you could describe what the room will look like.

It may not be possible for the child to see the person before they die. This is OK, and if this happens, try to remember that it's not your fault.

> We were all in the room when mum died – the nurses, my sister, and Thomas too. One of the things that Thomas did, that I will always be in awe of him for, is he wanted to be the last person that mum touched and felt near her. I was petrified about mum dying but it wasn't what any of us expected. It was so peaceful.
>
> Carole, whose mum was cared for in Marie Curie's Bradford Hospice

Philip Hardman/Marie Curie

When the person dies

It will be an emotional time for both you and the child when the person dies. You may want to seek support for yourself and the child.

We have more information on looking after yourself and a child in our booklet, *Supporting children and young people when someone dies*. You can read these online or order hard copies at **mariecurie.org.uk/publications**

You can also call our Support Line on **0800 090 2309*** for practical information and emotional support for when someone dies.

There is a list of organisations on page 44 which may also be able to provide support when someone dies.

Books to support children

Here are some books about illness which you might find helpful to read with or give to children or young people. These have been recommended by health and social care professionals, including children and family counsellors. If you would like some examples of books about grief and death, you can find some in our booklet, *Supporting children and young people when someone dies.*

As big as it gets, 2007 (Winston's Wish)
A book for adults on supporting a child when a parent is seriously ill. It includes suggestions about what parents and carers might say to children and how to offer support.

Mummy's lump by Gillian Forrest and Sarah Garson, 2015 (Breast Cancer Now fmr. Breast Cancer Care)
A booklet to help parents and carers talk to young children about breast cancer. It uses simple words and pictures to explain possible treatments, symptoms, and things which might change at home when an adult has breast cancer.

My brother and me by Sarah Courtauld and Rebecca Cobb, 2009 (Child Bereavement UK)
A storybook about a boy who has a serious illness and stays in hospital, and how his brother copes with his different emotions and feelings. Suitable for ages between four and ten.

The Secret C: straight talking about cancer by Julie Stokes and Peter Bailey, 2000 (Winston's Wish)
An illustrated guide aimed at supporting parents or carers when talking to a child about cancer. It talks about what cancer is, possible treatments and symptoms, and feelings children might have when someone close to them is ill. Suitable for ages seven to ten.

When someone has a very serious Illness: children can learn to cope with loss and change by Marge Heegaard, 1991 (Woodland Press)
An activity book to help children explore the feelings they have when they or someone close to them has a serious illness. It includes space for children to draw pictures to show how they are feeling.

How Marie Curie can help

We help everyone affected by a terminal illness get the care and support they need, including people who have been bereaved.

Marie Curie Support Line
0800 090 2309*
Ask questions and find support. Speak to a trained member of staff or a nurse for free confidential information on all aspects of terminal illness. Open 8am to 6pm Monday to Friday and 11am to 5pm Saturday. Your call may be recorded for training and monitoring purposes.

Marie Curie Online Chat
You can talk to our trained staff and get information and support via our online chat service.
mariecurie.org.uk/support

Marie Curie Community
Share experiences and find support by talking to people in a similar situation.
community.mariecurie.org.uk

Marie Curie Information
We have a range of free information available to view online or as printed booklets.
mariecurie.org.uk/support

Marie Curie Hospices
Our hospices offer the reassurance of specialist care and support, in a friendly, welcoming environment, for people living with a terminal illness and their loved ones – whether you're staying in the hospice, or just coming in for the day. Our hospices also support people who have been bereaved, and some offer support for children.
mariecurie.org.uk/hospices

Marie Curie Nursing Services
Marie Curie Nurses and Healthcare Assistants work in people's homes across the UK, providing hands-on care and vital emotional support. If you're living with a terminal illness, they can help you stay surrounded by the people you care about most, in the place where you're most comfortable.
mariecurie.org.uk/nurses

Marie Curie Helper Volunteers
We know the little things can make a big difference when you're living with a terminal illness. That's where our trained Helper Volunteers come in. They can visit you regularly to have a chat over a cup of tea, help you get to an appointment or just listen when you need a friendly ear.
mariecurie.org.uk/helper

Useful organisations

Barnardo's
barnardos.org.uk
A charity which supports children, young people, parents and carers.

Child Bereavement UK
0800 02 888 40
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
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
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
Scotland's national children's society, which provides advice and support for parents and families.

Cruse Bereavement Care
0808 808 1677
cruse.org.uk
A charity which helps bereaved people in England, Wales and Northern Ireland.

Cruse Bereavement Care Scotland
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 through its website.

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.

RipRap
riprap.org.uk
A website for teenagers who have a parent with cancer. Includes information on cancer and treatment, and real life stories from other young people.

Winston's Wish
08088 020 021
winstonswish.org
A child bereavement charity which offers specialist practical support and guidance to bereaved children, their families and professionals.

Did you find this information useful?

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

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 Marie Curie Support Line on **0800 090 2309***.

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.

Marie Curie – who we're here for

We're here for people living with any terminal illness, and their families. We offer expert care, guidance and support to help them get the most from the time they have left.

Marie Curie Support Line

0800 090 2309*

Ask questions and find support from trained staff and nurses.
Open 8am to 6pm Monday to Friday,
11am to 5pm Saturday.
mariecurie.org.uk/support

You can also visit **community.mariecurie.org.uk** to share experiences and find support by talking to people in a similar situation.

We can't do it without you

Our Information and Support service is entirely funded by your generous donations, so the work we do would not be possible without your help. Thanks to you, we can continue to offer people the free information and support they need, when they need it.
mariecurie.org.uk/donate

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

Marie Curie

Care and support through terminal illness