

**LIVING WITH BREAST CANCER**

# Talking with children about metastatic (secondary) breast cancer

## About this booklet

The information in this booklet is written for parents and carers affected by metastatic (secondary) breast cancer, but it may be helpful for any adult who needs to talk with children about metastatic breast cancer.

Metastatic breast cancer happens when cancer spreads from the breast to another part of the body, such as the bones, lungs, liver or brain.

It can be treated, sometimes for many years, but currently can't be cured.

INFO

If you have been diagnosed with metastatic breast cancer, you may worry about what to tell your children or grandchildren.

This booklet will give you some guidance and helpful resources when talking with children about metastatic breast cancer. It doesn't tell you exactly what to say, because every family communicates differently and you know the children in your life better than anyone.

You may want to talk to your treatment team or specialist nurse for additional support.

You can also speak to our specialist nurses on our free helpline **0808 800 6000** and on our website **breastcancer.org**

If you would like information on talking with children about primary breast cancer, see our **Talking with children about primary breast cancer** booklet.

INFO

## Talking with your children

Telling your children you have metastatic breast cancer can feel daunting, even if you've had to have difficult conversations with them before. However, there's evidence that open communication can help children feel less frightened and anxious about what's happening around them when a parent has a cancer diagnosis.

Children are often very aware when something feels different or wrong. They can usually sense when you're upset or worried too. If you don't tell them what's happening, they may feel hurt or left out. They may think they've done something wrong, blame themselves or try to make sense of the situation by using their imagination.

When children don't have accurate information, they often fill in the gaps on their own. This can lead to misunderstandings or unnecessary fears. They may also overhear conversations or accidentally learn about your diagnosis in a way you wouldn't have chosen.

Sharing your diagnosis may not be something you would ever want to choose to do, but being open in an age-appropriate way can help prevent confusion, reduce anxiety, and reassure children that they are not to blame.

Trying to carry this information alone as a parent can be exhausting and overwhelming.

Although telling your children about your diagnosis is hard, it can often be a relief, reducing anxiety for both parents and children and can help children feel valued and trusted. It also gives them a clearer understanding of what may happen in the future and helps them feel more prepared for any changes ahead.

It can be helpful to begin to talk with your children when there's plenty of time for them to ask questions or be with you afterwards.

You might want to talk to your children in a comfortable setting where you're unlikely to be distracted or disturbed. It might be helpful to have someone you and your children know and trust, such as a partner or friend, with you to offer support.

If you have more than 1 child, you might want to tell them about your diagnosis together. After you've told your children together, you can then have further conversations with them separately. This may allow you to give information that is more age appropriate.

It can be a good idea to plan to do something "normal" after talking for example, a walk, a trip to the park, cooking a meal so there is time to process it together and give room for questions. It's also a good idea to give yourself some time and space afterwards, to process the conversation and seek some support if you need it.

This will be an ongoing conversation and over time you can give them more information as and when it feels right, so let them know it's ok to continue to talk about what's happening and that they can come back to it at any time.

I felt I needed to be really honest with them, but that it was a huge responsibility and I needed to get it right and break the news gently. But I needed to do it properly. I was going through a huge shock myself and I knew I couldn't just cover it up and hide it as they would see it on my face immediately.



**Claire**

Children aged 11 and 13 at diagnosis

## **Support telling your children**

**INFO**

Organisations such as The Ruth Strauss Foundation, The Fruit Fly Collective and The Little C Club have useful resources and support to help you tell your children you have metastatic breast cancer.

You can find more information about these organisations on page 22.

## What to tell them

What you tell your children about your metastatic breast cancer will depend on different things, such as their age and what you might have previously told them about cancer or a serious illness.

Many people find it helpful to discuss what they plan to say with their partner, friends or other family members before speaking to their children. This helps ensure children are receiving consistent information from those close to them. You may disagree with your partner, friends or family members about what or how much to tell your children. You can ask your specialist nurse for support on how to discuss this with your partner, friends or family.

It may help to continue to make regular opportunities for your children to talk with you about what's happening and ask questions. Here are some topics you might want to talk to them about over time:

- What metastatic breast cancer is (see “Explaining metastatic breast cancer” on page 8, or the short definition at the beginning of this booklet)
- What part of the body it affects
- The treatments and care you're likely to have
- What you currently know about the cancer and the treatment
- Side effects you may have and what they may notice, and how these will affect you and your family's routine
- What will change for your children and who might help your family with changes to their routine

The support and information your children might need will depend on a variety of factors, including:

- Their age
- Whether they are neurodiverse
- Whether they have any learning difficulties

You can find a list of organisations who can support you when talking about metastatic breast cancer with a child with additional needs at the end of the booklet.

## Explaining metastatic breast cancer

If you haven't had to talk to your children about cancer before, it might be helpful to start by asking them what they know or understand about it.

Try to use clear language and avoid complicated terms. For example, it's best to use the word "cancer" from the beginning, and to explain it using language that your children will understand.

You may find the organisations listed on page 22 helpful when explaining metastatic breast cancer to your children.

My 17-year-old was told everything that we knew. My 10-year-old daughter has been told that my cancer is not curable, and I will die of it one day. But she knows that I am on treatment for now, and that it's keeping the cancer in check. I also talk openly about the side effects, such as fatigue, and the pain that I get.

**Alex**

Children aged 10 and 17 at diagnosis



## Younger children (6 and under)

Younger children are unlikely to have much knowledge about cancer. They may learn about the human body at primary school and have an understanding about different body parts and cells. You know your children best, so try to explain in terms they'll understand or be familiar with.

You might find storybooks or videos help to explain cancer to younger children. You can see a list of age-appropriate resources by scanning the QR code on page 27. Look at the resources first to make sure they're right for you and your family.

## Older children (7 to 12)

Children of this age begin to understand that people can have serious illness and can understand more about cells, cancer and the body.

A good place to start with older children is to tell them what's happening and how your treatment team are going to help you.

You can ask them what they want to know about your diagnosis or treatment and offer them the opportunity to talk about it when they're ready.

There are useful resources to help explain cancer to older children on page 22.

## Teenagers

Teenagers are likely to have begun to develop a similar understanding to adults.

As with older children, a good place to start with teenagers is to tell them what's happening and how your treatment team are going to help you.

You can also ask them what they want to know about your diagnosis or treatment and offer them the opportunity to talk about it when they're ready.

You can find some useful resources and organisations who offer support to young adults on pages 24 and 25.

## Talking with your children about an uncertain future

Many people live for years with a diagnosis of metastatic breast cancer. However, it's important to talk to your children about the future.

Depending on their age, and other factors, this might include:

- What treatment options you have available and what the side effects might be
- What happens when a treatment stops working
- What your possible outlook might be

The Ruth Strauss Foundation offers guidance, resources and emotional support to parents talking with children about incurable cancer. You can find more information about this, and other useful organisations, from page 22 onwards.

Your palliative care team or local hospice may also be able to signpost you to specialist family support services who can help you talk to your children.

Sometimes answering all questions can be hard. I've had to apologise on occasions when my reactions could have been better. We keep communicating, being very open, and that helps us as a family.



**Nicole**

Child aged 13 at diagnosis

## Explaining treatment and side effects

You may want to tell your children about the treatments you will be having. However treatment plans can change, so it's important to let your children know your treatment team will make sure you're getting the best treatment for you.

Different treatments will have different side effects, such as:

- Hair loss
- Feeling sick
- Feeling more tired than usual

Your children might not be aware that medicine can make you feel unwell before it makes you feel better. You may want to talk to your children about potential side effects you might experience. This may help prepare your children for any changes they notice.

It might be possible for your children to meet your treatment team so they can ask questions, find out who's looking after you and feel reassured about where you're having treatment. You can speak to your specialist nurse about whether this is an option for you.

## Talking with your children about dying

It's understandable that you may want to avoid talking with your children about dying.

However, having these conversations allows you to be open and honest with your children. Depending on their age, they may be able to help you plan for the future or feel more able to support you.

You can find a list of organisations to support you and your family during this time at the end of this booklet.

I am always open, honest and factual. I don't give them too much detailed info, but let them know what is happening. If they ask a question I always answer truthfully, i.e. will you die mum? I say yes, but we all die and I'm here now and have no plans to go anywhere.



**Ruth**

Children aged 14 and 18 at diagnosis

## Honest and open communication with your children

Feeling secure is a basic need for children, so it's important to continue to have honest and open communication with your children. This includes being honest even if you can't answer a question your child asks.

Expressing your own feelings shows that emotions are normal and helps your children to understand that showing their emotions is OK as well.

It's a good idea not to overload your child with too much information in the first conversation as you may find you need to repeat it a few times over a period of time.

You may find it helpful to look at age-appropriate stories or videos with your children to help talk about your breast cancer and encourage wider conversations. You can find a list of these by scanning the QR code on page 27. It's important to look at these first to make sure they're appropriate for you and your family.

We cuddle, we keep answering her questions and we show our own vulnerability (to an extent). The metastatic diagnosis made us finally get married in August and we had the best day and party. For our daughter to see that life goes on, and you can still have very happy (and even more meaningful!) times, is what helps her.

**Nicole**

Child aged 13 at diagnosis



## How your children may react

You may notice changes in your child's behaviour after you've started to talk to them about your metastatic breast cancer diagnosis.

Some children, including teenagers, may initially appear disinterested but may need time to process what is happening before they ask questions or want to talk.

These are very normal reactions. You may also notice changes to their:

- Eating habits
- Sleeping patterns
- Concentration (at school or at home)
- Mood

If you're worried about changes in your child's behaviour, whether its listed above or not, speak to their GP, your specialist nurse their school or nursery.

You can find resources and organisations to help support your whole family from page 22 onwards.

## **The Talking, Telling and Sharing Framework**

The Talking, Telling and Sharing Framework was developed to help people communicate with children about cancer. A version created to help families affected by metastatic cancer includes the 6W grid, which helps summarise some of what we've covered so far.

Below we've adapted the framework, which was created by the Family-Centred Cancer Care team at Ulster University.

### **Why**

#### **Why is it important to tell the children?**

Children may already suspect that "something is wrong". It is highly likely they will have noticed any whispered conversations or changes to your appearance and behaviour.

Your children may feel anxious or confused if they aren't told the truth. Parents also often find it a great relief once they have told their children.

### **Who**

#### **Who should tell the children?**

Ideally a parent or another trusted adult. If you're a 2-parent family, it is usually best if you tell the children together.

If you're a single parent, you might like to have a relative or close friend with you.

If you're finding it difficult, you could ask another family member or friend to have the conversation, but it's best if you're there.

Generally, the well parent or an adult who will have ongoing caregiving responsibilities for your children (such as your partner or close family member) will want to be involved in sharing this difficult news.

## When

### **When is the best time to tell the children?**

There may be no right time to start a conversation, so it's looking for the best time.

The best time to have these difficult conversations is soon after receiving your diagnosis and when you're feeling emotionally and physically able.

## What

### **What should families do to prepare children for what is going to happen?**

- Be honest about your diagnosis
- Capture life as it happens to create memories for the future
- Maintain routine when and where possible
- Let them know that they'll be told of any changes that happen
- Update key networks such as school teachers
- Asked to be referred to support networks when required
- Make forward plans for the future

## Where

### **Where is the best place to start the conversation?**

Try to choose a place:

- Without interruptions
- Where you won't feel rushed
- Where you're able to talk and express feelings

## Words

### **What words are appropriate to use?**

- Use age-appropriate language
- Don't give false hope
- Avoid euphemisms and confusing terminology
- Use clear and factual language, such as “cancer” and “die”

Words are only part of the telling – remember that children pick up on body language too

## School and education

It may be helpful to let your child's school or nursery know about your diagnosis. This is so staff can support you both.

You can find an example of a letter or email you can send to the school on page 19.

The support your child's school can offer them will vary, but may include:

- Pastoral support or counselling
- Free activities or clubs before or after school
- Extensions on homework and coursework
- Putting a support system in place if your child is feeling overwhelmed (for example, giving them a timeout card to show the teacher or a named member of staff they can talk to if they're feeling sad, upset or need support)

If your child is preparing for exams, the school can apply to the exam board for special considerations. You will need to contact the school to ask them about this.

Involve the school. I wrote to both my kids' schools. I explained the situation, my prognosis, I asked them to look out for the kids and to let me know if they saw any concerns.



**Claire**

Children aged 11 and 13 at diagnosis

## Example letter or email to school

Dear [teacher's name],

My child [child's name] is in class [class name].

I'm writing to you because I was recently diagnosed with metastatic breast cancer. This means my cancer can be treated but isn't curable. [Child's name] would like the following members of staff to know about my diagnosis: [staff members' names].

My treatment might disrupt [child's name]'s normal routine at home and they may need some extra support at school. I would really appreciate it if you could let me know if you have any concerns about [child's name] while they are at school.

It would also be very helpful if you could offer [insert reasonable adjustments if appropriate, for example, earlier pick up times, parking space nearer school, extra support with exams] while I'm going through treatment.

Please do contact me if you have any questions or concerns. You can contact me [on number / at email] [or I'd be happy to talk to you in person].

You can find out more information about metastatic breast cancer on the Breast Cancer Now website [breastcancer.org](http://breastcancer.org)

Yours sincerely,

[Your name]

## Support and resources

### Support from Breast Cancer Now

We have a range of services to help support you when you have a metastatic breast cancer diagnosis. You can find out more about these on our website **breastcancer.org/support**

#### Helpline

You can call our free helpline and speak to our specialist nurses on **0808 800 6000** or talk to us online at **breastcancer.org**

#### Living with Secondary Breast Cancer

Our Living with Secondary Breast Cancer services provide a space for you to talk, listen and learn with people who understand the challenges that metastatic breast cancer brings. From face-to-face groups to online groups and live speaker sessions, find the support that suits you.

#### Younger Women with Secondaries Together

Our Younger Women with Secondaries events allow you to come together and meet women in a similar position, share what's on your mind, and learn from expert speakers.

#### Speakers Live – secondary breast cancer

Our Speakers Live – secondary breast cancer sessions offer a chance to learn about different topics. Each month you can hear from expert speakers on topics relevant to people living with secondary breast cancer.

Our Living with Secondary Breast Cancer, Speakers Live and Younger Women with Secondaries Together services often include session on talking with children.

## Forum

An online discussion forum for people affected by breast cancer to share their experiences and offer each other support. There are numerous ongoing discussions about talking with children about breast cancer. Visit **[breastcancernow.org/forum](https://breastcancernow.org/forum)**

## **Explaining cancer**

### **Fruitfly Collective**

- [fruitflycollective.com](http://fruitflycollective.com)
- An organisation that supports families affected by cancer

### **The Little C Club**

- [littlecclub.com](http://littlecclub.com)
- Flashcards designed to help parents talk to children about cancer

### **The Ruth Strauss Foundation**

- [ruthstraussfoundation.com](http://ruthstraussfoundation.com)
- Offers free guidance and support to parents who have been diagnosed with a cancer that can't be cured, on talking with their children about this and how they may prepare them for the future. Their Family Support Service and resources also include information on grief, death and dying

### **Ulster University Talking Telling Sharing Framework (see pages 15 to 17)**

## **Support with childcare**

### **Coram Family and Childcare**

- [coramfamilyandchildcare.org.uk](http://coramfamilyandchildcare.org.uk)
- Promotes high-quality, affordable childcare for all, offering information and services to help people make the right decision about childcare for their child

### **Home Start**

- [home-start.org.uk](http://home-start.org.uk)
- Helps families with young children cope with challenges such as long-term illness in the family. Volunteers can offer support in a family's home

## **Support for children and young adults**

### **Hope Support Services**

- [hopesupport.org.uk](http://hopesupport.org.uk)
- Supports young people aged 11 to 25 when a close family member is diagnosed with a life-threatening illness

### **Maggie's Centres – Kids' Days and Teen Days**

- [maggies.org](http://maggies.org)
- Maggie's runs quarterly Kids' Days (ages 7 to 13) and Teen Days (ages 14 to 18) at some of their centres

### **Mencap**

- [mencap.org.uk](http://mencap.org.uk)
- Supports people with a learning disability, as well as their families and carers

### **National Autistic Society**

- [autism.org.uk](http://autism.org.uk)
- Provides support, information and advice for autistic adults and children in the UK, as well as their family members and carers

### **Partnership for Children**

- [partnershipforchildren.org.uk](http://partnershipforchildren.org.uk)
- Promotes the mental health and emotional wellbeing of children, with resources for parents and teachers to help young children cope with difficult situations

## **The Osborne Trust**

- [theosbornetrust.com](http://theosbornetrust.com)
- Supports children with a parent affected by cancer, offering emotional and practical support to children aged 18 and younger, including peer-to-peer support programmes, respite activities and helpful support packs

## **Young Minds**

- [youngminds.org.uk](http://youngminds.org.uk)
- Helping to improve the wellbeing and mental health of children and young people, offering a helpline for parents, along with information about feelings, mental health and ways to cope

## **Youth Access**

- [youthaccess.org.uk](http://youthaccess.org.uk)
- An advice and counselling network

## **Bereavement support for your children**

### **Care for the Family**

- [careforthefamily.org.uk](http://careforthefamily.org.uk)
- Provides support for families facing difficulties, such as those needing parenting support or bereavement support

### **Child Bereavement UK**

- [childbereavementuk.org](http://childbereavementuk.org)
- Provides information and support to help families rebuild their lives when a child is grieving

### **Cruse Bereavement Support**

- [cruse.org.uk](http://cruse.org.uk)
- Offers support, advice and information to children, young people and adults when someone dies

### **Hope Again**

- [hopeagain.org.uk](http://hopeagain.org.uk)
- The youth website of Cruse Bereavement Support where young people can read other people's stories and access information and support

### **SeeSaw**

- [seesaw.org.uk](http://seesaw.org.uk)
- Provides grief support for children, young people and their families in Oxfordshire, but their website has lots of useful resources

### **Winston's Wish**

- [winstonswish.org](http://winstonswish.org)
- Supports children when a parent has died, giving advice and support through their helpline and residential weekends

## **Books and resources**

For a list of books and resources you might find useful when talking with your children about cancer, scan the QR code or visit **breastcancernow.org** and search “Resources for talking with children about cancer”.



Look at these resources first to make sure they're right for you and your family.







**We're the UK's leading breast cancer charity. And we're combining the power of science and support to change breast cancer.**

**Life-saving science**

Uncovering how breast cancer develops and spreads. New and better treatments that can find and destroy cancer cells. And one day, cures that can stop it in its tracks entirely.

**Life-changing support**

Expert information on everything from signs and symptoms to chemotherapy. Help so you can live well. Meeting people who are going through the same thing – people who just get it.

**Change-making campaigns**

Making sure everyone knows the importance of checking their breasts and chests, and the signs to look out for. Pushing for better diagnosis and care. Making sure everyone can get the drugs they need.

**We don't get any government or NHS funding for our information or support. We rely on our supporters to make change happen.**

So if you've found this information helpful and you'd like to support us, go to: **[breastcancernow.org/give](https://breastcancernow.org/give)**

# About this information

**Talking with children about metastatic (secondary) breast cancer** was written by Breast Cancer Now's clinical specialists, and reviewed by healthcare professionals and people affected by breast cancer.



For a full list of the sources we used to research it:  
Email [health-info@breastcancer.org](mailto:health-info@breastcancer.org)



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We make every effort to ensure that our health information is accurate and up to date, but it doesn't replace the information and support from professionals in your healthcare team. So far as is permitted by law, Breast Cancer Now doesn't accept liability in relation to the use of any information contained in this publication, or third-party information included or referred to in it.

**BREAST  
CANCER  
NOW**

## **Whatever breast cancer brings, we're here.**

Information on everything from symptoms to treatment and beyond. Support to help you live well. Meet people going through the same thing – people who just get it.

We're here with life-changing information and support now. Whatever you're going through. However you need it.

Call **0808 800 6000** to talk to one of our nurses.

Visit **[breastcancer.org](https://www.breastcancer.org)** now for breast cancer information you can trust.

## **Breast Cancer Now**

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