

**LIVING WITH BREAST CANCER**

# Talking with children about primary breast cancer

## About this booklet

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

If you have been diagnosed with primary breast cancer (breast cancer that has not spread beyond the breast or the lymph nodes under the arm), you may worry about what to tell your children or grandchildren.

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

You may want to talk to your treatment team or breast care nurse for additional support. You can also speak to our specialist nurses on our free helpline **0808 800 6000** and on our website **breastcancernow.org**

Macmillan Cancer Support also have information on talking to children and teenagers on their website [macmillan.org.uk](http://macmillan.org.uk)

**INFO**

If you would like more information for partners of people with primary breast cancer, see our booklet **When your partner has primary breast cancer**.

If you would like information on talking with children about metastatic (secondary) breast cancer (breast cancer that has spread to other parts of the body, such as the bones, lungs, liver or brain), see our **Talking with children about metastatic (secondary) breast cancer** booklet.

## Talking with your children

Telling your children you have 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.

### Support telling your children

INFO

Organisations such as The Fruit Fly Collective and The Little C Club have useful resources to help you tell your children you have breast cancer.

You can find more information about these organisations on page 19.

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.

It can be exhausting and difficult to try to hold on to the information yourself. Telling your children about your diagnosis can help them feel valued and trusted.

I told my son 2 weeks after my diagnosis. I was extremely upset and worried after discovering I had breast cancer and I felt that my son, as he is so bright, would know something was wrong. I also took advice from my breast cancer nurse, who was supportive and was already at the end of the phone.



**Nicky**

Child aged 6 at diagnosis

It can be helpful 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 may 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.

We were at home. When they came in from school I sat them both down and said I had some news. And then I told them that I had been diagnosed with breast cancer but it was treatable and the overall prognosis was good. I then asked them how much more they wanted to know. I checked in regularly over the next few days and weeks and gave them lots of chances to ask questions and talk about how they were feeling.



**Sandra**

Twins aged 18 at diagnosis

## What to tell them

What you tell your children about your breast cancer will depend on different things, such as their age and your family's previous experience of 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 breast care 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 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 cancer is (see "Explaining cancer" on page 8)
- What part of the body it affects
- Any treatments you're likely to have
- 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 them 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 breast cancer with a child with additional needs at the end of this booklet. You can also find some helpful book resources aimed at children of different ages.

## Explaining 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. See our list of useful organisations on page 19 for more information about the language to use.

Be as honest as you can and always listen to your child. They will ask questions which are important to them and should always be answered truthfully.



**Paulette**

Grandchildren aged 1 and 4 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 22.

It is important you 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 19.

## 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 20 and 21.

## 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 most appropriate treatment for you.

I found that “normalising” hospital visits helps the child to see that it's OK to go to hospital a lot for different appointments and that's all part of the doctors looking after you.



**Kirsty**

Child aged 1 at diagnosis

Different treatments will have different side effects, such as:

- Hair loss
- Scar from surgery
- 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 breast care nurse about whether this is an option for you.

## 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 during your treatment. 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 22. It's important to look at these first to make sure they're appropriate for you and your family.

My son was 6 years old. Throughout my treatment we talked about the medicines and how amazing technology and scientists are at finding treatments. My husband and I made sure we were as open and honest as possible.



**Nicky**

Child aged 6 at diagnosis

## How your children may react

You may notice changes in your child's behaviour after you've told them about your breast cancer diagnosis or while you're going through treatment.

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 breast care nurse, their school or nursery.

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

You can find resources and organisations to help support your whole family on pages 20 and 21.

My daughter had lots of questions and wanted to talk a lot about what was going on and how she was feeling as well as wanting a lot of cuddles and time together. My son became quite quiet and withdrawn and seemed to retreat into his own world. We were clear with them both that they could talk to anybody they wanted to at any time and I know my son did talk to a close family friend.

”

**Sandra**

Twins aged 18 at diagnosis

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

The Talking, Telling and Sharing Framework was developed to help people communicate with children about cancer.

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.

## 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 do the children need to know?**

- What is cancer – use the word “cancer”
- What part of the body – be specific
- What is the treatment – if known
- What side effects are expected
- What is going to change for the children
- Update key networks such as school teachers

## 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
- Make sure communication is ongoing

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

### **While you're in hospital**

There are many ways for you and your child to feel connected if you need to stay in hospital for treatment.

It may be reassuring for your child to see where you are. If they're unable to visit you in hospital, you could suggest calling or video calling them.

If possible your child could stay with a friend or relative. If you don't have family and friends living close by who can help with childcare, a social worker at the hospital can give you advice about childcare in your area. Organisations such as Coram Family and Childcare and Home Start may also be able to help. You can find out more information about them on page 20.

## 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 23.

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.

I rang the form tutor at both schools and explained what was going on. I also rang several times when my children were having a bad time or were upset about things. Both schools were sympathetic and passed on messages to teachers who would be teaching my children that day.



**Sandra**

Twins aged 18 at diagnosis

## After treatment

As treatment varies from person to person, the time it takes to recover also varies. While chemotherapy may last a few months, hormone therapy can continue for several years. The need for support often continues even after your main hospital treatment had ended.

Each stage of your treatment and recovery may bring different feelings and experiences. Continuing to have open and honest conversations with your child may help you both feel more supported.

The resources and organisations on pages 20 and 21 can help you navigate family life after breast cancer.

Call on as much support as you can and don't be afraid to ask for help.



**Carol**

Child aged 14 at diagnosis

## Support and resources

INFO

### Support from Breast Cancer Now

We have a range of services to help support you during and after a breast cancer diagnosis. You can find out more about these on our website

**[breastcancer.org/support](https://breastcancer.org/support)**

#### Helpline

You can call our free helpline on **0808 800 6000** to speak to one of our specialist nurses.

#### Forum

You can connect with people going through a similar experience on our online forum

**[breastcancer.org/forum](https://breastcancer.org/forum)**

#### Someone Like Me

Our Someone Like Me services matches you with a trained volunteer who has had a similar experience to you.

#### Younger Women Together

If you are diagnosed with primary breast cancer under the age of 45, our Younger Women Together gives the chance to meet people your age who understand what you're going through.

#### Moving Forward

Our Moving Forward course gives you the tools to adjust to life beyond primary breast cancer treatment.

## **Explaining cancer**

### **Fruitfly Collective**

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

### **Parenting with Cancer (Fruitfly Collective)**

- [fruitflycollective.com/parentsupport](http://fruitflycollective.com/parentsupport)
- Specific support and resources for parents with a cancer diagnosis

### **The Little C Club**

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

### **Ulster University Talking Telling Sharing Framework (see pages 13 to 15)**

## 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](https://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](https://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](https://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](https://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](https://youthaccess.org.uk)
- An advice and counselling network

Call our helpline on **0808 800 6000** or visit **breastcancernow.org**

## 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.

## 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 breast cancer. [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 breast cancer on the Breast Cancer Now website [breastcancernow.org](http://breastcancernow.org)

Yours sincerely,

[Your name]







**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 primary 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**



You can order or download more copies from:  
**breastcancer.org/publications**



We welcome your feedback on this publication:  
**health-info@breastcancer.org**



For a large print, Braille or audio CD version:  
Email **health-info@breastcancer.org**

## Medical disclaimer

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 **breastcancernow.org** now for breast cancer information you can trust.

## Breast Cancer Now

6th Floor  
The White Chapel Building  
10 Whitechapel High Street  
London E1 8QS

Trusted  
Information  
Creator



Patient Information Forum