

4. What to do if you notice a change

Talk to someone you trust if you notice anything different about your breasts.

Your carer or support worker can get you some information to answer your questions.



You or your carer or support worker can make an appointment with your doctor.

5. Seeing your doctor



See your doctor as soon as you can if you notice a change in your breasts. You can ask to see a woman doctor and take someone you trust with you if you want.



You will need to take off your top and bra so the doctor can feel your breasts to check them.



The doctor will try to explain the problem with your breast.



You may need to go to a breast clinic at the hospital for another check.

6. At the breast clinic



A doctor or nurse will look at and feel your breasts to check the problem. You will need to take off your top and bra again.



You may need tests to help find out what the problem in your breast is. You might have a breast x-ray (called a mammogram) or an ultrasound scan.



The doctor may use a needle to take some cells from the breast.



You might have an injection first to make the area numb.



The doctor will look at the breast cells under a microscope.



You may need to go back to the clinic on another day to get your test results.

7. Who can get breast cancer?



Breast cancer is a disease that happens in some people's breasts.



Most people who get breast cancer are women aged over 50. But it can happen at any age.





Both women and men can get breast cancer.



Some people may get breast cancer if a lot of close relatives in the family have had breast cancer.

8. Having a breast x-ray

All women aged between 50 and 70 are invited for a breast x-ray (mammogram) every three years. This is called breast screening.

-  • Breast screening can help find breast cancer early, which is good.
-  • But sometimes it can mean having more tests or an operation that turn out not to be needed after all. Some people think this is not so good.

You can choose if you want to go for breast screening. Talk to someone you trust to help you decide.



You can visit the screening centre and see the x-ray machine before your appointment. The staff will answer your questions.



You will need to take off your top and bra for the x-ray. A woman called a radiographer will take the x-ray. It can be uncomfortable but it won't last long.



Afterwards the radiographer will tell you when you will get a letter with your results.

9. Keeping healthy



You may make your chance of getting breast cancer smaller by being healthy.



Don't eat too many fatty foods like crisps and cakes.



Do some exercise like walking or swimming two or three times a week.



Try not to drink too much alcohol.

And finally – get to know your breasts!

The Breast Cancer Care checklist



Look at and feel your breasts so you know what's normal for you.





Do this regularly to check for changes.



Tell your doctor as soon as possible if you notice anything.



Breast Cancer Care is a charity that gives free information and help to anyone who has breast cancer or is worried about their breasts.

UK Helpline  0808 800 6000
Text Relay  18001 0808 800 6000

You can look at our website too -
www.breastcancercare.org.uk

Central Office

Chester House
1-3 Brixton Road
London SW9 6DE
Phone: 0345 092 0800
Email: info@breastcancercare.org.uk

Thank you to all our models.
Photos posed by volunteers.

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Supporting people with learning disabilities to take care of their breasts

breast
cancer
care



Introduction

We hope this booklet will help you assist the person you support to be breast aware. It may also help you to be breast aware. If you would like further information on breast awareness or breast health for yourself or the person you support, visit www.breastcancercare.org.uk or call the Breast Cancer Care free Helpline on 0808 800 6000.

Why be breast aware?

Whatever our age, size or shape it's important we take care of our breasts. Breast cancer is the most common cancer in the UK, so it's important for everyone to look after their breasts by being breast aware.

Being breast aware is part of caring for our bodies. It means getting to know how our breasts look and feel so we know what is normal for us. We can then feel more confident about noticing any unusual changes.

Most changes won't turn out to be breast cancer, but if it is breast cancer, the sooner it's diagnosed the more effective treatment may be. Even though it's uncommon, men can also get breast cancer so they need to be breast aware too.

What you can do

If you can, try to talk to the person you support about checking their breasts. The accompanying book in this pack will help you explain how they can be breast aware and what to do if they have any questions or concerns. It explains what might happen if the person you support needs to go to the breast clinic and what happens when they are invited for breast screening.

You can reassure the person you support that most breast changes are not cancer. Most are caused by other reasons such as changes before a period or the breasts developing or ageing.

There are also changes that will be a benign (not cancer) breast condition. These can be easily treated or often won't need any treatment at all. But whatever the cause, it's important to see the doctor as soon as an unusual change is noticed. If you can't discuss being breast aware with the person you support, contact your health facilitation team or learning disability nurse for help.

Helping someone to be breast aware

The most important thing to know is that there is no right or wrong way for someone to check their breasts. The key thing is to encourage the person you support to get into the habit of regularly looking at and feeling their breasts if they are able to do so – ideally every four to six weeks. This time frame can help them get into a routine. They can then get to know how their breasts are normally and so notice any unusual changes.

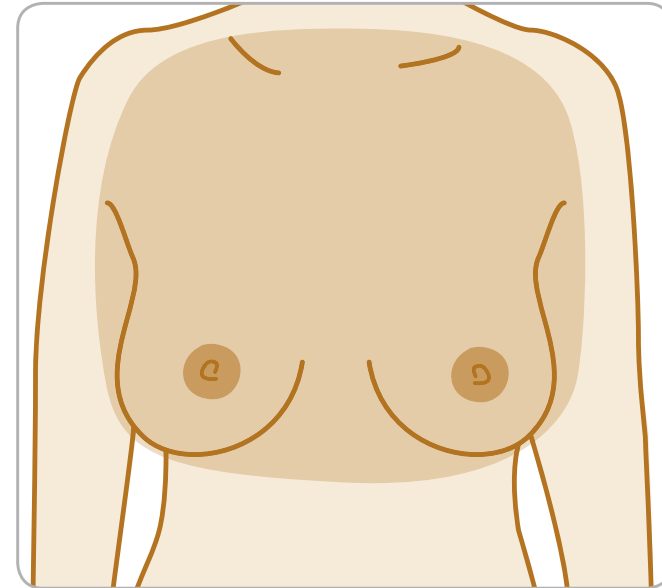
They could do this when washing by using a soapy hand. Another time could be when they are getting dressed, especially when putting on a bra or vest. Practising breast awareness in a private and safe place such as the bathroom or bedroom is important so that people feel comfortable and confident.

If the person you support isn't able to check their breasts on their own, try to look out for changes in the appearance of their breasts as you help them with washing and dressing. The changes to look for are pictured and described on the next pages. If it's helpful you can look at the pictures and explain the changes with the person you support.

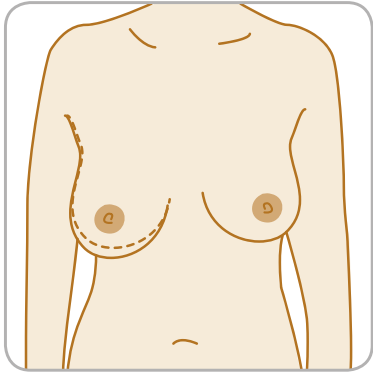
Only a doctor or specially-trained nurse should physically examine the person's breasts.

Changes to look and feel for

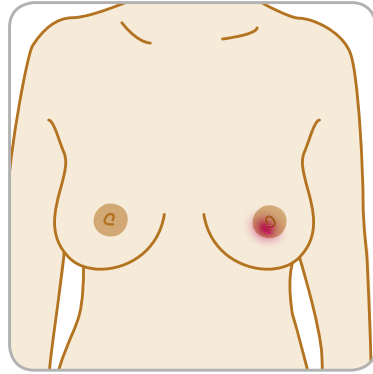
Everyone's breasts look and feel different. Some people have lumpy breasts, or one breast larger than the other, or breasts that are different shapes. Some have one or both nipples pulled inwards (inverted), which can be there from birth or happen when the breasts are developing. So try to be aware of any changes that are different or unusual.



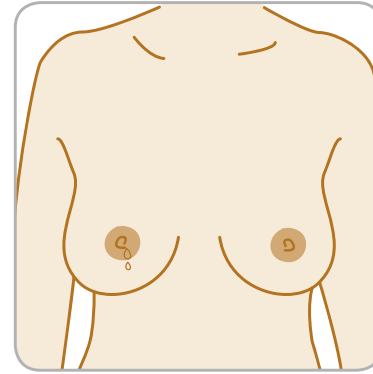
Check all parts of the breasts, the armpit and the chest area up to the collarbone.



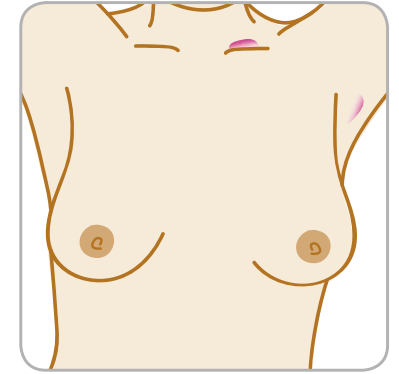
A change in size or shape



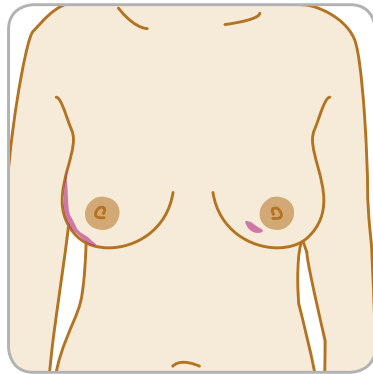
Redness or a rash on the skin and/or around the nipple



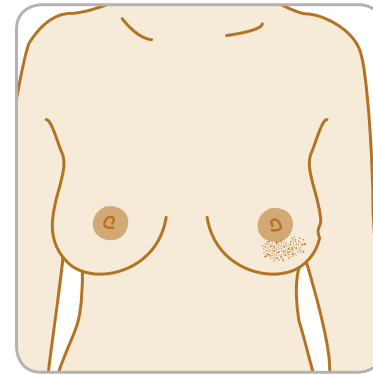
Discharge (liquid) that comes from the nipple without squeezing



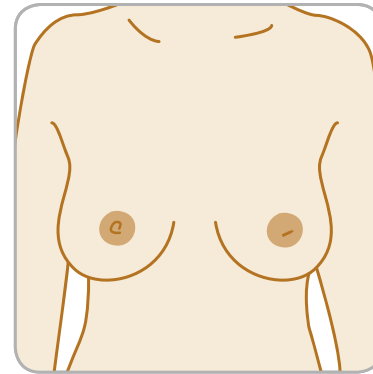
A swelling in your armpit or around your collarbone



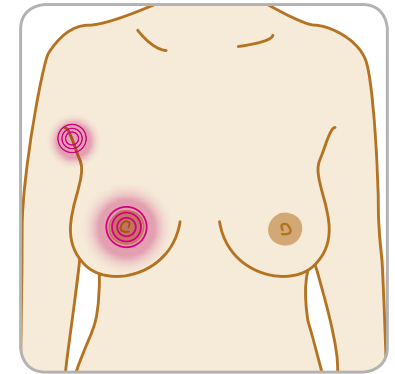
A lump or thickening that feels different from the rest of the breast tissue



A change in skin texture such as puckering or dimpling (like orange skin)



The nipple becoming inverted (pulled in) or changing its position or shape



Constant pain in the breast or armpit

Seeing the doctor

It's important for people with learning disabilities to have a health check at least once a year. During the health check you can ask the doctor to examine the breast area of the person you support if either of you are concerned. But don't wait until the yearly health check if there is a change that needs to be checked.

If the person you support needs to see the doctor about a breast change it's a good idea to be prepared so that you both get what you need from the appointment – the accompanying book that is for them will help. Importantly, if they are able to talk directly to the doctor, be there to support rather than speak for them. People with learning disabilities often complain that doctors talk to their supporter rather than to them.

- When you or the person you support make an appointment, you can ask to see a female doctor if either of you prefer.
- Write down any questions you would both like to have answered.
- Note down when and how the breast change was first noticed.
- The doctor will ask you or the person you support to describe what the problem is, plus any other changes that may have been noticed.

At the appointment, the doctor will ask a few questions. These could include:

- have there been any breast problems in the past?
- have any of the family had breast problems in the past?
- when was the last period? Are the periods regular?
- is there is any possibility of pregnancy?

The doctor will then ask permission to examine the breast area. This is done sitting or lying on an examination couch, usually behind a screen or curtain. If the doctor is a man he will ask for a woman to be present, perhaps the practice nurse or receptionist. The person you support will need to take off their top and bra. The doctor will ask you or the person you support to point out the change(s). They will examine both breasts and under the arms by touching and looking at them. This can sometimes be a little uncomfortable but will only take a few minutes.

After the examination the doctor will explain what they found and discuss the next steps. These may include:

- reassurance that changes are normal – they may ask you both to come back at a later date just to make sure everything is okay
- if the doctor thinks it's an infection, the person you support may be given antibiotics and have to come back in a week or so for a check-up
- if the doctor is uncertain about the cause of the change, they will want to have it checked out by a specialist at a breast clinic. The person you support shouldn't have to wait too long for an appointment; most people get seen within two weeks of seeing their doctor.

Try to make sure the doctor explains things in a way the person you support can understand, and that all questions are answered. It might be helpful to use the book that comes with this pack.

Going to the breast clinic

If the person you support is referred to a breast clinic, they are likely to have a triple assessment. This is

- a breast examination by a specialist
- a mammogram (breast x-ray) and/or ultrasound scan
- a possible biopsy to take some cells or a sample of breast tissue.

There is the option to come back later to have the biopsy once the procedure and the equipment have been explained.

If the person you support needs to have the biopsy, they are likely to get the results within a week. These are usually given at another appointment at the clinic or they may get a letter or a phone call saying no further action is needed. (If it's by phone the clinic can book an appointment to call so that you can be with the person you support if necessary.)

You can find out more from our [Your breast clinic appointment](#) booklet. You may also find our Benign breast conditions leaflets useful.

Being invited for breast screening

Breast screening (mammography/mammogram) is an x-ray examination of the breasts. It can detect breast cancer even before there are any obvious signs or symptoms. The sooner breast cancer is diagnosed the more effective treatment is likely to be.

All women are invited to have a mammogram every three years from the age of 50–70 (in England this age range may be extended to 47–73 in the future) as part of a national breast screening programme. The person you support should receive a letter from the screening service. If they haven't received a letter by the time they are 53, contact their doctor.

After the age of 70, a woman can continue to have breast screening every three years, but she (or her carer) will have to contact their breast screening unit and ask for it.

Your GP surgery can provide you with the contact details of your local breast screening unit or you can look this up online:

Scotland

www.nhsinform.co.uk/Screening/breast/screeningcentres

Wales

www.breasttestwales.wales.nhs.uk/screening-centres-in-wales

England

www.cancerscreening.nhs.uk/breastscreen/bsu-regions.html

Northern Ireland

www.cancerscreening.hscni.net/1965.htm

Why are women invited for breast screening?

Breast cancer is the most common cancer in the UK and the number of people diagnosed each year is rising. However, death (mortality) from breast cancer is falling. This is due to a number of factors such as earlier diagnosis, improved and newer treatment options and patients taking part in clinical trials. This may also be due to breast screening.

Is breast screening reliable?

Mammograms are the most reliable way of detecting breast cancer sooner but, like other screening tests, they're not 100% reliable. This can be because, for example, not all breast cancers can be seen on a mammogram, some breast cancers are very difficult to see or, very occasionally, the doctors reading the mammogram may miss the cancer, no matter how experienced they are.

Review of breast screening

There have been concerns in the past about women being able to make a well informed decision on whether to attend breast screening or not. This was because the information given to women invited to attend for breast screening by the National Health Service Breast Screening Programme (NHSBSP) did not explain the possible risks. So an independent review was set up to look at the benefits and risks of the NHSBSP. The review was published in 2012.

Below is information on the benefits and risks of breast screening. You can read more about the independent review on Cancer Research UK's website www.cancerresearchuk.org

What are the possible benefits of breast screening?

Going for breast screening will not prevent breast cancer from developing, but it can find a breast cancer sooner – before it can be felt. Invasive breast cancers (that have the potential to spread to other parts of the body) found through screening are more likely to be small and respond very well to treatment so that a mastectomy (removal of all the breast tissue including the nipple area) is not always needed.

The review of screening showed it prevented 1,300 deaths from breast cancer a year.

What are the possible risks of breast screening?

Having a mammogram can be a very uncomfortable experience for some women and can cause a lot of worry before an appointment.

Having a screening mammogram every three years means being exposed to a small amount of radiation, which can very slightly increase the risk of developing breast cancer in the future.

Breast screening cannot prevent cancer and it's possible for a cancer to develop in between each routine screening mammogram. This is called an interval cancer. When this happens the doctors will look at any previous mammograms to see if there was a change which may have been a cancer that was too small to notice at the time, or if this is a new finding. That's why it's important to continue to be breast aware and report any changes to your GP even if you've had a mammogram recently.

Mammograms can show an area of concern, which, after further investigations such as a biopsy, turns out not to be a cancer. This is called a false positive result.

Some cancers diagnosed through breast screening may not develop any further or may grow so slowly that they would never cause any harm during a woman's life. At the moment it's not possible for the doctors to tell which cancers can be left alone, so all cancers are treated. This means that some women will be given treatment that they didn't need. This is the main risk of screening. The screening review concluded that for every woman whose death was prevented by screening there would be around three women treated for breast cancer when it would never have become life threatening.

Some benign conditions diagnosed through screening cannot be confirmed by the mammogram alone. Further investigations and sometimes an operation may be needed to confirm the diagnosis. This can cause anxiety and fear as well as being painful and uncomfortable.

Because breast screening has risks as well as benefits you may need to help the person you support decide whether or not to go for the mammogram. If you would like further information to help you, talk to their doctor, practice nurse or to a breast care nurse at the local breast screening unit. Or visit www.cancerscreening.nhs.uk/breastscreen

You can also contact our freephone Helpline on **0808 800 6000**.

Going for a mammogram

Women may go to a mobile unit or to a screening centre for their mammogram. Most screening units are happy for women with learning disabilities to visit the centre and the room where the mammogram is done before the actual appointment.

Contact them to arrange a time to do this. Once there, ask the radiographer to show you both how the x-ray machine works and how the person's body needs to be positioned. If the person you support needs extra help with getting into position, you can both discuss the options with the radiographer at the same time.

The person you support needs to know that they will have to take off their top and bra when they have their mammogram. It should be explained that the radiographer will need to touch their breasts to put them in the right position, and that their breasts may feel quite uncomfortable during the mammogram but this will only last a short while.

Most screening units send out detailed information about having a mammogram with the invitation letter. Some screening units have information specifically for women with learning disabilities which you may both find helpful - contact them to find out.

Following the mammogram, a letter will be sent from the screening unit that will either ask the person you support to come back again for further investigation or say that they will be invited again in three years' time. Going for breast screening will not prevent breast cancer from occurring, so it's still important for them to be breast aware between their screening appointments and always go back to the doctor if there are any further worries or questions.

Who gets breast cancer?

Breast cancer is a common disease with 1 in 8 women developing it during their lifetime. We don't know exactly what causes breast cancer but we do know that being female and getting older are the main risk factors. To help reduce risk and look after our general health, it's important to try to:

- eat a well-balanced diet without too much saturated fat
- do regular exercise
- limit the amount of alcohol we drink.

Because breast cancer is common it's not unusual to have one or two people in an extended family who have had breast cancer. However, in a small number of families breast cancer may be caused by an altered gene (5% of all cases). For more information see our **Breast cancer in families** booklet.

Further reading

Books beyond words series

Books beyond words tell stories in pictures to help people with learning difficulties explore and understand their own experiences. They publish books and provide services for adults with learning disabilities, their family, carers, support workers and other professionals.
www.booksbeyondwords.co.uk

Easyhealth

Links to information for people with learning disabilities. Easyhealth was made so that people know where to find 'accessible' health information. 'Accessible' information is information that uses easy words with pictures.
www.easyhealth.org.uk
Tel: 020 8879 6333. Ask to speak to Jo or Mike.

Easy read health Wales

The Easy read health Wales website provides people with learning disabilities and their families with easy to read information on a wide variety of topics on health and wellbeing.
www.easyreadhealthwales.org.uk

NHS Fife

Going for a mammogram DVD - for women with learning disabilities
www.nhsfife.org/nhs/index.cfm?fuseaction=nhs.servicedisplay&objectid=DEF92B1B-02E6-5981-50D359280FE64710&OrgID=60304279-A856-11D6-BF4D0002A5349AC9

Other organisations

BILD - British Institute of Learning Disabilities

Easy read information.
www.bild.org.uk/easy-read/easy-read-information

Foundation for people with learning disabilities

They work with people with learning disabilities, their families and the people who support them.
www.learningdisabilities.org.uk

FAIR (Family Advice and Information Resource)

An information and advice service for people with learning disabilities, parents, carers and people who work with them in Edinburgh.
www.fairadvice.org.uk
General enquires: 0131 662 1962

Mencap

Provide information and advice for people with a learning disability, families and carers in the UK.
Find the right support and Mencap services in your area.
Helpline: 0808 808 1111 from 9am to 5pm, Monday to Friday
Email: help@mencap.org.uk
www.mencap.org.uk/mencapdirect

NHS Wales: Breast Test Wales

For women with a learning disability who would like to familiarise themselves with the equipment, staff and surroundings prior to being screened, special appointment arrangements can be made. To discuss the screening invitation visit the website for local unit contact details.
www.breasttestwales.wales.nhs.uk/women-with-a-learning-disability

We're here for you: help us to be there for other people too

If you found this booklet helpful, please use this form to send us a donation. Our information resources and other services are only free because of support from people such as you.

We want to be there for every person facing the emotional and physical trauma of a breast cancer diagnosis. Donate today and together we can ensure that everyone affected by breast cancer has someone to turn to.

Donate by post

Please accept my donation of **£10/£20/my own choice of £**

I enclose a cheque/PO/CAF voucher made payable to
Breast Cancer Care

Donate online

You can give using a debit or credit card at
www.breastcancercare.org.uk/donate

My details

Name

Address

Postcode

Email address

We might occasionally want to send you more information about our services and activities

Please tick if you're happy to receive email from us

Please tick if you don't want to receive post from us

We won't pass on your details to any other organisation or third parties.

Please return this form to Breast Cancer Care, Freepost RRRKZ-ARZY-YCKG, Chester House, 1-3 Brixton Road, London SW9 6DE



About this booklet

Supporting people with learning disabilities to take care of their breasts was written by Breast Cancer Care'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:

Phone **0345 092 0808**

Email **publications@breastcancercare.org.uk**



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Phone **0345 092 0808**

Email **publications@breastcancercare.org.uk**



When you have breast cancer, everything changes. At Breast Cancer Care, we understand the emotions, challenges and decisions you face every day, and we know that everyone's experience is different.

For breast cancer care, support and information, call us free on **0808 800 6000** or visit **breastcancercare.org.uk**

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