

# Supporting people with learning disabilities to take care of their breasts – a guide for supporters





# 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](http://www.breastcancercare.org.uk) or call the Breast Cancer Care 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 is 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 and 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 are benign (not cancer). 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. They can then get to know how their breasts are normally and so notice any unusual changes.

They could do this when getting washed by using a soapy hand or when drying themselves. 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.

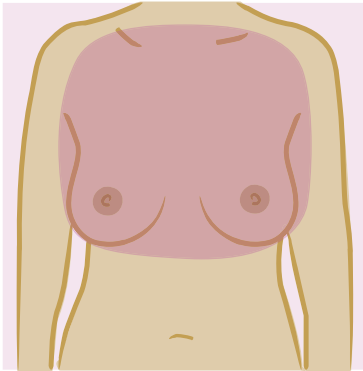
If the person you support isn't able to check their breasts on their own, try to look out for changes in the appearance of their breasts as you help them with washing and dressing. The changes to look for are pictured and described on the next pages. If it's helpful you can look at the pictures and explain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

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

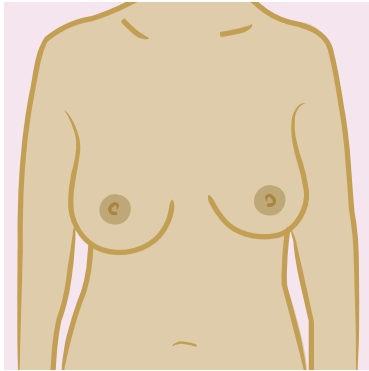
## Changes to look and feel for

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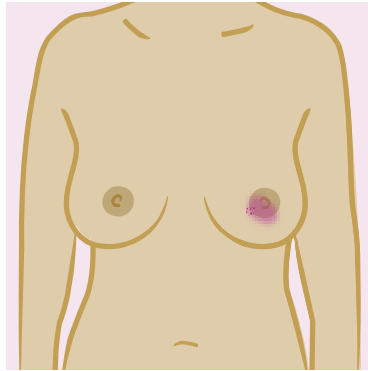
Everyone's breasts look and feel different. Some people have lumpy breasts, or one breast larger than the other, or breasts that are different shapes. Some have one or both nipples pulled inwards (inverted), which can be there from birth or happen when the breasts are developing. So try to be aware of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



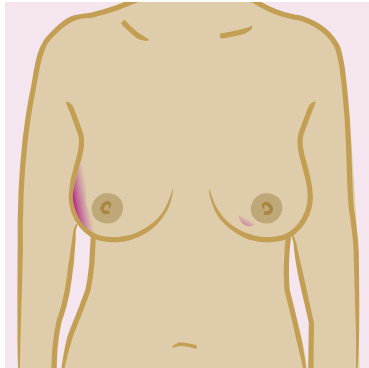
Check all parts of the breasts, the armpit and the chest area up to the collarbone.



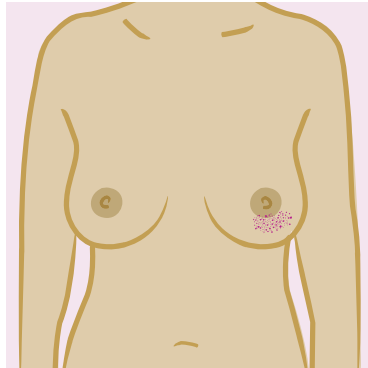
**A change in size or shape**



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

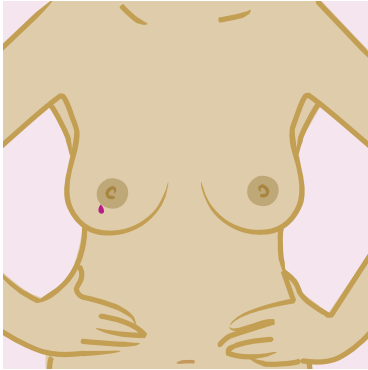


**A lump or thickening that feels different from the rest of the breast tissue**

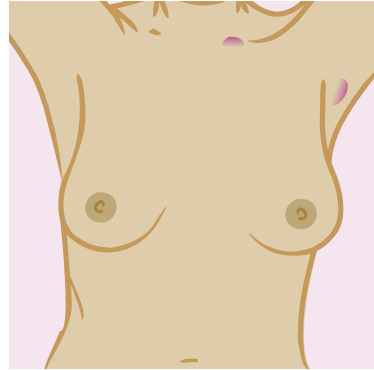


**A change in skin texture such as puckering or dimpling (like orange skin)**

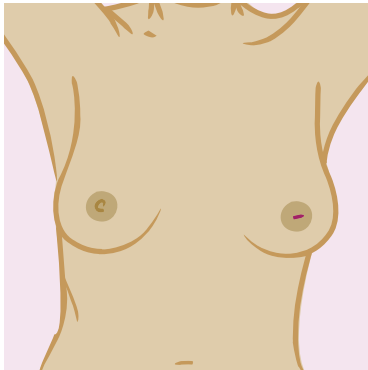




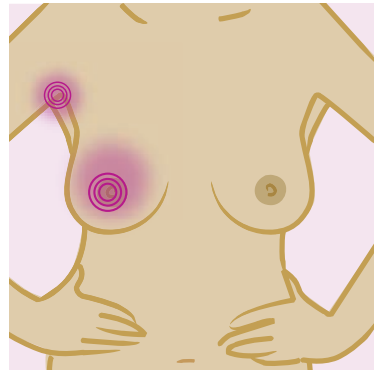
**Discharge (liquid) from one or both of your nipples**



**A swelling in your armpit or around your collarbone**



**If your nipple becomes inverted (pulled-in) or changes its position or shape**



**Constant pain in your breast or your armpit**



# Seeing the doctor

It is 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 annual 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 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 is 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 another breast examination by a specialist, a mammogram (breast x-ray) or ultrasound scan and possibly a 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) is an x-ray examination of the breasts. It may help to detect breast cancer before there are any signs or symptoms. The sooner breast cancer is diagnosed the more effective treatment may be.

All women are invited to have a mammogram every three years from the age of 50-70. (In England this age range is to be extended to 47 to 73 by the end of 2016.) 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, appointments can be requested every three years.

## Issues around screening

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Breast cancer is the most common cancer in the UK and the number of people diagnosed each year is increasing. But with earlier diagnosis and better treatment options fewer people are dying from breast cancer. Evidence suggests that breast screening has also contributed to this reduction. Breast screening will not prevent breast cancer from developing, but it can help find a breast cancer sooner, which means a better outlook is more likely. On the other hand, breast screening isn't 100% reliable – for example not all breast cancers can be seen on a mammogram and even the most experienced doctors may miss a cancer when reading the mammogram.

Some benign (not cancer) conditions diagnosed through screening need further investigations or an operation to confirm the diagnosis, which can cause a period of anxiety and some physical discomfort. Other conditions called DCIS (ductal carcinoma in situ) and pleomorphic LCIS (lobular carcinoma in situ) are more commonly diagnosed following screening but may never develop further, or may grow so slowly that they would never cause harm. However, in some cases these conditions can develop into invasive breast cancer (cancer that has the potential to spread to other parts of the body). Because of this uncertainty doctors will usually recommend treatment (including surgery) which can lead to some people being 'over-treated'. Our **Ductal carcinoma in situ (DCIS)** and **Lobular neoplasia** publications have more information about both these conditions.

Because breast screening has limitations 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](http://www.cancerscreening.nhs.uk/breastscreen)





## Going for a mammogram

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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 have information specifically for women with learning disabilities which you may both find helpful.

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 is still important for them to be breast aware between 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 is 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 a faulty gene (5-10% of all cases). For more information see our **Breast cancer in families** booklet.

This booklet is also available in large print, Braille or audio on request. Call **0845 092 0808** for more information.

**This booklet has been produced by Breast Cancer Care's clinical specialists and reviewed by healthcare professionals and members of the public.**

**If you would like a list of the sources we used to research this publication email [publications@breastcancercare.org.uk](mailto:publications@breastcancercare.org.uk) or call 0845 092 0808.**

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Email [cym@breastcancercare.org.uk](mailto:cym@breastcancercare.org.uk)

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Or to make a donation online using a credit or debit card, please visit [www.breastcancercare.org.uk/donate-to-us](http://www.breastcancercare.org.uk/donate-to-us)



Breast Cancer Care is here for anyone affected by breast cancer. We bring people together, provide information and support, and campaign for improved standards of care. We use our understanding of people's experience of breast cancer and our clinical expertise in everything we do.

We promote the importance of early detection of breast cancer and provide accurate answers to questions about breast health. We believe that up-to-date information, based on clinical evidence, builds confidence and helps people take control of their health. Our training, workshops and resources explain how to be breast aware and what changes to look and feel for.

Visit [www.breastcancercare.org.uk](http://www.breastcancercare.org.uk) or call our free Helpline on **0808 800 6000** (Text Relay **18001**). Interpreters are available in any language.

Calls may be monitored for training purposes. Confidentiality is maintained between callers and Breast Cancer Care.  
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