



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

Your breasts, your health



Why be breast aware?

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, but if you'd 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 helpline on 0808 800 6000.

Whatever our age, size or shape it's important we take care of our breasts. Breast cancer is now 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's 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 to be breast aware and what to do if they have any questions or concerns.

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 breast developing or ageing. There are also changes that are benign (non-cancerous). These can be easily treated or 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. They can help you to explain breast awareness. If the person you support doesn't currently have a learning disability nurse or any contact with the health facilitation team, you can ask your local social services department or your doctor for a referral.

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. They can then get to know how their breasts are normally and so notice any unusual changes.

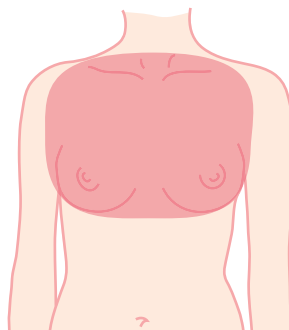
They could do this when getting washed by using a soapy hand or when dry using body lotion. Another time could be when they are getting dressed, especially when putting on a bra or camisole. Practising breast awareness in private and safe places such as the bathroom and bedroom is important so that people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

If the person you support is not 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.

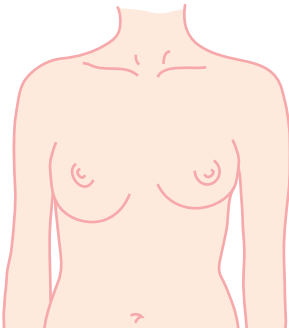
Remember that only a doctor should physically examine the person's breasts.

Changes to look and feel for

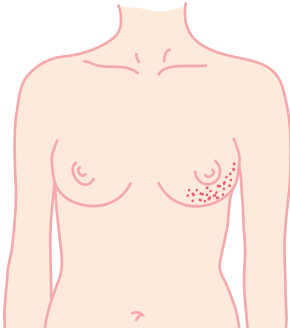
Everyone's breasts look and feel different. Some people have lumpy breasts, or one breast larger than the other, or breasts that are different shapes. Some have one or both nipples pulled inwards (inverted), which can be there from birth or happen when the breasts are developing. So try to be aware of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



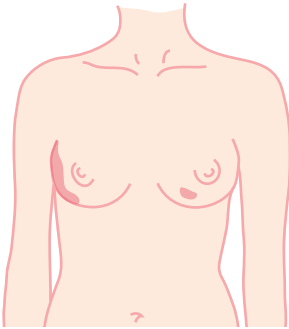
A change in size or shape



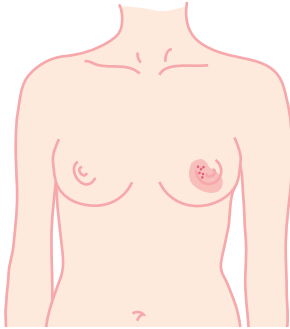
**A change in skin texture
such as puckering or dimpling
(like orange peel)**



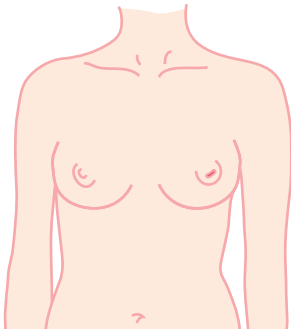
**A lump or thickening that feels
different from the rest of the
breast tissue**



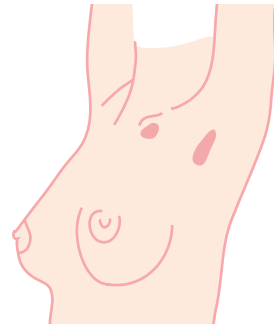
**Redness or a rash on the skin
and/or around the nipple**



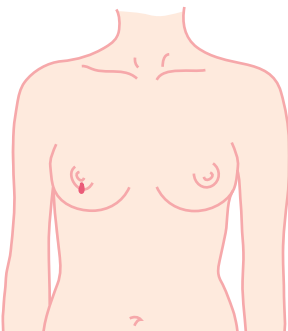
If your nipple becomes inverted (pulled-in) or changes its position or shape



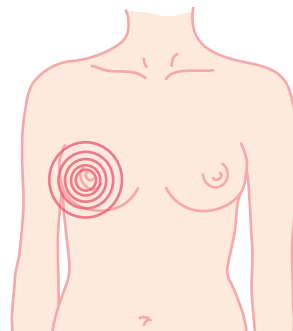
A swelling in your armpit or around your collarbone



Discharge (liquid) from one or both of your nipples



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 for a health check or about a breast change it's a good idea to be prepared so that you both get what you need from the appointment. Importantly, if the person you support is able to speak 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 you prefer.
- Write down any questions you would both like to have answered as well as any medicines or pills that the person you support is taking.
- If the appointment is because of a change in the breast area, write down when and how it 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? (This will depend on the age and health of the person you support.)

The doctor will then ask permission to examine the breast area. This is done sitting or lying on an examination couch behind a screen or curtain. If the doctor is a man he will ask for the practice nurse or learning disability nurse to be present. 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 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 couple of weeks. These may be given to them at the clinic at another appointment or they may get a letter saying that no further action is needed.

Being invited for breast screening

All women are invited to have a mammogram (breast x-ray) every three years from the age of 50–70. (Please note: this age range is to be extended to 47–73 in the future.) The person you support should receive a letter from the screening service. If they have not received a letter by the time they are 53, contact your doctor. After the age of 70 appointments can be requested every three years.

You may need to help the person you support decide whether or not to go for breast screening. 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

Women may go to a mobile unit or to a screening centre for the mammogram. Most screening units are happy for people with learning disabilities to visit the centre and the room where 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 understand that they will have to take off their top and bra when they have their mammogram. It should also be explained that their breasts may feel quite uncomfortable during the mammogram but this will only last a short while.

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 one in nine 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 you drink.

Many people believe breast cancer runs in families. Although it's not unusual to have one or two people in an extended family who have had breast cancer, in a small number of families breast cancer may be caused by a faulty gene (5–10 per cent of all cases). For more information see our **Breast cancer in families** booklet.

Central Office

Breast Cancer Care

5-13 Great Suffolk Street
London SE1 0NS

Telephone 0845 092 0800
Fax 0845 092 0820
Email info@breastcancercare.org.uk

Centres

London and the South East of England

Telephone 0845 077 1895
Email src@breastcancercare.org.uk

Wales, South West and Central England

Telephone 0845 077 1894
Email cym@breastcancercare.org.uk

East Midlands and the North of England

Telephone 0845 077 1893
Email nrc@breastcancercare.org.uk

Scotland and Northern Ireland

Telephone 0845 077 1892
Email sco@breastcancercare.org.uk

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

ISBN 978 1 907001 07 9

BCC163_B © Breast Cancer Care January 2008. This edition February 2010. All rights are reserved. No part of this publication may be reproduced, stored or transmitted, in any form or by any means, without the prior permission in writing of the publishers.

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

Photography: Philip Meech Photography. Thank you to all our models. Photos posed by volunteers.

Your donations allow us to provide publications like this one free. If you would like to make a donation, please send your cheque to:

**Breast Cancer Care,
RRKZ-ARZY-YCKG,
5-13 Great Suffolk Street,
London SE1 0NS.**

Or donate via our website at
www.breastcancercare.org.uk





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 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.

Registered charity in England and Wales 1017658
Registered charity in Scotland SC038104
Registered company in England 2447182

personal experience professional support