

Communications toolkit

Breast Screening Awareness Campaign – October 2017

Designed primarily for the 14 Transforming Care Partnerships, CCG's, Providers, GP practices, charities and advocacy groups across the south of England to assist in increasing awareness and uptake of breast screening amongst women with learning disabilities.

When Join the campaign this **October 2017** in conjunction with [Breast Cancer Awareness Month](#)

Why Women with a learning disability are far *less likely* than other women to attend breast screening. This might be because they do not understand why they should be screened, the invitation itself or are afraid of the screening process. Whatever the reason, we want to try and help address this by raising awareness and ultimately uptake of the test amongst women with learning disabilities.

The [latest data](#) on breast cancer screening for eligible female patients decreased in all age groups in both patients with and without a learning disability. Females aged 65 to 69 with a learning disability saw the largest decrease, from 54.6 per cent in 2014-15 to 52.3 per cent in 2015-16.

Thunderclap – sign up!

A thunderclap is scheduled for **Wednesday 18 October 2017** to highlight a short video. The video features nurses whose work has seen women with learning disabilities accessing screening *more* than other women. No mean feat given national [data](#) clearly indicates that across the rest of the country women with learning disabilities are *least likely* to attend.

[Sign up](#) today and encourage your stakeholders to sign up too!

Key messages

– All audiences

- As the likelihood of getting breast cancer increases with age, all women who are aged 50-70 and registered with a GP are automatically invited for breast cancer screening every three years. Sometimes younger women will be invited early.
- Women with a learning disability eligible for breast cancer screening are the least likely to attend.
- Females aged 65 to 69 with a learning disability saw the largest decrease, from 54.6 per cent in 2014-15 to 52.3 per cent in 2015-16
- About one in eight women in the UK are diagnosed with breast cancer during their lifetime.
- There is a good chance of recovery if breast cancer is detected in its early stages.
- Breast screening aims to find breast cancers early. It uses an X-ray test called a mammogram that can spot cancers when they are too small to see or feel.
- Don't wait – attending breast screening when invited because it can save your life.

– Women 50-70 with learning disabilities

- If you are aged between 50 and 70 years old and registered with a doctor you will be sent a letter about attending breast screening.
- Sometimes you might be invited when you are younger than 50.
- If you do not receive an invite to go for breast screening – talk to your doctor.
- Breast screening looks for cancer or lumps that might become cancer.
- Breast screening can stop you getting very ill and going to hospital.
- Your doctor or nurse will be happy to talk about breast screening – why you need it and what to expect.
- Your carer or a member of your family can go with you. You can also get extra time at your appointment. These are known as reasonable adjustments.

Video

In the UK, women with learning disabilities are the least likely to attend breast screening.

This [video](#) looks at what people in Cornwall are doing to change this. In fact, the work they have done in Cornwall to support women with learning disabilities attending breast screening has seen the number increase to above that of other women.

Find out how they have done this, what reasonable adjustments (changes to make things easier) have been used in Cornwall and how carers and family members can help women with learning disabilities.

All women aged 50 - 70 can have free breast screening. Some younger women will be invited early.

Suggested copy

– aimed at health and social care professionals

Support women with learning disabilities take care of their breasts

Breast cancer is the **most common cancer** in the UK and women with a learning disability eligible for breast cancer screening are the **least likely** to attend, even though it can save their life.

There are lots of reasons why this may be the case – fear, embarrassment or simply not knowing enough about the screening process. It could also be down to a lack of understanding, which is something you can help address.

Health and social care professionals have a duty to help this often overlooked, more vulnerable group of women receive equal opportunities to health and care interventions or treatment.

[Hear from colleagues](#) in Cornwall who have not only increased breast screening rates amongst women with learning disabilities, but increased rates to the point where women with learning disabilities are attending breast *more than* other women – a truly fantastic accomplishment.

Ensure you, your practice, organisation or colleagues are adhering to the [accessible information standard](#). It does not have to be onerous – use [readily available](#) easy read information and template invitation letters.

– aimed at carers and family members

Support women with learning disabilities take care of their breasts

Breast cancer is the **most common cancer** in the UK and women with a learning disability eligible for breast cancer screening are the **least likely** to attend, even though it can save their life.

There are lots of reasons why this may be the case – fear, embarrassment or not knowing enough about the screening process. Whatever the reason, we want to change this and need your help.

Help the person you care for understand why breast screening is so important, what it will be like on the day and how it will help them stay well. Share or read through [an easy guide to breast screening](#) with them or look at this [breast cancer and breast screening](#) information. There are also leaflets which show you how to [check your breasts](#). You can even order a [free reminder sticker](#) to put in the shower.

If it is hard to talk to the person you care for then speak to their doctor or a nurse at their GP practice. They will be able to help by providing easy to understand information, including easy read or can talk them through it during an appointment. You can even request extra time at appointments. This is known as a reasonable adjustment (change to make things easier).

Sometimes it is a small thing or simple reasonable adjustment which helps women with a learning disability attend breast screening. Hear from Sharon and Deborah, Learning Disability nurses in Cornwall, talk about how they have helped lots of women with learning disabilities attend breast screening when invited.

– aimed at women with learning disabilities

Whatever you call them, you need to look after them.

All women aged between 50 and 70 and registered with a doctor can have breast screening.

Make sure you are registered with a doctor and on the doctor's learning disability register to get the very best healthcare.

Women who can have breast screening will be sent a letter inviting them to an appointment. If you have not got a letter but are aged between 50 and 70 years old talk to your doctor or a nurse about looking after your breasts.

If you have received a letter inviting you to an appointment but do not understand it your doctor or a nurse will be able to help.

Read this [easy guide to breast screening](#) or look at this [breast cancer and breast screening](#) information with a member of your family, your carer or friend.

Breast screening takes a special picture (x-ray) of your breasts. It is taken to look for anything that might turn into cancer. You need to have the test every 3 years. The x-ray is normally done at a breast screening unit.

Your doctor or nurse will be happy to talk to you about breast screening. They can explain why you need it and what to expect. Your carer or a member of your family can go with you to the appointment. You can also get extra time at your appointment.

Going for breast screening can stop you getting very ill. In-between your breast screening appointments you can [check your breasts](#).

Graphics

The following four graphics can be used to accompany your print or online copy. Download the correct size graphic via the [resource hub](#).

Help make
breast screening
more accessible.





Support women with
learning disabilities
to take care of
their breasts.



Women need
to take care of
their breasts.



Whatever you call them.
You need to check them.



Suggested social media messaging

Twitter – change the Twitter handles to local organisations/partners/charities/advocacy groups or other stakeholders to encourage their involvement and support

- Carers can help women with learning disabilities access breast screening <https://youtu.be/qd9dYvNhsBY> #LDBreastTalk @LDCcommunity @CarersUK



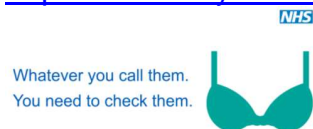
- This #BreastCancerAwarenessMonth help women with learning disabilities <https://youtu.be/qd9dYvNhsBY> #LDBreastTalk @WeLDnurses @LearningDisEng



- All women aged 50-70 (sometimes younger) can have free breast screening. Check yours and stay well [http://www.easyhealth.org.uk/listing/breasts-\(leaflets\)](http://www.easyhealth.org.uk/listing/breasts-(leaflets)) #LDBreastTalk



This #BreastCancerAwarenessMonth learn how to check your breasts by using easy read leaflets [http://www.easyhealth.org.uk/listing/breasts-\(leaflet\)](http://www.easyhealth.org.uk/listing/breasts-(leaflet)) #LDBreastTalk



Facebook

- We're urging carers to help women with learning disabilities access breast screening. If you care for a woman aged 50 or over, it's important that you watch this video <https://youtu.be/qd9dYvNhsBY> #LDBreastTalk



- Women with learning disabilities deserve the same level of access to screening services. Let's make a difference this #BreastCancerAwarenessMonth <https://youtu.be/qd9dYvNhsBY> #LDBreastTalk



- Regular breast screening can help doctors find breast cancer early. The earlier breast cancer is found, the better the chances of surviving it. If you are aged 50-70, make sure you attend breast screening when invited. #LDBreastTalk



- About 1 in 8 women in the UK are told they have breast cancer during their lifetime. This #BreastCancerAwarenessMonth learn how to check your breasts by using easy read leaflets [http://www.easyhealth.org.uk/listing/breasts-\(leaflet\)](http://www.easyhealth.org.uk/listing/breasts-(leaflet)) #LDBreastTalk

Existing resources to utilise locally – including easy read and templates

Resources used or developed by colleagues in Cornwall to increase uptake include:

- Easy read invitation letter for women with learning disabilities – available on the [resource hub](#)
- Changes in the breasts – word document including images – available on the [resource hub](#)
- NHS Health Scotland: Keep Yourself Healthy – A Guide to Examining Your Breasts (Easy Read) – available on the [resource hub](#)
- [Going for a Mammogram video](#) – for women with learning disabilities
- Leaflet: [My Boobs and Me! How are my boobs today?](#)

Breast Cancer Care

- [Your breasts, your health](#) – This resource is designed to help people with learning disabilities be breast aware, with the support of their carer. We want to help people feel safe and confident about checking their breasts, and to seek help early if they are worried.
- [Taking care of your breasts – mini guide](#)
- [What happens at a Breast Clinic?](#)
- [Not just a lump poster - general A3](#)
- Request and download all Breast Cancer Care resources [online](#)

Public Health England – [An easy guide to breast screening](#)

Coppafeel

- Coppafeel free stickers for the [shower](#) or [car](#)
- Coppafeel [poster - boobies, do you know yours?](#)
- [Request monthly text reminders](#) for yourself or a loved one

Easy Health

- [Breast cancer and breast screening](#)
- [Breast cancer and how to spot it](#)
- [Breast screening](#) - A leaflet by the Foundation for People with Learning Difficulties, Prodigy and Easyhealth.

Be Clear on Cancer

- [Easy Read breast cancer leaflet](#)
- [Large print breast cancer leaflet](#)
- Video: [Breast cancer in over 70s - British Sign Language leaflet](#)

Tell your local story

Access the latest data in order to develop a press release which reflects the local picture in your patch:

- [Health and Care of People with Learning Disabilities: 2015-16](#)
- [Prevalence rates - broken down by CCG](#)

Case studies

The following short case studies – inspired by real women – can be shared to illustrate the small, often simple adjustments which can be made by health and social care professionals to increase the number of women with learning disabilities attending breast screening.

The examples also include how family members and carers can assist, the importance of peer support and how in some cases further investigation is required but again, can be managed to support the woman with learning disabilities access treatment.

Families and carers are vital

The lasting impact of an ill-planned screen for a lady with learning disabilities can be hard to undo. This happened to Sally, a lady with learning disabilities whose last breast screening was scary, rushed and as a result – unsuccessful.

Liaison nurse Sharon went to visit Sally to encourage and support her to attend again, but Sally was clearly too anxious to even talk about it. However through spending time and working with Sally's family, Sharon soon realised how close Sally is to her niece, and while talking about breast screening was too nerve-wracking for Sally, hearing it from her niece was ok. Giving Sally information in a format she could understand, via her niece, helped her realise why it is so important.

A newly informed Sally and her family were prepared to try again. Sharon set about organising reasonable adjustments (change to make things easier) on the day and ahead of the appointment Sharon asked the radiographer to book out extra time. She also told her about Sally's love of cream teas – drinking and eating them, but also looking at pictures.

With this in mind, on the day of the screening the radiographer greeted Sally and her family with cups of tea. In addition Sally's niece was allowed in the room during her screen, while her mum stood reassuringly just outside room.

Meaningfully involving the family early on also highlighted how unsteady Sally is on her feet. This allowed staff to plan ahead with a chair made available for Sally to sit on while she was screened.

Spending a bit more time with Sally and her family resulted in a successful screen. Importantly Sally left the screening unit happy and confident to return when invited next. The day was finished with cream teas all round!

The importance of peer support

Don't underestimate the power of women. Women can and should inspire and encourage other women to attend breast screening.

Often ladies with learning disabilities report to hearing scary stories about breast screening from their friends or other women. Often this is why they say they have not and do not want to attend breast screening when invited.

This happened to June. June had been told some negative things about the process of breast screening from somebody she trusted. The things she had been told were not strictly true, but had put her off attending.

To help June attend and get screened the liaison nurse encouraged her to go with a trusted friend. On the day June's friend went first and once it was done she told June it was fine. The negative things she had heard were not true. This gave June the courage to have hers done. Both ladies were successfully screened and went away thinking it was not nearly as bad as they thought it would be.

If June had not been told the negative things she might have been screened sooner.

Women need to support other women.

A simple reasonable adjustment can make all the difference

Margaret is a very anxious lady who often does not leave the house other than to go shopping with her support workers. Talking about breast screening was extremely worrying, but she did want to talk to the liaison nurse about her wedding photos. It soon became clear just how important, comforting and reassuring her wedding photos were to her. The liaison nurse spent a lot of time looking through the wedding album with Margaret before talking about breast screening and how the radiographers would no doubt love to see her photos too. The idea of showing her photos to other people filled her with pride and she agreed.

Allowing extra time at the appointment for Margaret to show the radiographer her photos put her at ease, which allowed the radiographer to talk her through the screening process and why it is important. This little bit of extra time, care and compassion resulted in a successful breast screening for Margaret.

Providing much-needed support for further investigations

Doreen had successfully been screened with the support of a liaison nurse. The screen showed something which needed further investigation – a worrying prospect for any lady.

The radiographer knew this could be very worrying for Doreen so before sending her a letter, she contacted the local liaison nurse. The liaison nurse could visit Doreen and explain everything instead of her receiving a letter she might not completely understand, leaving her confused and worried.

The further investigations were going to be trickier for Doreen to cope with so lots of time went into preparing her. The liaison nurse showed her pictures of the procedures, explained what to expect and importantly why she needed the further investigations.

Preparation and the trusted support of the liaison nurse resulted in the lady attending the follow-up clinic and having her biopsy without upset – a real success story!