

Barnet, Camden, Enfield, Haringey and Islington

Helping people with learning disabilities to attend a cancer screening



A guide for family carers and support workers



What this leaflet is about

Do you support or care for a person with learning disabilities?

Do they find it challenging to attend medical appointments or participate in tests such as cancer screenings?

Data has shown that people with learning disabilities are less likely to participate in cancer screening programmes than the general population. This leaflet can help you to talk to a person with learning disabilities about cancer screening so that they can decide whether to participate when they are invited.

A cancer screening is a test which can help to detect cancer in its early stages or before it develops. This leaflet is about screening for bowel, breast and cervical cancer.



Easy-read information leaflets are also available to explain why it is important to attend a screening and what happens during a cancer screening. There are web links to easy-read information throughout this leaflet.



Supporting a person with learning disabilities to attend a cancer screening

A person with learning disabilities may find it challenging to attend a cancer screening appointment. There are reasonable adjustments that can improve their experience.

These are simple changes that healthcare providers can make to improve access to healthcare services. Reasonable adjustments are also a [legal right](#).

A person with learning disabilities can ask for the following [reasonable adjustments](#):

- Longer or “double” appointment times if they need more time with a doctor or nurse to make sure they understand the information and procedure.
- A preferred appointment slot, e.g. later or earlier in the day, if they find it difficult to wait in their GP surgery or hospital.
- To bring their family carer or support worker to appointments.
- Information in easy-read format to help explain the procedure. There are web links in this leaflet, or you can ask your GP to print a copy.
- Wheelchair or suitable access to the GP surgery or screening unit.
- A quiet place to wait or a private room.
- Help from a learning disability nurse.
- A telephone call from a healthcare clinician to answer any questions before or after the appointment.



Did you know that...

98 out of 100 people do not need further tests after completing their bowel screening test?



Breast screening saves around

1,300

lives a year?



You can do the bowel screening test **at home?**



Cervical screening checks for the **virus HPV** (human papillomavirus) and cell changes in the cervix?



NHS cancer screening programmes

The NHS cancer screening programmes are **free** for all eligible people registered with a GP. Eligible people will receive an invitation letter, text message or phone call to attend a cancer screening. The screening might be at your GP Surgery, a hospital, an NHS mobile unit or using a home-testing kit.

It is important to encourage and help people with learning disabilities to attend their screening when they are invited. Here is some information on the screenings that they might be invited for.

Bowel cancer screening




Regular bowel cancer screening can help prevent bowel cancer or find it at an early stage. **Bowel cancer is the fourth most common type of cancer.**

By 2024, everyone aged 50-74 who is registered with a GP, will be invited for a bowel screening. They will be sent an NHS bowel cancer screening kit every 2 years.

The kit used in England is the faecal immunochemical test kit – known as the FIT kit. You collect a small sample of poo on a plastic stick, put it into the sample bottle and post it to a lab for testing.

There are instructions that come with the kit. There is also an NHS bowel cancer screening film which shows you how to collect the sample for testing.

 You can visit this website to watch the video:
• www.nhs.uk/conditions/bowel-cancer-screening

The NHS bowel cancer screening test is usually done at home. Samples should then be posted in any post box to the lab for examination. A visit to the hospital or screening unit is not needed unless additional support is required, or the person you care for is asked to attend for further tests. If you need to order a new kit for the person you care for, you can call the freephone number 0800 707 60 60.

More information on bowel cancer screening can be found here:

- www.gov.uk/government/publications/bowel-cancer-screening-easy-guide
- www.booksbeyondwords.co.uk/resources-dl



Breast cancer screening



NHS breast screening uses X-rays to look for cancers that are too small to see or feel. The screening is sometimes called a mammogram.

Anyone registered with a GP as female will be invited for NHS breast screening every 3 years between the ages of 50 and 71. Most breast cancers are diagnosed in women over 50 years old.

Breast cancer is the most common type of cancer in the UK. Finding cancer early can make successful treatment more likely. You can have breast screening whatever the size or shape of your breasts.

More information on breast screening can be found here:

- www.gov.uk/government/publications/breast-screening-information-for-women-with-learning-disabilities
- www.breastcancernow.org/information-support/facing-breast-cancer/how-support-someone-breast-cancer/supporting-people-learning-disabilities

Booking a breast screening appointment:

If the person you care for or support has received an invitation for breast screening, you can help them to book an appointment by calling the Breast Screening Service:

020 3758 2024



Where to go for your breast cancer screening

- **Edgware Community Hospital**



Deansbrook House, Edgware Community Hospital,
Deansbrook Road, Edgware, Middlesex HA8 9BA.
Report to hospital reception desk.

- **Finchley Memorial Hospital**



Granville Road, London N12 0JE.
Report to hospital reception desk.

- **Forest Primary Care Centre**



308A Hertford Road, London N9 7HD.
Report to reception desk.

- **Kentish Town Health Centre**



2 Bartholomew Road, London NW5 2BX.
Very limited disabled street parking.

- **Sainsbury's (Kenton)**



1 Nash Way, Harrow HA3 0JA.
Mobile screening van in Sainsbury's car park.

- **North Middlesex Hospital**



Sterling Way, London N18 1QX.
Mobile screening van located near hospital car
park off Bull Lane.

- **Potters Bar**



Furzelefield Leisure Centre, Mutton Lane,
Potters Bar, Herts EN6 3BW.

Wheelchair users are advised to call the service to ensure that X-ray machines are wheelchair compatible.

Cervical cancer screening



Cervical screening helps prevent cervical cancer by checking for a virus called high-risk HPV (human papillomavirus) and cervical cell changes. **It is not a test for cancer, but it does identify if you need early care or treatment.**

The test is usually carried out by a nurse in the GP surgery. They will use a small hollow cylinder, called a speculum, to see the cervix. They then use a small brush to gather some cells from the cervix for testing.

Cervical screening is the best way to protect against cervical cancer and prevents over 7 in 10 diagnoses. People between the ages of 25 and 64 and registered as female with their GP surgery, will be automatically invited for cervical screening.

More information on cervical screening can be found here:

- www.gov.uk/government/publications/cervical-screening-supporting-women-with-learning-disabilities
- www.jostrust.org.uk/information/cervical-screening/cervical-screening-learning-disability
- www.eveappeal.org.uk/news-awareness/top-tips-for-talking-gynae/easy-read-tips-for-gynae-health-appointments/

Booking a cervical screening appointment

Eligible patients will receive a letter inviting them to make an appointment for a screening at their GP practice. If the person you care for or support is eligible and has not received an invitation or is overdue for their next screening, you can help them to contact their GP practice.



Cancer screening films

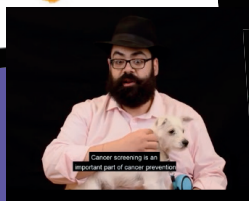
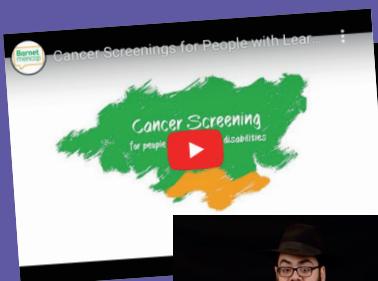
It might be helpful for a person with learning disabilities to watch a short film about taking part in a cancer screening.

There are films about people with learning disabilities experiences of receiving cancer screening invitations. There are separate films on bowel, breast and cervical cancer screening. Each film explains the symptoms of bowel, breast or cervical cancer and why it is important to participate in a screening when you are invited.

The films explain what happens during a cancer screening and what equipment is used for each procedure. This can help people to make their decision about attending a screening and help them to prepare for the screening itself.

Cancer screening films

▶ You can watch films on the Barnet Mencap website:
• www.barnetmencap.org.uk/cancerscreeningpack



▶ For those individuals that have high needs and don't have the capacity to consent then this decision should be looked at by people who know them well



Test your knowledge about cancer screenings

1. How often should you carry out a bowel cancer screening test?

Once a year

Once every two years

Once every three years

2. What is the name of the machine used to examine your chest during a breast cancer screening?

Ultrasound

MRI Scan

Mammogram



3. How long does it take to collect a cervical screening sample?

10 minutes

30 seconds

5 minutes

4. How often will you be invited for a breast cancer screening?

Twice a year

Once every 3 years

Once every 5 years

Now check your answers below!

Quiz answers

1. Once every two years

3. 30 seconds

2. Mammogram

4. Once every three years

This leaflet has been produced by Barnet Mencap, North Central London Cancer Alliance, Barnet Council, North Central London Integrated Care System, and Barnet, Camden, Enfield, Haringey and Islington Community Learning Disabilities Teams, and carers centres.