



## How social care staff can support people with learning disabilities to take part in screening programmes

### National screening programmes



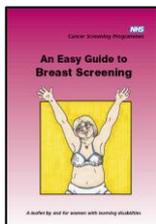
Screening programmes<sup>1</sup> can detect health problems early, before any symptoms are seen.

Finding out about a problem early can mean that treatment is more effective.

People with learning disabilities have as much right to take part in screening programmes as other people. They may need support to help them take part.

In order to receive an invitation for screening a person needs to be registered with a GP practice.

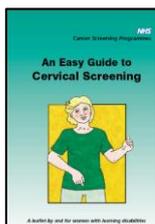
### Cancer screening



**Breast screening** is currently offered to all women aged 50 to 70 to detect early signs of breast cancer. The service is currently being extended to include all women aged 47 to 73.

The breast screening service takes an X-ray (mammogram) that can spot changes in the breast that might turn into cancer. It will also pick up cancers when they are too small to see or feel. Mammography is carried out at special clinics or mobile breast screening units by female radiographers.

Women need to know what the screening involves. Can the woman talk to someone she knows well who has had breast screening? There is a lot of easy read information and films<sup>2</sup> that can be used to help prepare women.



**Cervical screening** (also known as a smear test) is offered to women aged 25 to 64 to check the health of cells in the cervix. It is offered every three years for those aged 26 to 49, and every five years from the ages of 50 to 64.

Cervical screening picks up changes to the cells in the cervix that may turn into cancer. It is usually carried out by a practice nurse at the GP surgery.

The programme covers women whether or not they are sexually active as either can develop cervical cancer.

There is a film<sup>3</sup> about cervical screening that aims to give women and their carers information about smear tests.

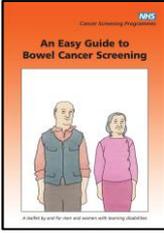
### **Bowel cancer screening**

A testing kit is sent to men and women aged 60 to 74 every two years at their home. This kit is used to collect small poo samples to send off to a laboratory to test for blood.

Blood in the poo can be a sign of many problems including cancer or polyps in the bowel that may turn into cancer.

There is an additional one-off test called bowel scope screening. This is offered to men and women at the age of 55. It involves a doctor or nurse using a thin, flexible tube with a tiny camera on the end to look inside the lower part of the bowel. This test also looks for cancer and polyps in the bowel that may change into cancer.

People with learning disabilities may need help to complete the home testing kit. They might be help with filling in the form or with collecting their sample. There is a set of films<sup>4</sup> about bowel cancer screening which includes advice on how to collect a stool sample.



### **Diabetic retinopathy screening**

People with diabetes may have problems with their eyes. Everyone with diabetes (aged 12 and over) should be sent an annual invitation for screening. If someone you support has diabetes and has not been invited for screening you should speak to their GP.

The screening test looks for damage to the blood vessels in the eyes. If damaged blood vessels are left untreated it may cause loss of vision and blindness.

The screening should take less than 45 minutes. The person will need to have drops put in their eyes and to sit still while photos of their eyes are taken. There is easy read information about the process here<sup>5</sup>.

Someone should go with the person when they have their screening. It is a good idea to take some sun-glasses as for a couple of hours after the test bright light might make their eyes uncomfortable.



### **Abdominal aortic aneurysm (AAA) screening**

AAA screening is available for all men aged 65 and over in England and is a way of detecting a dangerous swelling (aneurysm). The screening process involves an ultrasound scan of the abdomen. It is quick and painless and the results are provided straight away.



If the results are normal the person will never need to be tested again.

If there is a small to medium aneurysm, they will need to be regularly monitored.

If there is a large aneurysm, they will need to be seen by a specialist within two weeks to look at treatment.

There is [easy read information about the process](#)<sup>6</sup>.

## The Mental Capacity Act

In order to make a decision about taking part in screening people need information that they can understand. This should tell them what the benefits of having the screening are and what will happen to them when they have the screening.



If the person does not have capacity to take the decision then a best interests decision should be made.

The health professional responsible for carrying out the screening becomes the decision maker about whether the screening should be done, not the support worker or family members. It is important to speak with the screening team to discuss how a best interests decision can be made. A support worker should not decide on behalf of the person they are supporting not to have screening, or to not respond to the screening invitation.

When the screening is painless and not invasive it will generally be in the person's best interests to take part. This is the case for AAA screening and the bowel screening home test kit. There should be a record of how the best interests decision is reached.



In the case of bowel screening people who know the person well can make a best interest decision to complete the home test kit for them.

If the people who know them well do not feel that it would be in their best interests to complete the kit they should contact the persons GP to talk this through as the decision not to participate is a serious decision.

For more invasive screening a formal best interests process should be followed by the decision maker. You may need to advocate for the person you are supporting that this needs to happen.



There is a Public Health England [report](#)<sup>7</sup> with links to lots of resources about cancer screening.

Further information about all of these screening programmes, as well as resources to support people to take part in them are in this screening services strategy and [toolkit](#).<sup>8</sup>

## Key messages:

- people with learning disabilities are less likely to take part in national screening programmes than other people
- social care staff should support people with learning disabilities to access screening services
- there are lots of resources to use to help with this
- people should be given accessible information to help them understand what the screening involves and to choose if they want to take part, where possible
- if they do not have the capacity to decide if they want to take part then there should be a best interests decision taken about this

This is the eighth in a series of health factsheets for social care staff. You can find others and more [guidance](#) for social care providers.

There is a [supporting set of slides](#) for this document that can be used by social care staff as a training resource.

The pictures in this factsheet are from Photosymbols: [www.photosymbols.co.uk](http://www.photosymbols.co.uk)

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<sup>1</sup> <http://www.nhs.uk/Livewell/Screening/Pages/screening.aspx>

<sup>2</sup> <https://www.youtube.com/watch?v=HphkoUbfNQQ&t=1s> (part one of six short films)

<sup>3</sup> <http://www.jostrust.org.uk/videos/smear-test-film>

<sup>4</sup> [http://www.easyhealth.org.uk/listing/bowel-and-bladder-\(videos\)](http://www.easyhealth.org.uk/listing/bowel-and-bladder-(videos))

<sup>5</sup> [https://www.seeability.org/uploads/files/PDFs\\_Books\\_Easy\\_Read\\_/Diabetes\\_eye\\_screening.pdf](https://www.seeability.org/uploads/files/PDFs_Books_Easy_Read_/Diabetes_eye_screening.pdf)

<sup>6</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/627207/AAA01\\_easy\\_read\\_final\\_July\\_2017.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/627207/AAA01_easy_read_final_July_2017.pdf)

<sup>7</sup> <http://webarchive.nationalarchives.gov.uk/20160704153141/http://www.improvinghealthandlives.org.uk/gsf.php5?f=313998>

<sup>8</sup> <http://www.ndti.org.uk/publications/ndti-publications/screening-services-strategy-and-toolkit/>