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Guidance

Supporting women with learning disabilities to access cervical screening

Updated 23 April 2019

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This publication is available at <https://www.gov.uk/government/publications/cervical-screening-supporting-women-with-learning-disabilities/supporting-women-with-learning-disabilities-to-access-cervical-screening>

1. Overview

Cervical screening (also known as the smear test) helps prevent cervical cancer. It detects abnormal changes to the cervix so they can be monitored or treated before they get a chance to turn into cervical cancer.

Cervical screening should be offered to all women and people with a cervix aged 25 to 64.

It is offered:

- every 3 years for those aged 25 to 49
- every 5 years for those aged 50 to 64

See NHS population screening: information for transgender people

(<https://www.gov.uk/government/publications/nhs-population-screening-information-for-transgender-people>) for information on access to cervical screening for trans and non-binary people.

Evidence

(http://webarchive.nationalarchives.gov.uk/20180328130852tf_/http://content.digital.nhs.uk/catalogue/PUB22607/Health-care-learning-disabilities-2014-15-summary.pdf/) has shown that screening uptake is lower in people with learning disabilities (<https://www.nhs.uk/conditions/learning-disabilities/>) compared to the general population.

The Public Health England (PHE) screening inequalities strategy

(<https://phescrining.blog.gov.uk/2018/05/24/mind-the-gap-phe-screenings-inequalities-strategy-launches-today/>) explains how we are working with others to remove gaps in services that prevent everyone being able to access screening.

Health professionals should use this information and resources to help women with learning disabilities better understand cervical screening and take part if they choose to.

2. Resources

There are resources for health professionals (<https://www.gov.uk/government/collections/reasonable-adjustments-for-people-with-a-learning-disability>) to help improve healthcare access, including guidance for health professionals, social care staff and family members to help someone with learning disabilities to be screened for cancer (<https://www.gov.uk/government/publications/cancer-screening-and-people-with-learning-disabilities>). Health services should be aware that it is a legal duty (<https://www.gov.uk/government/publications/reasonable-adjustments-a-legal-duty/reasonable-adjustments-a-legal-duty>) to make reasonable adjustments (<https://www.gov.uk/government/publications/reasonable-adjustments-a-legal-duty/reasonable-adjustments-a-legal-duty#what-we-mean-by-reasonable-adjustments>) for people with learning disabilities.

Clear, concise, easy to understand information helps support communication and understanding.

2.1 Cervical screening easy guide

The PHE easy guide to cervical screening (<https://www.gov.uk/government/publications/cervical-screening-easy-read-guide>) explains cervical screening to help individuals with learning disabilities decide if they want to attend. Some people without a learning disability may also prefer the easy guide format.

Local cervical screening providers should download and print off this leaflet in colour for people identified by primary care as needing information in an easy read format.

2.2 Easy read invitation letter template

We have also developed an editable easy read version of the cervical screening invitation letter.

Local screening providers should use this template to invite eligible people identified by primary care as being known to have a learning disability. They should send the easy read invitation letter along with the easy guide instead of the standard national invitation letter and the helping you decide leaflet (<https://www.gov.uk/government/publications/cervical-screening-description-in-brief>).

2.3 Other resources

Jo's Cervical Cancer Trust has materials including an online video (<http://www.jostrust.org.uk/videos/smear-test-film>).

3. Overcoming barriers to screening

There are a number of factors affecting cervical screening uptake among women with learning disabilities.

The following advice for cervical screening provider and primary care staff can help to increase understanding and remove barriers to screening.

Consider:

- how the woman communicates – you may need to ask carers
- if the woman will need an interpreter or signer at the screening appointment (some people with learning disabilities would also use Makaton (<https://www.makaton.org/>) rather than British Sign Language (<https://www.british-sign.co.uk/>))
- which word the woman uses for vagina so that you don't get misunderstandings
- offering a pre-visit so the woman can feel safe while you explain the test
- using an alternative venue, if appropriate
- showing the speculum and sample brush to the woman – let her handle it and explain how they work
- showing the woman the position she will need to be in when she has the test and encouraging her to get onto the couch to see what this feels like
- suggesting the woman practices the position at home so she feels more comfortable about it (this can be done with her clothes on in her bedroom where she feels relaxed and carers may need to support this)
- reassuring the woman that she can have a friend, relative or carer present during the test if she would like to
- offering a longer appointment and a first appointment if needed
- ways to help the woman feel relaxed, such as music

Remember, the woman needs to have an understanding of what will happen at the test.

She must be able to:

- remember this information for as long as it takes to do the test
- understand that by having the test it will help her to stay healthy
- give consent, by any communication means, to try to have the test done

- have an understanding of the signs and symptoms of cervical cancer (see an easy guide to cervical screening (<https://www.gov.uk/government/publications/cervical-screening-easy-read-guide>))

4. Making a best interest decision

If the woman has not understood enough to make her own decision on cervical screening you need to make a best interest decision for her.

To make a best interest decision, you need to have a discussion with people who know her well. These would usually be her family and carers. Include the woman in your discussion as much as possible. Discussions do not have to be face to face. Opinions on what is in her best interest can be collected through telephone calls.

A best interest decision is based on your reasonable belief at that time.

Also consider:

- obtaining the opinion of an independent advocate if professionals, families and carers cannot or do not agree on what is in the woman's best interest
- reviewing the woman's past screening history
- her beliefs and wishes, which could influence a best interest decision for her

If the woman has previously attended screening, this implies she once felt it was important. This knowledge could influence you and others when making a best interest decision for her.

When a woman cannot manage to have cervical screening, you must consider other ways of keeping her safe from cervical cancer. This can include educating the woman, her family and carers about the signs and symptoms of cervical cancer.

Every time a best interest decision is made that cervical screening is not appropriate, education should be given. This ensures all family and carers have up to date information.

5. Tips for administration and reception staff

Primary care administration and reception staff play a crucial role in supporting people with a learning disability to access cervical screening.

5.1 Know your population

Ensure people with a learning disability are flagged on your computer system. The community learning disability team can help verify lists.

5.2 Know who is due to be invited for screening

You can identify women about to be invited for cervical screening who have a learning disability and may need additional support by using the prior notification list provided by the screening service.

A member of the practice team may want to contact the individual or their carer before they receive their invitation letter to ask if they need any support.

5.3 Know your community learning disability link

Find out who your community learning disability team link person is for your GP practice. This person may be able to offer additional support for a woman with a learning disability invited for cervical screening.

5.4 Know the facts

All women over 25, whether they are sexually active or not, are entitled to cervical screening. It is then the woman's decision if she takes up the invitation. This decision can only be made by the woman or through a best interest decision.

5.5 Know where to get more information

Read the PHE (<https://www.gov.uk/government/publications/cervical-screening-easy-read-guide>) and Jo's Cervical Cancer Trust (<http://www.jostrust.org.uk/resources/materials/information>) easy guides to cervical screening.

5.6 Know who else in your practice can give support

Find out who performs cervical screening within your practice and who you can go to if you have any questions.

You could consider:

- using a clock face to show time as well as writing in numbers the appointment information
- making sure a double appointment is booked to enable reasonable adjustments

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