

Women's health care for people with autism & learning disabilities

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Introduction

A study carried out by Biswas et al (2005) found that the rate of women with a learning disability who had undergone breast screening was in line with the general population. A number of studies, however, suggest that cervical screening, has a much lower than average uptake (between 13% and 25%) when compared with approximately 80% in the general population.

Who has cervical screening?

In England, Northern Ireland and Wales, the NHS invite women from ages 25 to 64 for cervical screening. Women aged 25 to 49 are invited every 3 years. After that, women are invited every 5 years until the age of 64.

In Scotland, women aged 20 to 60 are invited for screening every 3 years. But in 2016, this will change to follow the same screening schedule as England, Northern Ireland and Wales.

You need to be registered with a GP to get your screening invitations.

Staying healthy

Since 2008, girls aged between 12 and 13 have been offered a vaccination against the human papillomavirus (HPV). It is reported that the vaccine can prevent over 70% of cervical cancers and so it is important for girls to have the vaccination when it is offered at school.

The vaccine protects against the 2 types of HPV that cause most cases of cervical cancer, but it doesn't protect against all of them. This means that screening is still important for girls who have been vaccinated.

As well as attending the screening when invited, women still need to look out for any unusual changes to their body. Women should check for any abnormal bleeding, unpleasant discharge or pain after sex. If women notice anything unusual, then it is important that an appointment is made to see their GP.

Women's healthcare for people with autism

For people with autism and/or a learning disability the experience of accessing and receiving treatment can be extremely challenging. From sensory overload (bright lights, busy, noisy environment and touch) to difficulty in communicating their understanding and needs, this can sometimes be just too much of a challenge.

Barriers to cervical screening for women who have a learning disability

- Assuming that women who have a learning disability are not sexually active
- Lack of awareness amongst women who have a learning disability about the importance of screening

- Lack of preparation for the examination
- Communication difficulties
- Lack of assertiveness and confidence
- Health services reliance on written information
- Time pressures—women who have a learning disability may need a longer appointment time so that the procedure is not rushed.

‘Ceased from recall’

Women can choose to be ‘ceased from recall’ from clinical reasons and have their name permanently removed from the recall system. A high number of women who have a learning disability are ceased from the cervical screening programme. A study carried out by MENCAP (2000) found that 75% of women with a learning disability had been ceased from recall by their General Practitioner.

Having a learning disability is not a valid reason for ceasing women from the programme, nor can a parent or carer make this decision on behalf of an adult woman. It must be assumed that every adult has the capacity to consent until proven otherwise. Women should be assisted in making an informed choice about whether or not to participate in the programme. Accessible, easy read materials are available to maximise capacity and assist understanding. Many of these resources have been developed by women with learning disabilities.

Useful information

www.cancerscreening.nhs.uk has useful easy read guides that can be downloaded at cancerresearchuk.org

“Keeping Healthy Down Below” is a book that can be bought from the Royal College of Psychiatry. Phone: 020 7235 2351 ext 146

Good Practice in Breast and Cervical Screening for Women with Learning Disabilities document (NHSBSP, 2000)

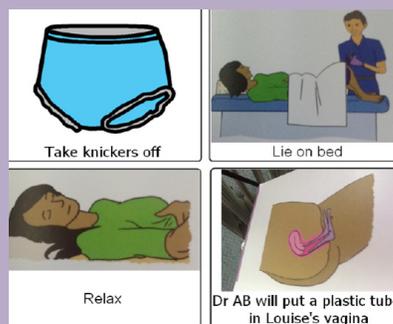
“Having A smear Test. What is it about?” available from jostrust.or.uk

easyhealth.org.uk offer access to a range of videos and leaflets

Case study

Louise is a 26 year old female, she has a diagnosis of autism and a moderate to severe learning disability, she sometimes displays behaviour’s that may challenge. She began experiencing some breakthrough bleeding between her periods and so it was advised by her Doctor that she should have a smear test. A storyboard was created by the Speech and Language Therapist to explain the process of a smear test to Louise. She comprehended this process and so consented to going to the surgery to have the test. To support Louise with the test she was provided with a keyring

which outlines each stage of the process. Please see below:



Louise was also provided with a stop card to enable her to communicate to the Doctor at any time during the test that she wanted it to stop.



Louise successfully completed the process and it was evident from her presentation after the test that she felt empowered by her achievements.

Spread the word...

If you found this help sheet useful please feel free to share it with anyone who you feel may benefit.

The complete series of help sheets can be found on our website www.optionsautism.co.uk/resources

For further information about our services:

call: 08442 487187 | **email:** info@optionsautism.co.uk | **website:** www.optionsautism.co.uk