Health and well-being

The importance of health screening

We are often asked about screening for cervical and breast cancer, so we have provided a little information about this below.

We would like to take this opportunity to stress the importance of people who have Down’s syndrome having the chance to take part in ALL national health screening programmes.

**Testicular cancer**

Testicular cancer is a relatively uncommon type of cancer but is one of the few types of cancer that is reported as occurring more commonly in men who have Down’s syndrome. It occurs in men usually between the ages of 15 and 44. It is one of the most treatable types of cancer with over 95% of men with early stage testicular cancer being cured.

The most common symptom is a painful lump or swelling of the testicle. Although most testicular lumps are not due to cancer, advice from the GP should be arranged straight away. Carers need to be aware of symptoms to be vigilant for especially if your son is not able to raise concerns himself. It is advisable to regularly check the testes and if your son is not able to do this himself then it can be included as part of the regular medical check with his GP.

**Cervical cancer**
All women between the ages of 25-64 years are eligible for a cervical smear test every 3 years (until age 50 years when the test is every 5 years). All women within this age range will be invited for a cervical smear. Cervical screening is not a test for cancer but is a way of preventing cancer by detecting and treating abnormalities which, if left untreated, could lead to cancer of the cervix (neck of the womb). Early detection and treatment can prevent approximately 70% of cancers developing but the test is not perfect and may not always show problems that may go on to cause cancer. Therefore, it is always important to see the GP with any unexpected bleeding so that the cause can be identified.

The test involves taking cells from the cervix using a small brush. A speculum (an instrument to open the vagina) is used so that the cervix can be seen at the top of the vagina. This can be uncomfortable, and an explanation of the procedure and reassurance should be given but some women with a learning disability may not be able to tolerate the procedure. The chance of developing cervical cancer is very low if a woman has never been sexually active. Therefore, it is worth considering the advantages of having the test undertaken and the difficulties of performing the test for each woman, also bearing in mind that a woman with a learning disability may be less likely to report early symptoms such as bleeding.

If the decision is made that a cervical smear is not in the best interests for a woman the GP surgery should be notified, so that it is understood that she is opting out of the screening at that point. She can always request a cervical smear in the future if the decision changes.

**Breast cancer**

Breast screening is a way of detecting breast cancer at an early stage. An X ray (mammogram) is taken of each breast. This can be uncomfortable for some women. All women are invited for screening every 3 years from age 50 years. (In some areas the age is lower.) Special appointments can be requested so that there is more time and support if needed. It is important that women are also ‘breast aware’. Every woman should know what is normal for her, look at and feel her breasts and report any changes without delay. Some women may need support in this. Breast cancer is much less common in women who have Down’s syndrome – around 10 times less frequent than in other women. Therefore, the risk is very small but still present and if there is a family history of breast cancer the risk will be higher. The very low risk of breast cancer in contrast to the possibility that a woman who has Down’s syndrome may be less likely to report early symptoms of breast cancer both need to be considered when breast screening is offered.

**Annual Health Check**

Please note that everyone who has Down’s syndrome (from age 14 years and upwards) is entitled to a free Annual Health Check with their GP – there is further information about this here (insert link)

An Annual Health Check will be in addition to any invitations to take part in screening for a specific health issue. An Annual Health Check does not replace the need to take part in national screening programmes.

**Further information/advice**

If you have questions about any health issues, you can call DSA’s Helpline (Tel: 0333 1212 300). If an information officer is unable to answer your question, they can make a referral to the medical adviser at the UK Down Syndrome Medical Interest Group. Please note DSMIG can provide general advice about health issues but they are not able to comment on individual
test results. DSMIG are happy for health professionals to contact them directly with enquiries. They will not take direct enquiries from parents or supporters.

**Resources**

Here are some links about these issues for people who have learning disabilities:

**Macmillan Easy Read titles**
- Breast care for women
- Cervical screening
- How to check your balls

**Books Beyond Words**
- Keeping healthy down below
- Looking after my breasts
- Looking after my balls

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