



**Down's Syndrome  
Association**

A Registered Charity No. 1061474

## Health Series



# Puberty, adolescence and sexual health



The  
Down Syndrome  
Medical Interest  
Group

A Down's Syndrome Association publication

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## Our resources and Information Team are here to help

Please see our website for up-to-date information: [www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk)

If you would like to talk about any of the issues raised in this resource, then please get in touch with our helpline by calling 0333 1212 300 or by emailing us on

[info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk).

**Helpline Monday - Friday 10am-4pm | Telephone: 0333 1212 300**

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## The Down's Syndrome Medical Interest Group (DSMIG)

This resource has been produced in collaboration with the Down's Syndrome Medical Interest Group (DSMIG).

DSMIG was launched in 1996 and is a registered charity. It is a network of healthcare professionals – mainly doctors – from the UK and Republic of Ireland whose aim is to share and disseminate information about the medical aspects of Down's syndrome and to promote interest in the specialist management of the syndrome.

***"Sexual health is a state of physical, mental and social well-being in relation to sexuality. It requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence"*** - World Health Organisation definition.

This resource aims to guide parents and carers through their child's puberty into adulthood and to answer some of the common queries about sexual health for adults with Down's syndrome. The information aims to help allay anxieties, give advice and, where needed, suggest some ways forward by explaining the options available and providing information about where to seek support.

It is important that parents and carers are able to access support for their child or young person and to be aware that there are many professionals who are able to support them and their child from childhood through adolescence and into adulthood. Puberty and sexual health is an area of their child's development that should be thought about, discussed and planned for. It is best if this is done in advance and support should continue throughout their adult life.

It is important that vulnerable children, young people and adults are protected but this should not be at the cost of respecting their human need to love and to be loved, to have friends and to express their sexuality (in ways that suit them and which are acceptable). People with a learning disability have the right to express their emotions and sexuality and to develop relationships. This is an important part of having a full and equal life and is based on their right to independence and choice.

Young people and adults with a learning disability have a right:

- To fulfilling personal and sexual relationships.
- To marry or cohabit.
- To make an informed choice about whether or not to have children.
- To take risks and make mistakes in personal relationships.
- To privacy and to be free from exploitation.
- To receive sex education, including counselling on personal relationships, sex and sexuality, contraceptive advice and sexual health support services.

Talking to your child, whatever their age, about sex can be difficult and daunting. If your child has a disability, there may be many reasons why you are worried about answering questions or bringing up sex in conversation. You may be concerned that, although they are adults and need to be treated as such, they may be vulnerable and need careful support.

You may feel uncomfortable because you are not sure how your child's disability will affect their ability to have sex. You may be unsure about how much they will understand about sex, or you may be worried that educating your child will encourage them to have sex. Your child's physical, social and emotional needs will be the same as most teenagers and they may have a lot of questions for you.

## Puberty

Puberty can be a worrying time for parents and carers of children approaching adolescence. Coming to terms with your child becoming an adult can be difficult to deal with, but it is important that your child is prepared for puberty and the physical and emotional changes it brings. Parents of children with Down's syndrome may have heightened anxieties due to issues associated with a learning disability or related health issues. Most young people also worry about the changes associated with adolescence. Parents and young people often ask "how are we all going to cope?" Most young people with Down's syndrome manage extremely well with adolescence. For those that find the changes difficult to cope with, help is available for both the young person and their parents. Young people with Down's syndrome have the same right to advice and support as everyone else.

## Pubertal changes

The physical and emotional effects of puberty can be worrying for a child if they do not know what to expect. It is important to start talking to your child before any changes occur, to ensure that they have some understanding of these changes. Your child needs to be given information about growing up in a way that they can easily understand. There are many books and DVDs available using different ways of describing the changes that are going to happen in writing, drawings or using symbols. There are some examples in the resource list at the end of this publication. It can be helpful to discuss your concerns with professionals working with your child such as teachers, doctors, nurses and family support workers. They will be able to support you and your child through these changes.

## Relationships

As your child goes through puberty, they will develop feelings that are just the same as in all other teenagers. They may wish to form relationships and be able to manage all aspects of their relationships. However, they may also need some extra support e.g. talking about pregnancy and contraception. They may want to get married, and a person with Down's syndrome, aged 16 years or over can get married, as long as they are able to give their consent.

Throughout their school life your child will be involved in lessons about friendships and relationships. It is often helpful to know what they are learning so that discussions can continue at home. These lessons usually include sex, sexual health, family matters and relationships, as well as personal and social skills. Some parents are worried that their child will be vulnerable. Teaching children about what part of their body is private and how to stay safe is very important in helping them to stay safe, as is making sure they know who they can talk to at home or at school if they are feeling sad or worried about something.

## Masturbation

Masturbation is a natural response to the hormone surges in puberty. It is a very normal activity that does not cause any harm. It is important that the young person is aware that it is ok to masturbate, but that it is a private activity. It is helpful for the young person to know where it is acceptable to masturbate, for example in their bedroom and bathroom with the door closed. This gives the emphasis that it is one of many private activities and not a public one.

## Consent and the Mental Capacity Act

All adults must be assumed to have capacity to consent to examination, tests or treatment unless it is established that they lack capacity. It is important that people are supported to have capacity and that it is accepted that a person can make an unwise decision. The Mental Capacity Act provides a framework for making decisions in relation to people who lack capacity. It clarifies who can make decisions for people who are unable to decide for themselves and how those decisions should be made.

A person has the capacity to consent if they can:

- Understand the information relevant to the decision.
- Retain the information long enough to make the decision.
- Use or weigh up the information.
- Communicate their decision.

If there are concerns that a person is unable to give consent then a Best Interest Meeting (BIM) is held under the Mental Capacity Act, as once a person is an adult no other adult can give consent for them. The BIM sets out a checklist of points to consider when family members and professionals are deciding what is in the person's best interest. For urgent medical treatment a doctor can act without consent in a person's

best interests. However, this would not be the case for non-urgent procedures such as contraception and where involvement of the courts is likely to be needed.

## Information about girls and women

### Puberty

The stages of puberty are the same for girls who have Down's syndrome as other girls. Breast development starts first (age range 8-13 years) followed by pubic hair growth, then the first period. The average age for 1st period in girls with Down's syndrome is 12 years 6 months (in the general population it is approx 13 years). Periods often begin 2 years after the start of breast development. Periods do not usually start before age 9 years and most girls will have started their periods by 15 years. The age that a girl starts having periods is often similar to her mother, but other factors can also play a part – a girl with low weight may be late starting her periods and a tall, heavy girl may start her periods earlier. Occasionally the usual sequence of pubertal changes is not followed and the start of periods has been seen as the first sign of puberty in young women with Down's syndrome. Girls have a growth spurt usually at the start of puberty and often their height only increases slightly after the start of periods. During puberty your daughter may also notice skin changes such as spots, body odour and mood changes.

There is a wide age range for starting puberty but medical advice should be sought if puberty starts before age 8 years or if there are no signs of puberty by age 14 years. Thyroid problems which occur more commonly in people with Down's syndrome may also affect the timing of puberty.

### Management of periods

It can be useful to think in advance about how your daughter will manage her periods. Except in a very few cases it is not advisable to use medical treatment to stop periods before they have started. It is not possible to predict precisely when periods will start, what the periods will be like and, most importantly, how she will cope with them.

Most girls who are independent for toileting are also likely to be able to cope independently with their periods. They may initially need some support and it is therefore helpful to plan in advance how this support will be arranged, so that when her first period does arrive a plan is already in place and all of her carers are aware of how to support her. It may be helpful if she is able to use a more private toilet during school hours and be supported with changing her sanitary protection and pants. If your daughter is using continence aids it can be useful to use sanitary towels in addition to these. Additional support to manage periods may be needed initially and it is helpful to plan this support in advance, so that when your daughter does get her first period she knows who to go to and that those individuals know what to do and say.

### Problem periods

Periods can take between 1 and 2 years to settle down into a regular pattern. Initially periods can be very light and irregular but they can also be heavy and very frequent. Once they have settled down the usual pattern is a 5-7 day bleed every 28 days. It can be helpful to keep a diary of periods initially as it may be possible to see a pattern of

when periods occur. It may be that your daughter will experience other things, too, around the time of the period such as mood changes, tummy ache or headache. Women with epilepsy sometimes find that they have more fits around their periods and if this is occurring it should be mentioned to their epilepsy doctor.

### **Painful periods (dysmenorrhoea)**

During the first few days of a period or just before a period starts women can have abdominal pain/tummy ache. This is often mild but can also be very painful. Simple measures such as a hot water bottle or a warm bath may help. Paracetamol or Ibuprofen can be tried. Other medications are available and can be prescribed by the GP or hospital specialist.

### **Heavy periods (menorrhagia)**

Periods can be heavy and interfere with daily activities. Thyroid abnormalities can cause heavy periods so it is worthwhile ensuring that thyroid function is normal.

### **Irregular periods**

It is very common for periods to be irregular in the first 1-2 years. They usually do settle into a regular pattern. Thyroid abnormalities can cause irregular periods. Some women regularly have a longer time between periods and this can be quite normal.

### **Premenstrual Syndrome**

Many women experience symptoms such as pain, mood swings and bloating leading up to their period. These symptoms can be very variable in severity. Even if they are very mild they can affect a woman's ability to function in many ways. It may be more difficult for women with a learning disability to report these symptoms; however, parents and carers may notice distress or a change in behaviour or mood. Keeping a diary of behaviour and mood can be helpful to identify timing of symptoms in relation to periods. Hormonal treatments can be used to treat these premenstrual symptoms.

### **Medical treatments**

If periods continue to be troublesome medical advice should be sought as there is a range of available treatments. It is important to consider the benefits of treatment as well as the potential side effects or risks. The risks of some of the medications used to help with problem periods are greater in certain medical conditions seen more commonly in women with Down's syndrome, for example valvular heart disease or conditions where the blood is more liable to develop blood clots (e.g. due to immobility, obesity, or a high platelet count). In some cases, the medication may interact with other tablets being taken e.g. epilepsy medication. It is also important to consider how easy the treatment will be to take. For example, some women with learning disabilities may find it difficult to remember to take a daily pill, whilst others may find it better to take medication daily and not have a 7 day break every month. There are different treatment plans and it is important to identify which option will fit best with the woman's lifestyle and routine. If swallowing tablets or pills is difficult, other types of treatment are available e.g. injection, patch, implant. These treatments can be discussed with the GP or hospital

specialists such as a gynaecologist, contraception and sexual health team or paediatrician.

## Available treatments

### Mefenamic acid

This is an anti-inflammatory medication which can help reduce pain during periods. It can also help reduce blood loss. It should be taken 3 times a day during a period. Common side effects include nausea and diarrhoea. It should not be used in women with heart failure, asthma or kidney problems and should not be used under the age of 12 years.

### Tranexamic acid

Tranexamic acid can be used for heavy periods. It helps to reduce blood loss by up to 50% during a period. The tablets need to be taken 3 times a day during the period only. Side effects can be nausea, vomiting and diarrhoea. It should not be used in women with a history of thrombosis (blood clots) or convulsions.

## Hormonal treatments

A number of treatments are available which can help with problem periods – making them less painful, lighter, and more regular or stopping them altogether. A number of these treatments are also contraceptives and can be used for both purposes if wished.

### Norethisterone (NET)

This is a progesterone hormone tablet. To regulate periods and reduce blood loss NET tablets can be taken twice daily for 3 weeks, followed by a week off during which a period occurs. This can then be repeated for several months after which the tablets are stopped and periods monitored to see whether they have become lighter and more regular. NET can also be used to delay the start of a period, for example over a holiday. Tablets are taken 3 times a day starting 3 days before the period is expected to start. The tablets should be continued until it is convenient for a period to start. Side effects of NET can include nausea, headache and weight gain.

### Combined hormonal contraceptive pill (CHC)

This is a tablet that contains 2 types of hormones – oestrogen and progesterone. It works by stopping the ovaries producing an egg each month. The tablet is taken daily for 3 weeks and then during a 7 day break a light bleed occurs. It can be very helpful in the management of painful, heavy and irregular periods. In some women with very troublesome symptoms the tablets are taken continuously for 9 weeks followed by a 7-day break so that only 1 bleed occurs in 3 months. The CHC is generally well tolerated but side effects can include skin changes, moods, headaches and nausea. These are usually mild and settle down but sometimes a change in pill type is needed. Irregular bleeding can occur and if this persists a change in medication is recommended.

The CHC should not be used in women who have a history of focal migraine, being very overweight, high blood pressure or some types of heart disease. Also any woman who

has had thrombosis (blood clot) or is at a high risk of thrombosis due to reduced mobility, high BMI (body mass index) or thrombocythaemia (high platelets) should not use the CHC. All these medical problems will be carefully considered before the CHC is prescribed. Whilst the CHC is being taken it is important that any side effects are discussed as well as monitoring weight and blood pressure.

Certain medications interact with the CHC – some antibiotics and epilepsy medications make the CHC less effective and so an alternative dosage or type is advised. As well as helping troublesome periods, as long as the CHC is taken regularly as directed, it is a good contraceptive with over 99% effectiveness. The CHC tablets are small tablets that can be crushed and put with food if necessary.

### Patch

The patch is a small plaster (approximately 4x4cm) containing similar hormones to the CHC. It is applied to the skin and left in place for 7 days then replaced weekly for 3 weeks after which there is a 7 day break during which a bleed will occur. As it contains similar hormones to the CHC all of its effects and side effects are similar to the CHC. The patch can be useful if swallowing a daily tablet is difficult.

### Progesterone only pill – desogestrel

Desogestrel is a newer type of pill that just contains a progesterone hormone and can be helpful in some women with problem periods. It is a daily tablet taken without a break. The tablet is crushable. In many women (over 50%) it may stop periods completely or there can be light bleeding. In a few women troublesome bleeding continues.

Unlike the CHC, (due to its active ingredients and different safety profile) desogestrel does not require monitoring of blood pressure. Therefore, desogestrel can be useful for women who find blood pressure measurement distressing. Side effects of desogestrel are usually mild but can include nausea, headache, spots and moods. The use of desogestrel with epilepsy medication should be discussed with the doctor. When taken regularly as prescribed, desogestrel is a good contraceptive (over 99% effective at preventing pregnancy).

### Depo-provera

Depo-Provera (Depo) is a long acting progesterone hormone given as an injection every 10-12 weeks. The injection is usually given into the buttocks but can also be given in the thigh or upper arm.

In many women (approximately 60 %) the Depo will stop periods completely but in some women irregular, light bleeding or troublesome bleeding can occur. This bleeding often settles down after 2 or 3 injections but in a few women bleeding continues and the Depo is usually stopped.

Other side effects seen can include an increased appetite and weight gain, spots and moods. There have been concerns raised regarding a negative effect of the Depo on bone strength and osteoporosis. Osteoporosis may be more common in women with Down's syndrome and therefore it is not usually recommended for use within the first 2 years after periods start while bone strength is still increasing.

When the Depo is stopped it can take up to 12 months for periods to return to normal. When the Depo is regularly given every 12 weeks it is over 99% effective as a contraceptive.

### **Mirena Coil – IUS**

The Mirena coil is a small T shaped plastic device that is inserted into the womb and contains a small dose of progesterone hormone which is released directly to the womb. The lining of the womb becomes much thinner and as a result periods become much lighter, less painful and in many cases stop altogether. The Mirena coil works for 5 years and once inserted does not require any regular monitoring. To insert the coil a speculum is used (instrument put into the vagina so the cervix can be seen at the top of the vagina). The procedure can be uncomfortable and some women are unable to manage this. It can however be inserted under a general anaesthetic and this is often needed for a woman with a learning disability. The coil can be removed at any time and a speculum is used to visualise the coil. Removal is a quicker and more comfortable procedure compared with insertion.

Very few side effects are reported by women using the Mirena coil as the hormone works in the womb. However, there can be irregular bleeding particularly initially, but this usually settles down within the first few months. The Mirena coil is also a very effective (over 99%) contraceptive.

### **Implant**

Nexplanon is a progesterone releasing implant that can be helpful with painful, heavy periods. It can reduce blood loss and in some women stops periods completely. It is a small flexible rod, about the size of a matchstick that is inserted under the skin on the inside of the upper arm. The insertion is similar to having an injection, but takes a little longer. The implant lasts for 3 years and removal is usually done using a local anaesthetic to numb the skin. Side effects of the implant include irregular bleeding, which usually settles but occasionally can be problematic, nausea, headaches and an increased number of spots.

The implant may be affected by certain epilepsy tablets and antibiotics and in heavier women it may not be effective for the full 3 years. The implant is an excellent (over 99% effective) long acting contraceptive.

### **Fertility**

Studies have shown that most women with Down's syndrome ovulate (produce an egg each month) and that approximately 70% of women with Down's syndrome are fertile. There have been many pregnancies in women who have Down's syndrome and in many cases both mother and baby have been healthy without complications. However, there is an increased chance of miscarriage. There is a 50% chance of their child having Down's syndrome and the chance of other congenital anomalies is higher than in the general population and babies born to mothers with Down's syndrome have a higher chance of being premature or stillborn, are more likely to have low birth weight and have health problems soon after birth.

Therefore, careful monitoring in pregnancy is needed. In some women who have heart problems, pregnancy can put additional strain on the heart and so this should be discussed with the cardiologist (heart specialist). Other medical problems in the mother such as epilepsy, thyroid and liver disease can also cause complications during pregnancy.

## Contraception

It is very important that all people have access to advice about contraception and sexual health and that it is provided by professionals with skills to support people with a learning disability. Many areas do have specialist clinics with experienced clinicians and information available specifically for people with a learning disability.

### For women there are hormonal and barrier methods

Barrier methods include the Femidom, (female condom) and the diaphragm which both need much practice to use safely and therefore may not be practical for those with a learning disability or who are not very dextrous. Hormonal methods have been mentioned previously as they are often helpful for managing problem periods too. There are the CHC pill and patch, POP, Depo-Provera, Implant and Mirena coil which are all over 99% effective at stopping pregnancy. The standard coil (IUD) can be used and is inserted similarly to the Mirena coil but has no hormone action. It can be left in the womb for between 5 and 10 years depending on the type used. It is over 99% effective but can cause heavier and more painful periods.

### Emergency Contraception (EC)

EC can be used after unprotected sex. Advice should be sought as soon as possible from the GP or Contraception and Sexual Health Clinic Family Planning Association. EC is available as a hormone tablet and a copper coil that is inserted into the womb both of which can be used up to 5 days after having sex.

The effectiveness of EC depends on the type taken and the timing in the woman's menstrual cycle but is not always as effective (particularly the EC tablet) as taking regular contraception such as the CHC, Implant or Depo.

### Sterilisation and Hysterectomy

Sterilisation is a permanent (usually irreversible) method of contraception where the fallopian tubes are blocked. It is performed under general anaesthetic usually by keyhole surgery. Possible complications include infection and bleeding. The failure rate is about 1 in 200. As the other long acting contraceptives such as the Mirena coil, Implant and Depo are almost as effective these should be considered before sterilisation is undertaken. A hysterectomy is a major operation which involves removing the womb. Periods will therefore stop and pregnancy cannot occur. Sometimes it is performed due to painful or heavy periods.

It is only usually considered after other methods e.g. the Mirena coil have been unsuccessful. Both sterilisation and hysterectomy are major operations which are rarely required because of other treatment options. However occasionally they are needed and

consent for the procedure needs to be obtained. In view of the major surgery required and irreversibility often legal advice is sought to ensure adequate consent is obtained.

### **Vaginal Discharge and Sexually Transmitted Infections**

It is very common for women to get vaginal discharge and it is important to see the GP for advice if it is troublesome. It is normal and healthy to have a clear or white discharge from the vagina. During the menstrual cycle the amount and type of discharge can vary. A healthy vaginal discharge does not usually have a strong smell or colour and should not cause itching or soreness.

One of the commonest causes of a troublesome discharge is thrush which often causes itching and soreness around the vagina and a thick white discharge. It is not a sexually transmitted disease but is an infection caused by yeast-like fungus (*Candida Albicans*). Women are more likely to have thrush with some antibiotic treatments and with diabetes (which occurs more commonly in Down's syndrome). Sometimes perfumed soap and bubble baths can cause thrush. It is easy to treat with cream, pessaries or pills which can be obtained from the GP or pharmacy. To reduce the likelihood of recurrent thrush, it is advisable to wear cotton underwear and avoid perfumed soap and bubble bath.

Sexually transmitted infections (STIs) are infections that pass from one person to another during sex or genital contact. They often cause troublesome discharge and soreness but can also cause no symptoms. Using barrier contraceptives such as condoms during sex helps to protect against STIs. Most STIs can be treated easily with antibiotics. Information and treatment is available at the GUM (genitourinary medicine) clinic or CASH (contraception and sexual health) clinic.

### **HPV vaccination**

The Human Papilloma virus (HPV) vaccine is offered to all 12-13 year olds. It consists of two injections given preferably over six months and is usually given in the UK at school by the School Nursing service. The HPV vaccine can cause side effects but these are usually minor and last only a short time. The commonest side effects are redness and pain at the injection site and headaches. There are over 100 different types of HPV, some of which cause cell changes that can lead to cervical cancer. Some types of HPV can cause genital warts. HPV is transmitted through sexual contact. The HPV vaccine protects against certain types of HPV and the current vaccine used helps to prevent genital warts, premalignant genital lesions and cervical cancer. The duration of protection from the vaccine has not been established but current studies suggest that protection is maintained for at least 6 years. The risk of cervical cancer is very low if a woman has never been sexually active and so often it is asked whether the HPV vaccination is necessary in these women. When making the decision it is important to remember that it is difficult to predict future sexual behaviour. Also that although the risk of cervical cancer is very low it can still occur and may be less easily identified in women with a learning disability either because symptoms are not reported or because screening tests for cervical cancer (cervical smear tests) are not tolerated.

### **Cervical Smears**

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 awareness and breast screening**

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 slightly 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 with 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 with Down's syndrome may be less likely to report early symptoms of breast cancer both need to be considered when breast screening is offered.

### **Menopause**

The menopause occurs when a woman's ovaries stop producing eggs each month and her periods stop. Women with Down's syndrome on average reach the menopause earlier than in the general population at around 44 years. The symptoms commonly experienced are hot flushes, mood swings, and night sweats and are due to a change in hormone levels. Most women do not need treatment for the menopause but if a woman has troubling symptoms then the GP may recommend treatment such as hormone replacement therapy. As menopausal symptoms can be so varied, a general medical

assessment is recommended, including checking thyroid function, for women who experience a change in their functioning.

## Information about boys and men

### Puberty

The timing and sequence of pubertal changes in boys with Down's syndrome is similar to other boys. Initially there is growth of the testicles (age range 9-14 years) and then growth of the penis. Pubic hair growth occurs usually from 10 years of age. Sometimes puberty can start very early or be very late in starting. It is advisable that medical advice is sought if there are pubertal changes before age 9 years or if there are no signs of puberty by age 14 years. Boys have a growth spurt usually when puberty is well underway. Other features which may be seen in your son during puberty include skin changes such as spots, body odour and mood changes. Thyroid problems which occur more commonly in people with Down's syndrome may also affect the timing of puberty.

### Fertility

Men with Down's syndrome have lower fertility than the general population. There have however been at least 2 reported proven cases of men with Down's syndrome becoming fathers. Therefore, although there is lower overall fertility, contraception should always be used unless the couple are planning a pregnancy.

### Contraception

For men condoms can be used and if used correctly can be 98% effective at preventing pregnancy. However, there are many factors to remember when using condoms and generally their failure rate is much higher. It is important to consider for each individual whether they will remember how and when to use condoms and also that they have the manual dexterity to put condoms on. As condoms are a barrier contraceptive they are also useful to prevent sexually transmitted infections.

### Testicular self-examination

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 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.

It is hoped that the information in this booklet has helped to answer questions about adolescence and sexual health. There are many services available that will be able to help and it is important that help and advice is sought when needed.

## DSA Training

The DSA runs scheduled workshops about supporting young people with Down's syndrome through puberty and adolescence.

We are also able to offer this workshop, by arrangement, with support groups, schools/colleges and local authorities.

The full day workshop covers how to talk about physical and emotional changes, sex and relationships education and supporting friendships and self-esteem. A reduced programme is available for half a day.

For further details please email [training@downs-syndrome.org.uk](mailto:training@downs-syndrome.org.uk) or call us and ask to speak to the training team (Tel: 0333 1212 300).

## Annual health checks for people with Down's syndrome (aged 14 years plus)

In the past people with learning disabilities have not had equal access to healthcare compared to the general population. This, amongst other reasons, has given rise to poorer mental and physical health and a lower life expectancy for people with learning disabilities. Free annual health checks for adults with learning disabilities, with their GP, were introduced in 2008 as a way to improve people's quality of life.

The annual health check for people with learning disabilities is a Directed Enhanced Service (DES). This is a special service or activity provided by GP practices that has been negotiated nationally. Practices can choose whether or not to provide this service. The Learning Disability DES was introduced to improve healthcare and provide annual health checks for adults on the local authority learning disability register. To participate in this DES, staff from the GP practice need to attend a multi-professional education session run by their local Trust. The GP practice is then paid a sum of money for every annual health check undertaken.

### Who can have one?

Annual health checks have been extended to include anyone with learning disabilities aged 14 years or above. So anyone with Down's syndrome aged 14 years or over can have an annual health check.

### The benefits of annual health checks

- additional support to get the right healthcare
- increased chance of detecting unmet, unrecognised and potentially treatable health conditions
- action can be taken to address these health needs.

### How to get an annual health check

- The GP may get in touch with the person with Down's syndrome to offer an annual health check but this doesn't always happen.
- A person with Down's syndrome and/or a supporter can ask their GP for an annual health check. You do not need to be known to social services to ask for an annual health check.

Not all GPs do annual health checks for people with learning disabilities but they should be able to provide details of other GPs in your area who offer this service.

### What happens next?

- The GP practice may send out a pre-check questionnaire to be filled out before the annual health check takes place.
- The GP may arrange for the person with Down's syndrome to have a routine blood test a week or so before the annual health check.

### Who attends the annual health check?

If the person with Down's syndrome (age 16 years or over) has capacity and gives their consent, a parent or supporter can attend the health check as well.

### How long should an annual health check be?

Guidance from the Royal College of GPs suggests half an hour with your GP and half an hour with the Practice nurse.

### What areas of health should be looked at as part of the annual health check?

We have produced a check list for GPs which contains information about what should be included as part of a comprehensive and thorough annual health check. This includes a list of checks that everyone with a learning disability should undergo as part of an annual health check and a list of checks specific to people with Down's syndrome. You can find the health check list at the 'annual health checks' section of our website under 'families and carers and 'health and wellbeing'.

### What happens after the annual health check?

Your GP should tell you what they and the nurse have found during the annual health check. You should have a chance to ask any questions you have. Your GP may refer you to specialist services for further tests as appropriate. Your GP should use what they have found during your annual health check to produce a health action plan. This should set out the key actions agreed with you and (where applicable) your parent or carer during the annual health check. Your GP has to do this as part of the annual health check service.

## Information about health issues for GPs

There is information at our website for GPs about some of the more common health conditions seen in people with Down's syndrome. You will find this information at the 'annual health checks' section of our website under 'families and carers and 'health and wellbeing'.

### GPs learning disability register

People with learning disabilities experience poorer health compared to the rest of the population, but some ill health is preventable. Over one million people in the UK have a learning disability but only 200,000 are on their GPs learning disability register.

We know that people with a learning disability often have difficulties accessing health services and face inequalities in the service they receive. The Government is asking parents and supporters to speak to their GP and ensure their sons/daughters or the people whom they support are registered. It is hoped that this drive will ensure better and more person centered health care for people with learning disabilities.

The Learning Disability Register is a record of people with a learning disability who are registered with each GP practice. The Register is sometimes referred to as the Quality Outcomes Framework (QOF) Register.

If you are not sure you are on the Register, you can ask the receptionist at your GP Practice to check for you.

The doctor may have made a note on the record that a person has Down's syndrome but this does not automatically mean they have been put on the Register. When you speak to the GP about being registered, the needs and support of the person in health settings can be discussed. This information can be entered on the person's Summary Care Record (SCR) so that all health professionals at the practice know about their needs and how best to support them.

If the person is over 16 years of age or older, they must give their consent (see section in this resource about the Mental Capacity Act 2005):

- for information about their support needs to be added to their SCR
- to which information can be shared and with whom

**It's never too early (or late) to join your GP's Learning Disability Register; you can join at any age. It's a good idea for children with a learning disability to join the learning disability register at an early age. This means adjustments and support can be put in place before they reach adult services.**

## Reasonable adjustments in health care

You may have heard of the term 'reasonable adjustments' and wondered what it meant. Since the Disability Discrimination Act (1995) and the Equality Act (2010) (this does not apply to Northern Ireland) public services are required by law to make reasonable adjustments to help remove barriers faced by people with disabilities when trying to use a service. The duty under the Equality Act to make reasonable adjustments applies if you are placed at a substantial disadvantage because of your disability compared to people without a disability or who don't have the same disability as you.

So for people with physical disabilities reasonable adjustments may include changes to the environment like ramps for the ease of wheelchair users. For people with learning disabilities 'reasonable adjustments' may include easy read information, longer appointments, clearer signs at the practice, help to make decisions, changes to policies, procedures and staff training.

**If a patient with Down's syndrome is NOT on their GP's Learning Disability Register then reasonable adjustments to care for that person cannot be anticipated and made.**

## Resources

The Family Planning Association <https://www.fpa.org.uk/shop/home> (see 'Working with people with learning disabilities') has resources to help you talk to your child about growing up and information about contraception and sexually transmitted infections. They also produce 'All about us' – a CD Rom for people with a learning disability on growing up, personal and sexual relationships. It is also possible to identify local contraception and sexual health clinics on their website.

*Jason's Private World, Kylie's Private World, You, Your Body and Sex.* These are comprehensive Sex Education DVDs for people with learning disabilities. They are produced by [www.lifesupportproductions.co.uk](http://www.lifesupportproductions.co.uk)

Couwenhoven, T. *Teaching Children with Down Syndrome about Their Bodies, Boundaries, and Sexuality. A Guide for Parents and Professionals.* Woodbine House (available from online booksellers)

Easy health website [www.easyhealth.org.uk](http://www.easyhealth.org.uk)

This website has downloadable easy read information about all aspects of health and healthcare much of which is free of charge. A resource called 'Let's talk about puberty' can be found at this link:

[http://www.easyhealth.org.uk/sites/default/files/Lets\\_Talk\\_About\\_Puberty.pdf](http://www.easyhealth.org.uk/sites/default/files/Lets_Talk_About_Puberty.pdf)

The BBC also have some resources at the Personal, Social and Health Education (PSHE) section of their website:

<http://www.bbc.co.uk/education/subjects/zqtnvcw>

including a section on PSHE for young people with SEN:

<http://www.bbc.co.uk/education/topics/zr9dxnb/resources/1>

Books Beyond Words <https://booksbeyondwords.co.uk/>

Hollins, S. et al. *Susan's Growing Up*. A book using pictures to explain the changes occurring in puberty.

Hollins, S. et al. *Keeping Healthy 'Down Below'*. A book using pictures to support women who are invited to have a smear test.

Hollins, S. et al. *Looking After My Breasts*. A book using pictures to explain breast screening and to raise breast awareness.

Hollins, S. et al. *Looking After My Balls*. A book using pictures to help men with learning disabilities to learn more about their testicles and how to look after them.

Bailey, H. et al. *Loving Each Other Safely*. A book using pictures to explore what you need to do to stay healthy and safe in a loving relationship.

Hollins, S. et al. *Falling in love*. A book using pictures that explores the ups and downs of Mike and Janet's relationship.

Hollins, S. et al. *Hug Me, Touch Me*. A book using pictures to help people talk about safe ways to make friends.

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The Down's Syndrome Association provides information and support on all aspects of living with Down's syndrome.

We also work to champion the rights of people with Down's syndrome, by campaigning for change and challenging discrimination.

A wide range of Down's Syndrome Association publications can be downloaded free of charge from our website.

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