



## **Adolescence and sexuality - Information sheet**

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### **Introduction – sexual rights**

The basic rights of young people with Down's syndrome (as with anyone else) include that they:

- Exist as sexual beings, and enjoy happy, healthy relationships.
- Receive accessible advice and support to enable them to enjoy sex, if they so choose, to gain personal satisfaction and to feel comfortable about themselves, their desires and their sexuality, which may include marrying or forming ongoing sexual relationships or remaining celibate.
- Receive contraceptive advice and services to avoid pregnancy and the risk of sexually transmitted infections.
- Enjoy parenthood if desired. Young people should be helped to develop necessary parenting skills, with appropriate counselling and teaching.
- Choose to avoid parenthood, or seek an abortion.
- The right not to be sexually abused and to be protected from sexual abuse.

### **Why is it important to address the issues of sexuality and relationships (SRE)?**

Issues may arise when families and professionals consider approaching this topic because:

- They are aware that people with learning difficulties may be vulnerable.
- Their own personal experiences and attitudes may colour or act as a barrier to supporting the young person.
- They are frightened of getting it wrong and of not having the skills or knowledge to tackle the issues.
- Parents/ carers and staff are often embarrassed to address the issues and need help in developing knowledge, skills, awareness and strategies for effective work.

It is important to find a balance between helping young people to understand and experience different kinds of relationships, and empowering them with the skills they need to protect them from any kind of abuse. The protection of vulnerable people is crucial and their welfare must be considered at all times. Risk assessment should be undertaken. The restrictions that the law places on everyone regarding sexual activity also apply to young people with Down's syndrome, e.g. sexual activity should not occur in places that may offend people or be abusive. Staff should always be working in an anti-discriminatory way, and need to understand people's social, ethnic and cultural backgrounds. Your own personal attitudes to sex cannot take precedence over your professional duty.

## Issues to do with adolescence

Around the start of adolescence young people with Down's syndrome will often become aware of their disability and struggle to come to terms with their 'differences'. They see their school friends and siblings doing things that they are not doing, like going out on a date, going to town by themselves, and generally enjoying a more independent lifestyle. This can be a very frustrating time for the teenager with Down's syndrome. Adolescents with Down's syndrome will want to explore their sexual feelings, some of which may be quite confusing.

## Dealing with sexuality

It is essential that staff and family explore ways of teaching appropriate public and private behaviour such as shows of affection, masturbation or seeking consent in relationships. If clear, explicit input is given on appropriate behaviour in all contexts then as staff and family we must give clear, consistent messages back eg not holding hands or hugging the young person in school or public places. This is a time when careful counselling and guidance to reduce the risk of sexual abuse will be helpful.

## Sexual development

Almost all young women with Down's syndrome ovulate, and the average age of beginning menstruation is between eleven and thirteen years, so that preparation for menstruation should start at Key stage 2 for those girls showing signs of puberty. The menstrual cycle occurs every 26 – 34 days in about two thirds of young girls. The menstrual flow generally lasts for, on average 4 days.

Most girls with Down's syndrome cope with menstruation well, looking after their own needs independently. The manufacturers of tampons and pads produce clear, well illustrated information about how to deal with periods for girls with learning difficulties – and provide some free samples. If menstruation looks imminent make sure that they go to school prepared with pads, or whatever they have decided to use in their school bag, along with spare underwear, and that staff are informed. For more information see the DSA Information Sheet on menstruation.

The majority of studies available to us concerning fertility and pregnancy are from the time when many people with Down's syndrome were in institutions, in segregated wards, and therefore not having sex at a normal rate. In the past young women with learning disabilities were often sterilised without their consent to prevent unwanted pregnancy. We therefore do not know about fertility rates - of 30 reported pregnancies in women with Down's syndrome, about half of the children also had Down's syndrome.

The development of primary and secondary sexual characteristics for pubescent boys with Down's syndrome is the same as that for their typically developing peers. There is some evidence that the testicles may be larger and the penis slightly smaller, but this is not statistically significant.

With regard to fertility in men with Down's syndrome, there are only reports of a few children being fathered. This may reflect lack of opportunity rather than lowered fertility. There are still many unanswered questions relating to men's sexual function, sperm production and fertility.

## What about contraceptive advice?

These days it is accepted that young people with Down's syndrome should have access to contraceptives when they choose to be sexually active, accompanied by appropriate practical advice on their use. Depending on the young person's level of learning ability, some contraceptives may be more suitable than others. This should be a matter of consultation between the young adult, support/teaching staff and parents/carers, respecting the young person's rights to have their voice heard.

There are some reliable long-term contraceptives for young women, eg oral contraceptives, the Depo-provera injection, or an implant. Intrauterine devices can cause heavier vaginal bleeding and other risks of infection. Condoms (male and female - Femidom), if used correctly, are the only methods of contraception that will provide protection from many, although not all, sexually transmitted infections.

Some schools have organised mock family planning clinics so that pupils can practice going to a clinic and asking for what they want. These mock clinics are followed up by an accompanied trip to an actual clinic. For more information contact your local education authority or family planning clinic.

### Sex Education

It is important that young people are empowered by education to seek help and to say no if they are coerced into activities they do not like.

Good information ensures that pupils with Down's syndrome:

- Know what is appropriate and inappropriate behaviour.
- Recognise potentially threatening behaviour.
- Know how to reject unwanted attention.
- Know how to summon assistance.
- Understand how relationships work.
- Are equal within their relationships.
- Understand about pregnancy and contraception.
- Are aware of, and able to meet their own sexual needs in a private and safe place.

Most students with Down's syndrome are able to be included successfully in mainstream sex education lessons. Pupils should be included in PHSE/ Citizenship lessons, and some students will need a SRE target on their Individual Education Plan. Differentiated materials, according to the ability of the pupil, should reinforce the lesson, as in any subject. Students with Down's syndrome generally need additional one-to-one help when learning about sex education to help understand the vocabulary and concepts. They benefit from access to books with clear and simple pictures alongside the written word, while some will benefit from the use of additional symbols and signs. School staff should always work closely with and involve parents and carers.

### The law in relation to sexual activity

There are many laws relating to this. People with learning difficulties have the same rights and responsibilities in law as any other person. Exclusions may apply to people with very severe learning disabilities who are deemed unable to give consent in law. This only affects a very small percentage of people with Down's syndrome, at the least able end of ability. The new Sexual Offences Bill is still being amended. It aims to change many of the laws relating to people with learning disabilities and sexual activity.

### Sources of help

The following publications are intended to be used by young people with learning difficulties themselves and by school staff, parents and carers.

- Usbourne books (geared towards primary school children).
- The Family Planning Association's 'Talking together about growing up', and 'Talking together about sex and relationships'. (They are written for pupils with learning difficulties who are at the age of puberty). Scott and Kerr-Edwards.
- The Shepherd School in Nottingham publishes a set of 6 booklets for youngsters with learning difficulties dealing with issues around masturbation and menstruation.
- Books Beyond Words (The Royal College of Psychiatrists) have colourful clear pictures with no text. 'Susan's growing up' is concerned with a girl who has her first period, and 'Hug Me Touch Me' explores inappropriate behaviour to social/sexual meetings.
- Down's Syndrome Scotland 'Let's talk about Puberty'

- Talk to Me - a guide for mothers and daughters with Down's syndrome produced by DSA New South Wales, from [www.dsansw.org.au](http://www.dsansw.org.au).
- 'Ready, Steady, Change' is a comic book about puberty for boys who have learning difficulties.
- 'Let's do it' – Johns et al. (1997) - Creative activities for sex education for young people with learning difficulties. 80 drama based activities. Also 'On the Agenda' – Scott (1994).
- There are some good mainstream books that deal with stranger danger in story form that are helpful in teaching about potential abuse e.g. 'We can say 'No''
- Factsheet no.32 from the Sex Education forum (2004).
- Male and female cloth models available from Jane Fraser on 01684 594715 or [brook@revjane.demon.co.uk](mailto:brook@revjane.demon.co.uk)
- [www.howitis.org.uk](http://www.howitis.org.uk) – free downloadable signs, symbols and pictures for use in communication about emotions, choices and relationships.
- [www.do2learn.com](http://www.do2learn.com) – free downloadable signs for use in communication about emotions, schedules and routines.
- Hollins and Roth (1994) 'Hug Me, Touch Me' and Hollins and Sinason (2001) 'Susan's growing up' - Books Beyond Words, Gaskell, St George's Hospital Medical School

### Further Reading

- Blake S (2002) – '*Sexuality and Relationships Education – a step-by-step guide for teachers*' – David Fulton Publishers
- Brook (2003) – '*Living Your Life*'.
- DfES – Sex and relationships Education Guidance (2000).
- National Children's Bureau – '*Sex and Relationships Education for Children and Young People with Learning Difficulties*'. [www.ncb.org.uk](http://www.ncb.org.uk)
- Drury J '*Holding on, letting go*' - Souvenir Press, 2000. Tel. 020 7454 0454.
- DSA Journal Issue 105 – Article '*Sexuality Education: Building a foundation of healthy attitudes*' by Terri Couwenhoven.
- Ebdon, Hopkins and Hayes '*Ready, Steady, Change*' - Gloucestershire Health Promotion Resources Service Tel. 01452 429363.
- Franstone and Katrak (2003) '*Sexuality and Learning Disability - A resource for staff*' FPA, 2-12 Pentonville Road, London N1 9FP
- Meredith S (1985) '*Growing Up: Adolescence, Body Changes and Sex*' Usbourne Books
- Pithers D and Greene S '*We can say No*' Pub. 'Tell a Story'
- Pueschel and Sustrova (1997) '*Adolescents with Down syndrome*' Paul H Brookes
- Sex Education Forum 020 7843 6000, [www.ncb.org.uk/sef](http://www.ncb.org.uk/sef)
- Shepherd School (1999) Tel. 0115 915 3265
- Schwier and Hingsburger – '*Sexuality – Your Sons and Daughters with Intellectual Disabilities*' – Jessica Kingsley Publishers - [www.jkp.com](http://www.jkp.com)
- Voice UK (2003) '*Stop – No More Abuse*' Voice UK, The College Business Centre, Uttoxeter New Road, Derby DE22 3WZ
- Thistle, S. (2003 – '*Secondary Schools and Sexual Health Issues – Forging the Links*' – National Children's Bureau [www.ncb.org.uk](http://www.ncb.org.uk)
- Wood, M. (2004) – '*Sexuality and Relationships education for People with Down Syndrome*' – Down Syndrome News and Update, Volume 4, Issue 2

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