

Growing up, sex and relationships

A guide for young disabled people



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Introduction

Disabled young people – all young people

Do you do any of these things?

- join in team sports at school
- enjoy geography lessons
- love going to the cinema
- dislike all green vegetables
- quite fancy someone in the year above
- tried smoking a cigarette
- do things your family don't know about.

All young people, including disabled young people, will tick at least one box on the list. Some will really enjoy going to the cinema, others will find it really boring. Some will detest the idea of sitting through another geography lesson, others will look forward to it.

Young people have likes, dislikes and interests which are often similar. This is true for all young people. All young people also at some point would like to know about sex and relationships. Often what you know about sex is from home, or from friends, the TV or internet, as well as from



school. It doesn't just happen when you're young – throughout your life you continue to learn about love, relationships, sexual health and wellbeing.

This leaflet is for disabled young people. It has information that might help you to find answers to some questions you might have about sex and relationships. We hope it is helpful. There is lots of information and advice available for young people about sex and relationships and all things related to them. We have listed some ways of getting more help throughout this leaflet so you can get more information if you want.



1 Friends and relationships



For all young people, growing up is not just about having sexual partners. It's about changing on the inside and outside. You will start to have interests in new things, want to try new activities, maybe experiment with the way you dress and look.

On the outside you will start to change too. Growing up is about learning about being comfortable with who you are. This is often very hard! Many young people feel sensitive about the changes happening to them at this time. This is normal – remember all your friends are going through the same thing.

It is great to have a group of close friends who you know you can rely on. Friends are there when you need them and they value you as part of their lives. Friendships develop over time and can be one of the most important aspects of young people's lives as they grow up. You learn about life together, commiserate each other's mistakes and celebrate each other's successes.

“ I had a strong group of friends and I'm mobile enough to get about most places. My friends always made an effort to help me keep up and are well practised at helping me dress. ”

Making friends

If you go to a mainstream school where there are few or no other disabled young people, you might feel like you want to find opportunities to contact other disabled young people who may have similar experiences to you. It is sometimes helpful to be in contact with people who share similar experiences to you. You could do this by getting in contact groups that already exist, going to clubs or starting your own group locally.

If you attend a special school, especially if it's outside of your home area, you might want to join in with local activities either near your school or home so you get to mix with young people who are from different areas.



Ask if you can invite friends home or if it's possible for you to visit them at home. You might have to find out if their house is accessible first.

Making friends isn't always easy, but here are some tips. You could:

- do something you enjoy, like take a class or join a club with people who share the same interests
- volunteering is a great way to meet people
- smile!
- be genuinely interested in your friends, listen to what they have to say
- respect the opinions of others, we are all different
- be generous with compliments
- make the effort to stay in touch
- accept all invitations!
- be the friend you would like to have.

If it is not possible for you to visit much or attend local clubs you could try keeping in contact by phone or social media with your friends.

Find out about local clubs that you could go to. Ask who goes already, and if they are specifically for disabled people or for everyone.

“ At sixteen all my friends had boyfriends and I hadn't and I wondered then if my disability was the reason. I didn't know anyone else with a disability so I couldn't swap notes and whilst my friends listened they didn't know how I felt. ”

How confident are you?

Feeling good about yourself and how you look can boost your self-confidence. You should:

- wear the clothes you want – that you feel comfortable in
- wear make up if you want to
- choose nice perfume, body spray, deodorant and shampoo you like
- be assertive and think about getting what you want
- be proud of who you are
- only answer questions you want to about your condition

- be good at something
- make and be involved in decisions that affect your life
- learn about and manage your condition as you get older.

“ I have always had a positive attitude toward my body image. I have to choose clothes that suit my body shape and that are easy to take on and off but that applies to everyone to some extent. ”



Peer pressure

It is really important to have friends of your own age. It is great to have a group of friends and feel like you are special to them. Sometimes though, these or other friendships can be uncomfortable. This can happen when young people start to experiment with being more independent and want to try new things like smoking, going to places which they know might be dangerous, taking drugs (which could affect medication you are taking) or by having sex.

It can be very difficult to resist if friends are trying to pressure you into doing something you don't want to do. You might worry that people will stop being friends with you if you don't join in. Actually, people admire those who have their own opinions so even though it feels horrible, it is better to only do things you want to, rather than things you think you should do to fit in.

“ My role models are the late Christopher Reeves and Stephen Hawking. Both refused to lay back and pack in and have shown the world that disabled people can be just as good if not better than the mainstream world. ”

If you are being hurt or abused by an adult or someone your own age, tell someone. It is not your fault, and you need to ask somebody to help you. You might feel this is too difficult. It can feel difficult talking about feelings and asking for help, but if you talk to someone it will help get it stopped. If you're not sure who to talk to call Childline – see below.

What about bullying?

Bullying takes many forms, and may include verbal abuse, physical attacks, and racial harassment. All bullying is unacceptable, both in and out of school.

Often with young people bullying can be teasing or name calling. This can be really upsetting. Tell someone what is happening so they can help you deal with the situation. Schools must protect all pupils from bullying. Sometimes people don't

understand about difference. If the teasing is about your condition you could:

- have some phrases you use to say something about your condition to others, (if you think they need to know). This will inform the other person and you will be confident in saying what you want about yourself which will encourage others to do the same.
- offer people another way of explaining your condition that you are happy with, if you're not happy with the way people describe your condition. Like if your parents are explaining to a new teacher – ask to do this yourself or make sure you are happy with what they say.

If you're being hurt or bullied call Childline and speak to one of their counsellors on the phone or online and get support from other young people.

> ChildLine

Helpline for children and young people in who need advice and help or who are in trouble/danger

 Helpline 0800 1111

 www.childline.org.uk



2 Growing up



Growing up from being a child into being an adult is a long process. It begins as different hormones are produced and start to make changes to your body. This is the start of puberty. All young people go through puberty at some point, usually between the ages of 9 to 17. Some young people with very rare medical conditions may have medication to start the process.

During puberty, everyone develops at different rates – in fact, changes in your own body will happen at different speeds and times too. Although this may make you feel worried it is important to remember you are not alone – everyone is going through it!

Boys

The beginning of puberty for boys usually starts between the ages of 10 and 16 and ends between 14 and 18. The main body changes for boys are:

- your genitals (scrotum and penis) start to grow
- hair begins to grow under your arms and around your genitals

- you may grow in height and weight, often in quick bursts
- your voice breaks and becomes deeper
- you may sweat more and get spots
- you may wake up one morning to find you have had a wet dream. This is when semen is released from your penis leaving a patch on your sheet slightly wet – this is perfectly normal
- later you will get more facial hair and you might start shaving
- you may feel moody.

Girls

The beginning of puberty for girls starts between the ages of about 9 and 15. The main body changes are:

- you may grow in weight and height, often in quick bursts
- your breasts and nipples grow larger. You might have tingling or sore breasts, this is normal
- hair grows around your genitals and under your

- armpits
- your skin and hair might get greasy, you might get spots
- you will sweat more
- later, you will start to have regular periods (menstruation). It may take some time for them to become regular. They usually last a few days and happen about once a month. It might be helpful for you to start a diary of when your period starts so you know when to expect the next one. You will also be able to plan and have pads or tampons with you
- you may feel moody.

You will learn about these changes at school in sex education classes and other lessons. You might want to talk to your teacher before or after these classes, especially if you have any worries or concerns. If you don't want to talk to your teacher you could ask questions at home or contact one of the organisations listed on page 14. Questions might be:

- will my body go through all the changes at puberty?
- will I ever have a relationship?
- will I be able to have sex?
- will I be able to have children?

It might be helpful to contact organisations that know about your particular condition. They will be able to give information on how it may affect your puberty and sexual development.

Masturbation

Discovering your body and what it can do is a natural part of growing up and, as much as possible, every young person should be given the opportunity and privacy to explore the parts of their body that feel good to touch.

Masturbation – when a boy strokes his penis or a girl strokes her clitoris because it is pleasurable – is a natural expression of sexuality. As a disabled young person you might need to ask for some changes to be made so you can learn about this.

“ Splints stopped me from playing with myself, when younger when you want to explore but now splints are no longer needed. Great! I found an adaptation of a normal way due to hand problems but you just get on with it ”

Ask your family members and any personal assistants who work with you to give you a little more privacy as you grow up, and if it is helpful to you, ask them to knock and wait a moment before coming into your bedroom or the bathroom. It may be that exploring your body or masturbating is difficult due to your condition. However, by experimenting you may find ways to do this.

For example, night splints can be a barrier to exploration of the body. While it is very important that these be worn, you may like to ask your doctor whether it would be ok to occasionally not wear them at night.

It is important for all of us that we are comfortable with our body and for this to happen we need to get to know our body better.

Personal care

Intimate personal care is a necessary part of some disabled people's lives. Many young people feel self-conscious about the way they look as their bodies grow and change and may begin to feel shy of others seeing their body. This is perfectly normal. You need to feel happy and comfortable with who helps with personal care and have confidence in them.

Because growing up is about becoming more independent, you could ask for more privacy or to try and do things differently to give you more independence. You could find out, with them, if there is any equipment you could have to make it possible for you to do more of your personal care yourself. You could ask to see if fewer people can be involved in your personal care.

3 Developing sexual relationships

Being friends, making each other laugh and knowing you can trust each other are all very important aspects of a loving relationship.

Sex is usually a small part of this wider picture. Sexual desires and behaviour are a normal and exciting part of growing up. At first it can be a little confusing and strange to have these different feelings and sensations and it can take time to get used to.

It might seem like everyone else is involved in relationships, knows all about sex or is having sex. This is very unlikely to be the case! Most young people do not start to have sex until they are older.

If you do have a girlfriend or boyfriend that's great – being in a loving and caring relationship doesn't mean you have to have sex or be involved in any sexual activity unless you feel comfortable with this.

You might find that you are attracted to other young people the same sex as you; this is just as common for disabled young people as it is for non-disabled young people. It is up to you who you want to tell about having gay or lesbian feelings. If you feel you can't talk to your friends and family, but still need to talk about your feelings, there are organisations that help disabled gay and lesbian people. These are listed at the back of this leaflet. You will need to think about the same issues as young people in opposite sex relationships when you are considering what you want that relationship to be like.

Some people believe you should be married before you have sex whilst others think it is more important to be in a strong relationship. Some people believe that gay or lesbian relationships are wrong whilst the majority of people think they are acceptable. You need to make your own choices and decisions about what is right for you.



You might have religious or cultural reasons for not wanting to get involved in a sexual relationship, which is fine. It is important that you think about what you want and what you might feel comfortable doing, then tell your partner. You need to feel absolutely certain that you want to be involved so it's important to say what you want. Try and talk to your parent or carer, or another adult you trust before making big decisions. The organisations at the back of this booklet can also give advice.

If you do decide you want to be in a sexual relationship, there are many ways for you and your partner to express your sexual feelings. You might want to talk about how your condition will affect what you do.

“ I was quite nervous on my first sexual experience and what my partner would think of my body ”

“ If your partner is disabled too what will their needs will be? You can experiment to find positions which are comfortable for you both. ”

Sex doesn't just mean sexual intercourse or having an orgasm. Cuddling and kissing your partner can also be satisfying and pleasurable for you both. You need to think responsibly about using contraception and safer sex and what methods will work best for you and your partner. You need to discuss what you will use and be happy that you both agree.

Sometimes relationships don't work out. It might be that you don't feel attracted to each other any more, or it might be that one person wants to move on so ends the relationship. When relationships which have been intimate end it can be very upsetting, frustrating and unsettling. This is another part of growing up and learning about how relationships work. Usually, your friends and family are particularly valuable and good people to talk to if this happens.

If you do not have a partner that's also perfectly normal! Many young people do not feel ready to be in a relationship with a girlfriend or boyfriend until they are older. This means they still go out with friends and have a great time, but they also get time to learn about themselves and who they want to be.

You should get the opportunity to learn about these issues at school in Sex and Relationship Education (SRE) classes. These classes should help all young people to learn about relationships, emotions, sex, sexuality and sexual health.

Sometimes disabled young people are not offered sex education, or the classes they have don't talk about their particular needs. If this happens, you could ask your teacher about when the classes will be. You could also ask them for some time after the class so you could ask specific questions which you might not feel confident asking in front of the rest of the class.



Don't bottle it up! If you have questions or concerns then talk to someone about them. Someone from your family, or you could contact one of the organisations listed on page 14 for a chat.

4 Contraception



If you are having sex, and don't want to get pregnant, you need to use contraception. You will also need to think about safer sex to avoid sexually transmitted infections. There are many different contraceptive methods to choose from. A GP (doctor) or Family Planning Clinic will help you choose the best one for you.

You will need to tell them about any medication that you take as they may affect the effectiveness of the contraceptive. You will also need to tell them of any allergies like latex. The staff need to know about your condition so they can help you choose the best method. You might need to get information from an organisation that knows about your condition then let the clinic staff know. For example, if you have epilepsy an IUD being fitted may trigger a reflex seizure.

Remember – any contraception only works if you use it properly!

Types of contraceptives

This is a short list of the most popular types of contraceptive. The organisations at the back of this leaflet can give you information in much more detail.

Contraceptive pills, injections and implants

Contain hormones, which stop the ovaries releasing eggs, or which thicken the mucus in the cervix, creating a barrier to sperm.

Prescribed medicines such as those for epilepsy and tuberculosis make these options less effective. They will not protect you against infections or HIV.

The intrauterine device – IUD (the coil)

A small plastic and copper device is put into the womb. It may stop sperm meeting an egg and makes the lining of the womb (uterus) less likely to accept a fertilised egg.

Intrauterine system – IUS (Mirena)

A small plastic device is put in the womb. It releases the hormone progesterone. It works by stopping sperm reaching an egg or makes the lining of the womb less likely to accept a fertilised egg.

These devices do not protect you against infections or HIV.

Diaphragm/cap with spermicide

A flexible rubber/silicone device used with a spermicide is put into the vagina, covering the cervix and creating a barrier.

Male and female condoms (condoms and femidoms)

Form a barrier, preventing sperm from reaching an egg. They are the only form of contraception that can offer some protection against sexually transmitted infections.

Emergency contraception

If you have sex without using contraception or think your contraception might have failed, taking emergency contraception will usually stop you from becoming pregnant. You must act quickly though, as emergency contraception can be used only for a limited time after having sex. You will need to contact your doctor or family planning clinic as soon as possible – emergency contraception is free if your doctor or other NHS service provides it. Women aged 16 or over can buy emergency contraception at most pharmacies.

When you are thinking about contraception, it is helpful to discuss this with an adult you trust. They can help you to decide what is best for you and will know your needs. But you can go alone to get confidential advice and treatment from your GP or a clinic even if you are under 16. Health workers have to keep what you tell them private unless they believe that you are being abused or that you do not understand the advice or treatment you are being given.

You can also get confidential advice from organisations such as Brook, listed at the end of this booklet.



5 Sexually transmitted infections (STIs)

Anyone can get a sexually transmitted infection if they do not have safer sex. This means using a condom if you have vaginal, anal or oral sex. There are at least 25 different Sexually Transmitted Infections (STIs). These include:

- chlamydia
- gonorrhoea
- genital warts
- genital herpes
- syphilis
- HIV.

You don't need to have a lot of sexual partners to get an STI, although the more partners you have, the greater the chance is that one of them may pass on an infection.

Often STIs have no symptoms so are difficult to detect. The most common symptoms are:

- unusual discharge or liquid from vagina or penis
- pain or burning when passing urine
- itches, rashes, lumps or blisters around the genitals or anus
- pain and/or bleeding during sex
- bleeding after sex and/or between periods.

If you think you might have an STI get it checked out as soon as possible.

Safer sex – how to avoid sexually transmitted infections

You should use a condom (male or female) correctly and consistently when you have sex to prevent the transmission of most STIs including HIV. A condom does not offer 100% protection against infections but it is the most effective method available.



Where to go for help and advice

Sexual health and genitourinary medicine clinics specialise in diagnosing and treating all STIs. Most large hospitals have a sexual health clinic and many areas have young people's sexual health advisory services. You can find details of your nearest clinic by:

- visiting the Family Planning Association (fpa) website www.fpa.org.uk/find-a-clinic
- call Brook or visit their website – 0800 0185 023, www.brook.org.uk
- looking in the phone book or searching online under genitourinary medicine, STD or VD
- calling the Terrence Higgins Trust on 0808 8021221
- calling NHS 111 (24hrs).

It's important to get treatment for an STI. Many are easy to treat with a range of medicines.

It is important to check how this might affect any other regular medication you take.

If you don't get treatment, some infections can start to damage your reproductive system and affect your general health.

6 Pregnancy

Becoming a parent is one of the biggest decisions you can make, and it is important to get lots of information and advice before having a baby.

If you find you are pregnant you will need to discuss your options with an adult you trust as soon as you can. Making a decision about what to do is a big step and you will need some support to do this. You will have to decide whether you want to have the baby, have the baby adopted or have an abortion. Discussing your options with an adult you trust will give you time to consider what you want to do.

There may be extra health issues to consider in relation to your condition. Organisations like the Disabled Parents Network, fpa or Brook can give you confidential advice. They are listed on page 14.



7 Being who you want to be

“ Exciting, scary, weird stuff, excellent all through, strange feelings but nice, took a long time, wicked mostly, makes you feel mature in the end. ”

This is what disabled young people have said about growing up and going through puberty, making friends and having relationships.

All of these things are common experiences as you move into adulthood.

Although the changes in your body and new experiences can be daunting they can also offer you great new adventures and opportunities. This is one of the most exciting and challenging times in your life! Everyone can take part in learning from these changes, making new friends, gaining independence, and finding new interests.

Make sure you do too!



8 Further information

! 0800 numbers are free from many mobile phones now, check with your provider.

> NHS Choices

Information for teenage girls on puberty, sex and relationships and health

📄 www.nhs.uk/livewell/teengirls/pages/teengirlshome.aspx

and for boys

📄 www.nhs.uk/livewell/teenboys/pages/teenboyshome.aspx

> Sexwise

From the BBC World Service. Information on sex, relationships and contraception in 22 different languages.

📄 www.bbc.co.uk/worldservice/sci_tech/features/health/sexwise/

> Brook

Free and confidential advice on sex, relationships, contraception and pregnancy for young people under 25. Including sexually transmitted infection (STI) testing, contraception and emergency contraception as well as counseling. It offers:

- a webchat service run by advisors - look for the blue tab in the bottom right-hand corner of your screen.
- a text chat service run by advisors 07717 989 023 (standard SMS rates).
- the Ask Brook 24/7 tool
- 📞 Helpline 0800 0185 023 (Mon-Fri 9am-5pm)
- 📄 www.brook.org.uk

> fpa (Family Planning Association)

Information on contraception and STIs, unplanned pregnancy and abortion and your nearest clinic.

📄 www.fpa.org.uk

> Switchboard

Helpline open 365 days a year supporting the lesbian, gay, bisexual and transgender (LGBT) community.

📞 Helpline 0300 330 0630

📄 <http://switchboard.lgbt>

> Young Stonewall

Help and advice for the young LGBT community, including coming out, health and wellbeing, and staying safe online.

📄 www.youngstonewall.org.uk

> Disabled Parents Network

Support, advice and information for disabled parents and those planning to become parents. Helpline 0870 241 0450

📄 www.disabledparentsnetwork.org.uk

> Disability Pregnancy & Parenthood

Practical information and peer support online for disabled parents, with articles from parents sharing their personal experiences, including Tanni Grey Thompson.

📄 disabledparent.org.uk

> **British Pregnancy Advisory Service**


Clinics offering information and treatment for unplanned pregnancy including counselling to help women choose between options.

 Helpline 03457 30 40 30

 www.bpas.org

> **The Foundation for People with Learning Disabilities**

Tips for people with learning disabilities on staying safe on social media and online.

 www.learningdisabilities.org.uk/publications

> **ChildLine**

Helpline for children and young people in who need advice and help or who are in trouble/danger.

 Helpline 0800 1111

 www.childline.org.uk

> **Thinkuknow**

Website with information for children from age 5-14+ on how to stay safe online. It has information for teenagers on sex, relationships and the internet, including how to spot 'paedos, creeps and weirdos', what to do if you're worried about a friend, 'sexting', naked pictures and porn. Also information on staying safe if you are gay.

 www.thinkuknow.co.uk

This resource was originally developed by Contact a Family together with:

> **Council for Disabled Children**

The Council for Disabled Children provides a national forum for the discussion, development and dissemination of a wide range of policy and practice issues relating to service provision and support for children and young people with disabilities and special educational needs.

> **National Children's Bureau**

The National Children's Bureau (NCB) promotes the interests and wellbeing of all children and young people across every aspect of their lives. NCB advocates the participation of children and young people in all matters affecting their lives. NCB challenges disadvantage in childhood.

> **Sex Education Forum**

The Sex Education Forum is the national authority on sex and relationships. It is an umbrella body of organisations that work together to share good practice and to articulate a common voice in support of all children and young people.
www.sexeducationforum.org.uk

Original editor Helen Christophers

We would like to thank all of the young people and their parents who have been involved in the development of this leaflet. Their views and experiences have been essential to its production. The quotes in this booklet are taken from a survey of parents and young people conducted by The Arthrogyposis Group.

How Contact a family can help

Contact a Family is a UK charity that provides support and information to families with disabled children, whatever the condition or issue.



Our helpline

Our freephone helpline can give advice about any aspect of raising a disabled child, including help with finances, education, emotional and practical support.

 **0808 808 3555**  **helpline@cafamily.org.uk**



Guides for parents

We have a range of free guides for parents, including:

- *Personal Independence Payments and other benefits at 16*
- *Preparing for adulthood*
- *Holidays, play and leisure*
- *Aids, equipment and adaptations.*

A full list of our guides is at the link below. All our guides are free to parents who call our helpline, and are free to download.

 **www.cafamily.org.uk/publicationslist**  **0808 808 3555**

Get in contact with us

209–211 City Road, London EC1V 1JN

 020 7608 8700

 info@cafamily.org.uk

 www.cafamily.org.uk

 www.facebook.com/contactafamily

 www.twitter.com/contactafamily

 www.youtube.com/cafamily

Free helpline for parents and families

Access to over 200 languages

 **0808 808 3555**

Open Mon–Fri, 9.30am–5pm

 helpline@cafamily.org.uk

Free family linking service

 www.MakingContact.org

contact a family
for families with disabled children



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