

Growing up, sex and
relationships: a booklet for young
disabled people



contact a family
for families with disabled children

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.

There are two booklets that go with this leaflet. One for parents and one for teachers to help them understand more about some of the things that are important to young people learning about sex and relationships.

Copies of this leaflet and the others are available free of charge from Contact a Family – telephone 0808 808 3555 (Mon – Fri 10am to 4pm), textphone 0808 808 3556, or email helpline@cafamily.org.uk



friends and relationships

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
Have tried smoking a cigarette
Do things your family don't know about

All young people, including those with disabilities 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 or the TV 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 well-being.

This leaflet is for physically disabled young people firstly – although all young people can use it – it has particular information that might help physically disabled young people to find answers to some questions they might have about sex and relationships. We hope it is helpful to you. 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 at the back of this leaflet so you can get more information if you want.

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.

'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'

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 others mistakes and celebrate each others successes.

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

'My friends don't see I have limitations which is good but causes problems when I can't do certain activities like ice skating, 18 – 30 holidays, catching an underground with a wheelchair etc.'

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 emailing 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.

'Before the age of about 10 years old my mother used to dress me in long dresses because she thought it best to cover up my callipers. Only as I got older and expressed myself did I manage to try and dress a bit more trendy.'

'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 it is not possible for you to visit much or attend local clubs you could try keeping in contact by phone or email 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.

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 or body spray, deodorant, shampoo
- Be generous with compliments
- Be interested in your friends
- Be good at something
- Only answer questions you want to about your disability
- Respect the opinions of others
- Be assertive and think about getting what you want
- Be proud of who you are
- Make and be involved in decisions that affect your life
- Learn about and manage your condition as you get older.

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

'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'



'I am me and I am what I am, if people don't accept that, it's their hard luck'

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.

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. This might be difficult but it will help get it stopped. Organisations listed at the back of this leaflet can offer support.

What about bullying?

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

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. If the teasing is about your disability you could also try these things:

- Sometimes people don't understand about difference. It can be useful for you to have some phrases you use to say something about your disability 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.

- Are you happy with how other people describe your condition? If not, you could offer them another way of explaining that you are happy with. 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.

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!!

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 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

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

'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...'

- 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 9.

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 disability or 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

'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...'

a disabled young person you might need to ask for some changes to be made so you can learn about this.

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 disability. 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.



developing sexual relationships

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 ask your family and carers to knock and wait a minute before coming into your room or bathroom. 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.

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 disability will affect what you do.

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





Also, if your partner is disabled too what 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.

'The first time I...saw other people with arthrogyriposis with wives, husbands and young people, who were driving/working/living independently I never worried about my future.'

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 9 for a chat.

What you need to know 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 disability so they can help you choose the best method. You might need to get information from an organisation that knows about your disability 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!!

what you need to know



What types of contraceptives are there?

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 (EC) will usually stop you from becoming pregnant. You must act quickly though, as EC 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. Women aged 16 or over can buy emergency contraception at some 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 Sexwise, which are listed at the end of this booklet.

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

being who you want to be

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:

- calling fpa's (Family Planning Association) helpline on 0845 310 1334
- looking in the phone book under genitourinary medicine, (GUM clinic) STD or VD

- check the websites listed at the back of this booklet

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.

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 disability.

Organisations like the Disabled Parents Network, fpa (Family Planning Association) or Brook clinics can give advice. They are listed on page 9.

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!!





Useful organisations

Remember - 0800 numbers are free as long as you do not use a mobile phone.

Brook Advisory Centres

Provide free and confidential advice on sex, relationships, contraception and pregnancy to young people under 25.

www.brook.org.uk/

Helpline (recorded information) 0800 0185 023

Like it is

Information for 11-15 year olds on sexual health information and related subjects.

www.likeitis.org.uk/ Marie Stopes

Information Line: 0845 300 80 90

Gemma

National group for disabled and non-disabled lesbian and bisexual women.

Gemma, BM box 5700 London wc1n 3xx

Email: gemma@group@hotmail.com

Regard

National group of disabled lesbians and gay men.

secretary@regard.co.uk

Address regard, BM Regard, London wc1x 3xx

Sexwise

For young people. provides information on sex, relationships and contraception and on local services.

Helpline 0800 28 29 30 7am to midnight every day

www.ruthinking.co.uk/

fpa (Family Planning Association)

Provides information on contraception and sexual health and your nearest clinic.

Helpline 0845 310 1334

www.fpa.org.uk

Disabled Parents Network

Offers information to disabled parents and those planning to become parents.

www.disabledparentsnetwork.org.uk

Helpline: 0870 2410 450

Lifebytes website

For young people aged 11 – 14, has information about all aspects of health.

www.lifebytes.gov.uk/

Mind, Body and Soul website

For young people aged 14-16, information on all aspects of health and well being

www.mindbodysoul.gov.uk/

Playing Safe website

This site has advice about safer sex and avoiding sexually transmitted infections.

www.playingsafely.co.uk/

ChildLine

Confidential helpline for children who need advice or who are in trouble or danger.

Helpline 0800 1111

www.ChildLine.org.uk

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