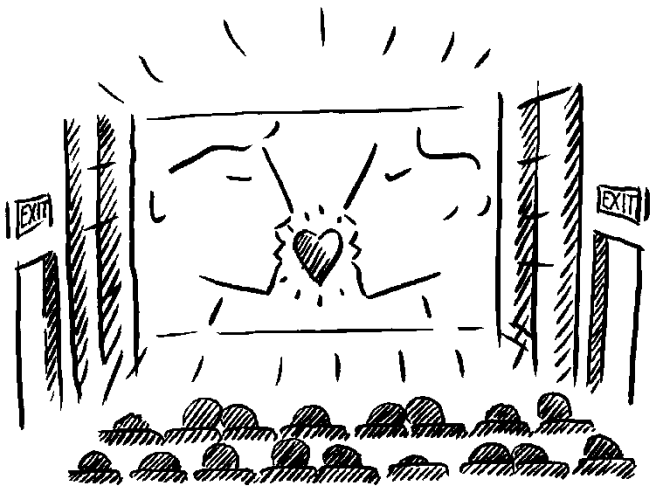


## CHAPTER 4

### Social lives and relationships



Friendships and intimate relationships are an important part of life. We all recognise the value of having friends who share similar interests, have fun with us, laugh at the same sort of things and share both the good and difficult times. For most teenagers their friendships are important to them. Young adulthood is the time when many make friendships that will last a lifetime. Friends can provide more support and advice than whole teams of professionals.

For teenagers with special needs, making friends and meeting up and going out with them can be trickier than for other teenagers – perhaps because of communication difficulties, mobility issues, or not being able to travel independently.

Experiences at school or college can affect young people's access to friends and leisure outside school. National research has found that many young disabled people experience isolation, loneliness and exclusion.

*'Ben's doing really well at the day centre in Seaford. He's starting to make friends with his peers, but the fact is they're so far away. It would be lovely to invite some of them back, if there weren't issues with transport. That's one of the downfalls about him going to a day centre out of his community.'*

We often have to do a lot to support our children's social life and help them meet new people or maintain friendships.

*'He'll go out now and again, but if he does go anywhere, we have to take him there and pick him up, because he can't really get the bus to go on his own.'*

Sometimes we even have to share our friends with our children because of the difficulties they face making their own friendships.

*'Friendship is the one area I get really sore about and every once in a while I have to take a step back. On the one hand, Oliver's great company, he's such a good laugh and we are good mates but I am his mum and there are times when I think "where are your own friends?" And what I find I have to do is double my friends up, and they've got busy lives. I've got to book them up twice. "If you come round at this time and Oliver can talk and then can we please go out another time when I can talk!" It's tricky.'*

### MAKING FRIENDS

Many of us meet our friends through a common interest – work for example, a sport, an evening class, or through other friends.

Those of us whose children need more support with friendships might start by thinking about what our children enjoys doing and then look for a club or an activity where they can meet other young people with similar interests.

It can be helpful to think about what other young people are doing, or to find places nearby that your child can go to on their own.

*'The pub's just over the road, so he will go over there which is really good.'*

## Local clubs and activities

There are lots of activities young people can try locally.

**Spiral** runs social clubs, leisure and sports activities (including music, drama, swimming and basketball) for adults with learning disabilities , they also run Spiral Wave Radio.

**Albion in the Community** has a range of activities for young people with special needs, including football.

**Cherish** runs holiday play schemes and youth clubs for young people with learning disabilities aged 13-18 and runs schemes for young adults with learning disabilities aged 18-25.

**Carousel** is an accessible creative arts project for people with learning disabilities that runs film, music and arts projects, as well as a regular club night called **Blue Camel** for over 14 year olds.

**Extratime and Sussex Central YMCA** have youth activity programmes in the holidays and a scheme to help disabled young people take up mainstream youth activities.

For young people who enjoy activities like climbing or canoeing, **Adventure Unlimited** offers opportunities locally and includes young people with special needs.

You can find contact details for all these organisations at the back of this handbook.

## Amaze's Compass Card

If your child is under 20 and has disabilities or special needs that significantly affect daily living, they may be eligible for a **Compass Card**. The card provides leisure discounts and special offers across Brighton and Hove and is managed by Amaze. The Compass Card includes almost 70 benefits, including free swimming at the city's main pools, cinema discounts, free gym membership for 16-19 year olds at seven local gyms, off-peak discounts at Brighton Bowlplex and much more. Offers include special needs-friendly classes called Compass Card Activities which are supported by Amaze. You can see the latest Compass Card Activities on the Amaze website at [www.amazebrighton.org.uk](http://www.amazebrighton.org.uk) (click the Compass Card link) or ring the Amaze helpline for more details.

## The Carers' Card

If your child has a Compass Card, you automatically qualify for a Carers' Card to look after your own health and wellbeing. Amaze develops the card and there are around 50 offers, including gyms, the Duke of York's cinema, complementary therapies and a range of classes. To apply, call 01273 295153 if your child is under 18, or 01273 295555 if they're over 18 – and have the Compass Card to hand because you'll be asked for the number on the back. Young carers aged 8 to 25 also qualify for a Carers' Card.

Children and young people with a Compass Card automatically qualify for **Gully's Day Out**, a scheme run by Albion in the Community which provides free days out to people with

disabilities and their friends and families. Venues that are signed up to the scheme include Cineworld, Bluebell Railway, Brighton and Hove Albion and Sea Life Brighton. Email [AITCGullyDayOut@bhafc.co.uk](mailto:AITCGullyDayOut@bhafc.co.uk) or call Christina Szwarc on 07823 884311 for details.

Brighton & Hove City Council has a list of local activities and sports opportunities. Call 01273 292724 for an **Active For Life** booklet or look at the website [www.activeforlife.org.uk](http://www.activeforlife.org.uk) It has a whole section aimed at young people.

You may also find Amaze's free factsheet, **Fun Things to do for All Ages**, useful. Call the Amaze helpline if you want a copy sent to you, or download it from the website at [www.amazebrighton.org.uk/resources/publications/factsheets](http://www.amazebrighton.org.uk/resources/publications/factsheets)

*'Before I started playing cricket my life was boring and I did not have many friends. Also I got bullied when I was at school. Now I have got lots of friends who will all stay with me for life and I meet more friends all the time.'* (Danielle, 18)

### Who else can offer support?

Some of us realised we couldn't be all things to our children and that being a friend was a different role to being a parent. We had to find ways to help them make their own friendships. This might mean having a carer or assistant who is a bit closer in age to them, who can take them out and about or to activities. If your child is under 18 and has a Children's Disability Team social worker, you could talk to them about getting direct payments to pay for a personal assistant.

If they are over 18, and they have a transition worker or social worker from the Adult Social Care team, discuss getting Direct Payments with them. If you have had no involvement with social care so far, your child will need an assessment of their

needs to see if they are eligible for support from social care. See the 'Social care' chapter (page 123) for more information. If you do get Direct Payments, the Fed has a noticeboard of personal assistants (PAs) looking for work and employers seeking PAs, and they can also help with managing the Direct Payments. Visit [www.thefedonline.org.uk](http://www.thefedonline.org.uk) or find out more in the Social Care chapter.

*'We use Direct Payments to pay for support for Rachel. Her PAs are her friends, because she has no one. She has no friends. She can't sustain a friendship. That's part of her difficulty. But I see these two carers as her friends.'*

**Aspire**, a local organisation that supports people with Asperger Syndrome, provides a trained volunteer mentor who works with adults with Asperger's. This is for a set period of time and there is a waiting list for support. The mentor is a mixture of a friend, a guide and sometimes a teacher. They also run a range of social and discussion groups and activities for adults with Asperger Syndrome. Visit [www.bh-impetus.org/aspire](http://www.bh-impetus.org/aspire) to find out more

**Assert** works with adults with Asperger Syndrome and high functioning autism. They run regular social groups, courses and support. Visit [www.assertbh.org.uk](http://www.assertbh.org.uk) for more information

*'They found a mentor for him, a man in his late 20s, early 30s. He's also got Aspergers, but he's out, he's got a job, he's got a flat, he's a great role model. He meets Oliver, usually once a fortnight, in the evening, for about an hour and a half and they just sit and eat cookies and drink milkshakes and just talk. He gets a lot out of that as well.'*

Not all young people find it easy to socialise. Some may prefer to socialise online – but you'll need to check this is safe. Mencap, Cerebra and Ambitious about Autism have produced a

useful guide for parents about internet safety. Download it at [www.mencap.org.uk/internet-safety-guide](http://www.mencap.org.uk/internet-safety-guide) or call the helpline and ask us to send you a printed copy.

## Helping children develop self-esteem

Growing up is about having relationships and growing into a confident adult who may have sexual partners and a range of close friendships. It's about developing self-esteem, a good body image and the confidence to be happy with who you are. It is also about developing a sense of responsibility for your own actions.

All children and families are different and what works for some may not work for others. What feels right for you and your child is very important. The following suggestions are from parents and disabled young people in *Contact a Family's: 'Growing up, sex and relationships: a booklet to support parents of young disabled people'*.

- Reinforce with your child the fact that everyone is different
- Encourage your child to take an interest in their appearance e.g. wear fashionable clothes
- Encourage your child to keep clean, use deodorant, wash their hair regularly and so on
- Be generous with compliments
- Remind them of the things they are good at
- If your child is self-conscious about certain aspects of their appearance, don't dismiss it, support them by helping them to dress in a way that will divert attention

## PUBERTY

Young people with special needs go through puberty like any other child. Although puberty may be early for some and

delayed for others, it is a biological and emotional process that has to happen.

As far as possible all children and young people need to be prepared for the changes to their body before they take place. These are summed up as follows:

- Body hair starts to grow
- Breasts begin to grow for girls and periods begin
- For boys, the voice starts to break
- Mood swings can be more noticeable
- Young people will have sexual desires and boys will start having wet dreams

You may want to talk to a teacher at school about your child's sex education programme, especially if you feel they might be anxious or if you feel they might benefit from some preparation at home beforehand. Your child may also need some points to be reinforced at home afterwards.

They may come home with worries relating to their medical condition or disability. For example:

- Will my body go through the changes at puberty?
- Will I be able to have sexual relationships?
- Will I be able to have children?
- What if my voice doesn't break properly?
- What if the bleeding doesn't stop?
- I don't want breasts!

If possible, you need to be able to allay their fears. If you don't have the answers, you could contact the support group for your child's condition.

You may also find it helpful to contact the FPA (formerly the Family Planning Association). It produces a range of leaflets

and a DVD to help parents overcome difficulties talking about puberty and sexual issues with their children.

### **Changes for girls**

Having periods is one of the visible signs of growing up. It marks a new phase in the development of emotional and physical maturity. Ideally information should be given well before the first period so that the young person can be reassured it's a normal process. She needs to know she's menstruating and it will stop in a few days. Once a regular cycle is established, it may be useful to keep a diary of the menstrual cycle, or encourage her to, so she knows roughly when it will happen again.

The age at which menstruation may begin can vary – as young as nine is not uncommon. There is nothing wrong if menstruation begins early, or if it starts much later than average.

Make sure your daughter has information about pads and tampons, what they are for and how they are used. Buy some products, take them out of the wrappings to show her and perhaps demonstrate on a doll. Usually pads are quite easy for a girl to put in place herself, but sometimes she may need help because of the nature of her special needs or disability. Emphasise the importance of personal hygiene and cleanliness during menstruation.

It is important to emphasise that periods are a private thing and she should not talk to everybody about it. But let her know that she can talk to you, her teacher, the school nurse or a female friend.

### **Changes for boys**

Most young men with special needs or disabilities are likely to go through adolescence and puberty at about the same time as everyone else. Tell your son about wet dreams and that they are perfectly normal and may sometimes happen when he's asleep. Your son needs to understand that ejaculation can also occur during masturbation.

Boys may be embarrassed or worried and need reassurance that this is a normal part of growing up. They also need to know that this is a private thing, and that semen should be wiped up with a tissue and thrown away. Along with personal hygiene, this is a responsibility which is part of growing up.

### **Useful information about puberty**

There are a number of good resources to help you explain changes during puberty to a child with learning disabilities. 'Talking together about growing up: a workbook for parents of children with learning disabilities' by Lorna Scott and Lesley Kerr is available from FPA. See their website [www.fpa.org.uk](http://www.fpa.org.uk) or ring their helpline on 0845 122 8690 and ask what resources they have.

### **Masturbation**

Discovering one's body is a natural part of growing up and as much as possible, every child should be given the opportunity and privacy to explore parts of their body that feel good to touch. It is important for all of us to be comfortable with our body and for this to happen we need to know our body. Masturbation – when a boy strokes his penis or a girl strokes her clitoris because it is pleasurable – is a natural expression of sexuality. For a disabled young person there can be issues over both opportunities and privacy.

As your child grows up, you should try to knock and wait a moment before going into a bedroom or bathroom. Encourage others, such as support workers, to be equally respectful.

Some children and young people masturbate because it helps them feel warm, relaxed and loved. Young people with learning disabilities sometimes don't understand the difference between private and public. It is important to try and support children to know what they are doing is natural and not wrong, but that it is only right on their own in a private place, like their bedroom or in the bathroom.

## SEXUAL RELATIONSHIPS

Parents are key people in teaching their children about sex and relationships, helping them cope with the emotional and physical aspects of growing up and preparing them for the challenges and responsibilities that sexual maturity brings. Most of us found it uncomfortable talking to our children about growing up, puberty and sex. It's not just parents of teenagers with special needs that feel like this, but it can seem more difficult when your child has a disability or special needs.

Our young people are sexual beings like everyone else and have the same rights to good sex education and sexual health care. They deserve the same opportunities for socialising and sexual expression as their non-disabled peers. As parents of disabled young people, we have a special role in providing support and guidance to help our children embrace the challenges of adolescence and grow into informed, confident adults.

Disability can affect sexual development. For example, a lack of privacy and independence in daily living can mean a young disabled person misses out on early sexual experiences like kissing and flirting. Cultural prejudices, professional and parental attitudes, lack of social opportunities and a lack of

appropriate services can also stop disabled people achieving sexual and emotional fulfilment.

Some families and professionals working with young people may avoid discussing issues of sexuality. Fear of exploitation and pregnancy, or the reluctance to see their child as a sexual being, makes some parents unwilling or unable to tackle issues surrounding sex and relationships. Many of us have had a difficult journey in accepting our child as a young adult who has their own values and opinions.

Young people who understand the changes in their body during puberty can find the experience frightening and bewildering. Especially as without 'formal' sex education, learning can be a mish-mash from the playground, TV and internet etc. There are many myths and a real risk of misunderstandings and misconceptions.

Avoiding the issue of sex and sex education will not make your child's sexual development, feelings and desires go away - but it may make your child feel confused and fearful. Open communication that respects your child's own attitudes and beliefs is key.

## What does my child need to know?

Every young person is different, but here are a few ideas that you might want to consider.

- How their body works and grows
- What changes to expect at puberty
- The name and function of the sex organs
- Relationships and responsibility
- How society expects them to behave in public
- Keeping safe from exploitation and abuse
- Preventing unplanned pregnancy and sexually transmitted infections

## When and how to talk about sexual relationships

- Start talking to your child early so that problems are less likely to arise – certainly before puberty
- Talk openly and casually – while you're doing something else, like washing up or driving the car – as this gives the message that it's not something to be secretive about or afraid of
- Be open about your own beliefs and attitudes, but be prepared to discuss them and listen to your child's point of view
- Read books, leaflets and watch DVDs or use something on TV for example to trigger a conversation
- Reinforce the fact that the most important aspects of a relationship are love, friendship and mutual respect
- Listen rather than judge. Try asking them what they think
- Answer questions and don't be afraid to say: 'I don't know – let's look it up together'
- Don't bombard your child with questions or talk too much. Many children say it's awful to get a formal lecture on sex or have questions fired at them. 'Little and often' can be best to give them an opportunity to absorb information, rather than lots of detail all at once
- Remember disabled people have relationships with other disabled people and with non-disabled people
- Remember same sex relationships are as common for disabled people as for non-disabled people

## What words should you use?

Use words your child is familiar with and gradually introduce the correct medical names for the genitals and other body parts. Even if your child chooses to use the original words, it's helpful if they can understand and use the correct medical terms in certain situations.

This is especially important if your child is going to be in hospital on their own. They may be embarrassed if they can't explain a problem to a doctor or nurse because they don't know the correct words. If your child needs personal or intimate care, consistency in the language used to describe the genitals and other areas of the body is also very important.

If your child relies on the help of support workers when going to the toilet, or if they are used to undressing regularly for doctors or therapists, the concept of private parts of the body may need reinforcing.

## PROTECTING YOUR CHILD FROM ABUSE

Disabled children and young people can be more vulnerable to abuse. Their need for sex education and an understanding of appropriate touch is essential because:

- They may rely on intimate care and assistance in using the toilet, getting dressed, etc.
- They may have less understanding about personal and private parts of the body because of their learning disabilities
- They may have less understanding about 'personal' and 'private' parts of the body because of frequent medical examinations where they need to undress or be undressed
- They may have communication difficulties which affect their ability to speak out about abuse

The best way to protect your child is to have an open and loving relationship based on honesty. You can reassure your child there is nothing so awful and embarrassing they couldn't talk to you about it. If your child uses signs or symbols, be sure to introduce ones which allow them to communicate about their body and feelings.

Try to make sure your child understands as much as they can about love and sex and the difference between wanting to touch and kiss someone and doing something that feels wrong or scary. Discuss with them openly how they might handle a situation where they feel uncomfortable; rehearse and role-play – practice shouting ‘NO’ and calling for help. Be open about discussing who a child or young person might turn to if they are frightened or worried – you as their parent, a teacher, a police officer, taxi driver, bus driver, a lifeguard - depending on where they are at the time.

Don’t over-estimate the risks and over-protect your child. Thankfully, it is still rare for children to experience abuse or assault by a stranger. Arm them with the confidence, knowledge and skills to protect themselves, and let them enjoy exploring all that life has to offer.

It’s not always easy, but talking to your children about growing up or about sex and relationships is an essential part of parenting and can be rewarding for you and your child. As young people enter adulthood they need to explore their own needs and express their own opinions and become their own person. To do this they need your continuing love, support, advice, encouragement and understanding.

*‘For me it’s been quite positive ‘cause Simon’s been able to tell me more about what it’s like to be autistic and I’ve been able to see and have insight about how he functions. He says, “I learn through pictures, everything you say, I see a picture in my head” and he’s been telling me all these stories “Do you remember when I was little, you know, I could hear all these noises”, he’s really explaining more about it and it’s so interesting. I’m so interested and he’s really happy to tell me about it.’*