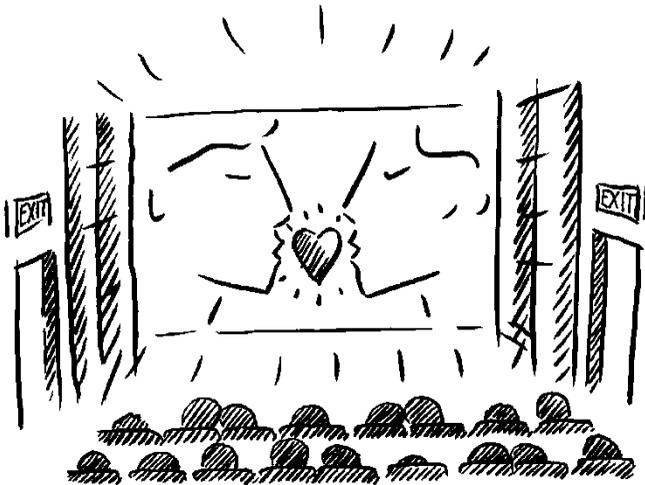


CHAPTER 4

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 educational needs or disabilities, 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 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 child 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 to play pool 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 educational 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 14s.

Extratime and YMCA Downslink have youth activity programmes in the holidays and an inclusive youth club for young people up to 25.

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

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

Amaze's Compass Card

If your child is under 25 and has disabilities or additional 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 around 70 benefits, such as free swimming at the city's main pools, cinema discounts, free gym membership for 16-24 year olds, off-peak discounts at Brighton Bowlplex and much more.

Compass Card holders can also attend special needs-friendly classes called Compass Card Activities which are supported by Amaze. You can see the latest Compass Card Activities by downloading the Compass Card app to your iPhone or Android smart phone. The app provides the most up to date information on Compass Card offers and activities, as well as news updates. To download it, visit the Apple App Store or Google Play and search 'Compass Card'. You can also find our Compass Card offer and activity guides on the Amaze website at www.amazebrighton.org.uk.

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 55 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 – call the Carers Centre on 01273 746222.

Children and young people with a Compass Card automatically qualify for **Gully's Days 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, Butlin's, Frankie & Benny's and Sea Life Brighton. Email AITCGullyDayOut@bhafc.co.uk or call 01273 668590 for info.

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. 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. It's packed with leisure ideas and has over 130 individual entries. 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

'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 Chapter 6 on 'Social care' 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 or find out more in Chapter 6.

'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 is a local organisation that supports adults with Asperger Syndrome, high functioning autism and similar social issues through mentoring and group activities. They can provide a trained volunteer mentor. 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. Visit www.bh-impetus.org/projects/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 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 or call the helpline and ask us to send you a printed copy.

GETTING READY FOR RELATIONSHIPS

Growing up is 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. We want to equip our young people with the tools they need to grow into confident adults who develop close friendships, including sexual relationships.

Building self-esteem

Building self-esteem so that your young person feels happy and confident is extremely important for all children, and especially so for children with SEN and disabilities. The following suggestions to help you develop your child's self-esteem are based on tips from parents and disabled young people in Contact a Family's guide, 'Growing up, sex and relationships: a booklet to support parents of young disabled people'.

Developing a positive body image:

- Reinforce with your child the fact that everyone is different and that this is OK. It can help to find positive role models for your child to relate to in the media.
- Encourage your child to keep clean, use deodorant, wash their hair regularly and so on
- If your young person wants to experiment with clothes, hair or make up, help them to try out different looks, even if they are not looks that you would choose. Encourage them to develop their own style.
- If your child is self-conscious about certain aspects of their appearance, don't dismiss their concerns. Listen to them and support them to talk through their feelings. It's important to tell them that everyone has things they do and don't like about themselves. If you can get them to talk about their good points this can help them to feel more confident about their appearance.
- If your child is happy with an aspect of their appearance directly affected by their condition, be proud of their confidence. For example, if they wear leg supports do not assume they want them covered up with trousers or long skirts. That might give them the message that the way they look is not acceptable.

Boosting confidence

- Remind them of all the things they are good at and, if things do go wrong, reassure them that making a mistake is fine too
- Be generous with compliments – this could be something as simple as telling them they've made a good choice
- Respect their opinions. If your young person feels that you respect their opinion, they are more likely to speak up in other situations such as medical appointments.

Developing life skills

- Encourage them to be assertive. Teach them how to deal with people who ask questions about their condition that they do not wish to answer, for example by telling them it's OK to change the subject.
- Encourage them to learn about and manage their condition themselves, as they grow older
- Encourage them to make their own decisions about all aspects of their life as far as possible – you can read lots more about this in Chapter 2, 'Involving your child'. And remember to respect their choices if they are not what you were hoping they'd decide upon
- Try not to talk about your child or their condition as if they were not present. This often happens in medical appointments.

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. Most parents find talking to their children about puberty and sex a bit awkward. However, for all children and young people, regardless of whether they have a disability or special educational need, being open and honest from an early age is important. Puberty and the swirl of confusing adolescent emotions that go with it is far easier to cope with if the young person knows what is happening to their body and what changes to expect.

It's a good idea to start talking to your child about how their body works and grows from an early age and to gradually build on their knowledge as they get older. If they ask questions, be honest with them and factual, but don't feel like you have to go into too much detail in one go, as this may be overwhelming. Building your child's knowledge slowly and at their own pace

will be far less scary than sitting them down to have a 'big talk' about sex.

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. Visit www.fpa.org.uk

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 their own 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.

What does your child need to know?

As far as possible, all children and young people need to be prepared for the changes to their body before they take place. Every young person is different, but here are a few ideas you might want to talk about:

- The name and function of the sex organs

- What changes to expect at puberty
- How society expects them to behave in public
- How to keep safe from exploitation and abuse
- Relationships and responsibility
- Preventing unplanned pregnancy and sexually transmitted infections (STIs)

Many children will have sex education lessons in Years 5 or 6 in primary school or certainly as part of their PSHE (Personal, Social and Health Education) or science lessons in secondary school. These will cover puberty, sex and relationships. 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. If possible, you need to be able to allay their fears. If you don't have the answers, you could contact the local or national support group for your child's condition (many are listed in the Useful contacts at the back of this book) to draw on their experience and advice.

Changes for girls

Most girls begin puberty at some time between 8 and 14 years of age, with 11 being the average age. Girls generally develop quicker than boys and most girls reach full sexual maturity within four years of starting puberty.

Girls will develop body hair in their underarms and around their genitals. Their breasts will grow and they may begin to have sexual desires. They may also experience psychological changes like rapid mood swings, self-consciousness and increased aggression or begin to experiment with certain risky behaviours like smoking or drinking.

Periods

Having periods marks a new phase in the development of a young woman's emotional and physical maturity. It makes sense to talk to your daughter about menstruation well before the first period so that they can be reassured it's a normal process. She needs to know why she's bleeding and that 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 educational need 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

Boys tend to develop a little later than girls. Most boys begin puberty at 9-14 years of age, with 12 being the average age. Again, most boys reach maturity within four years of starting puberty.

Your son may experience a rapid growth spurt and experience the mood swings and changes in behaviour we mentioned in the 'girls' section. He will begin to grow hair on his face, in his underarm area and around his genitals. His voice will break at some point in this process and his penis will grow. He will begin to experience sexual desire and may have wet dreams.

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.

Personal care

Children and young people who need intimate personal care such as help with washing or going to the toilet, may find it embarrassing as they get older and go through puberty. It's important, therefore, to ensure that you or any carers who provide personal care are respectful and sensitive towards your young person. You can do this by:

- Giving your young person a say in their personal care plan
- Making sure that the care plan is assessed and updated as and when your child's needs change
- Finding out if there are ways that your young person could manage their intimate care needs themselves, using aids or equipment
- Making sure that the number of people who provide intimate care to your young person is kept to a minimum

- Asking your young person before you provide intimate care and ensuring that they know why it is needed.
- Keeping things consistent – ensure that anyone who provides intimate care to your young person uses the same language for parts of the body and functions

Masturbation

Exploring your body and getting to know what feels good is natural as you grow up, but for young people with learning disabilities, there may be issues with both opportunities and privacy.

Your young person's right to privacy should be respected. You should try to knock and wait a moment before going into a bedroom or bathroom and ensure that other carers, such as support workers, are equally respectful.

Some young people with learning disabilities don't always understand the difference between private and public. It is important to try and support your child to know that masturbation 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

Our young people are sexual beings like everyone else and 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, however. 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 for fear of exploitation and pregnancy, or a parent may be reluctant to see their child as a sexual being. But avoiding the issue of sex and sex education will not make your child's sexual desires go away - it may instead make your child feel confused and fearful, especially if they misunderstand what they've learned or hear incorrect information from their peers. Being open and honest when you talk about sex is vitally important, as is ensuring your child has access to good sex education and health care.

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
- Share 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 'big talk' 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 too
- Remember same sex relationships are as common for disabled people as for non-disabled people

PROTECTING YOUR CHILD FROM ABUSE

There are a number of reasons why disabled children and young people can be more vulnerable to abuse. Their learning disabilities may mean they have less understanding about 'personal' and 'private' parts of the body, particularly if they rely on intimate care or have frequent medical examinations where they need to undress or be undressed. Or they may have communication difficulties which affect their ability to speak out about abuse. So the need for sex education and an understanding of appropriate touch is essential.

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 the difference between wanting to touch and kiss someone and doing something that feels wrong or scary. Teach them that their body belongs to them and that it is not OK for someone to touch them if they do not want them to.

Discuss with them how they might handle a situation where they feel uncomfortable or perhaps you could rehearse and role play - practice shouting 'No' and calling for help and talk to

them about who they might turn to if they are frightened or worried – you as their parent, a teacher, a police officer, a bus driver, a lifeguard - depending on where they are at the time.

However, it's important to keep these risks in perspective. Thankfully, it's still rare for children to experience abuse or assault. Give your child the confidence, knowledge and skills to protect themselves, and let them enjoy exploring all that life has to offer.

Useful information

There are a number of useful resources to help you explain changes during puberty to a young person with learning disabilities. 'Talking together about growing up: a workbook for parents of children with learning disabilities' by Lorna Scott and Lesley Kerr is produced by the FPA. Download it from their website at www.fpa.org.uk.

Contact a Family's 'Growing up, sex and relationships' booklet has a variety of useful contacts at the back that may be able to help you. There are also a number of books written for children and young people with additional needs that explain many topics around this subject. Jessica Kingsley (www.jkp.com) has a number of titles, including a series of easy to read picture books called 'Sexuality and Safety with Ellie and Tom'. This covers puberty, masturbation and sex as well as a guide to using public toilets safely. They also publish 'The Growing Up Guide for Boys' and 'The Growing Up Guide for Girls' which are geared to young people on the autistic spectrum.

Scope has a number of links to material on sex and learning disability. Visit www.scope.org.uk/Support/Families/Landing/Learning-disability/Sex.