

Growing up, sex and relationships

A guide to support parents of young disabled people



About this guide

This guide looks at how being disabled might impact on issues around sex and relationships. We use the term disabled children to include children who are affected by any type of impairment, special educational need, health or genetic condition or developmental delay. It offers guidance on what parents can do to support their child as they grow into young adults and start to form intimate relationships. There are thousands of different causes of impairments and the range of difficulties a child may have will depend very much on the diagnosis, how their condition is managed and what support and help is available.

Throughout this guide we use terms such as 'talk to' and 'discuss'. Not all children are able to communicate verbally, and you will know best how to explain some of these ideas to your child. We also have an information leaflet for young people, written for disabled young people in or approaching their teenage years. Parents may wish to read some of the information with a younger child or a child with learning disabilities. Or you may want to obtain some of the resources listed in this guide which explain the process of puberty and growing up in simple words and pictures.

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Introduction

Parents are key 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. Parents of all young people face a range of issues around sex and relationships. Disabled young people are sexual beings like everyone else and have the same rights and needs for good sex education and sexual health care, and the same opportunities for socialising and sexual expression as their non-disabled peers. Parents of disabled children and young people have a special role in providing support and guidance to enable their children to embrace the challenges of adolescence and grow into informed and confident adults.

Why does my child need to know about sex and relationships?

Learning about sex and relationships is a lifelong process, beginning in early childhood and continuing through adult life. Children and young people are exposed to sexualised images from an early age, both online and in the media, for



example in music videos and advertisements. They have unprecedented access to digital technology like smart phones and tablets, with better internet access at home and outdoors. Half of ten-year-olds now own their own smartphone, and by the age of 15 almost all children own do¹.

¹ Children and Parents: Media Use and Attitude, Ofcom, February 2020

There are also ongoing concerns about how easy it is for young people to access pornography, the impact it may have in shaping their expectations, and behaviours, especially in the absence of high-quality sex and relationship education, and the pressures it may be creating for them.²

While children and young people may be able to look up answers to their questions about sex and relationships more easily, they may be subjected to many different, often conflicting messages about what good sex and relationships look like. Strong stereotypes around what it means to be male or female may be reinforced which may not be helpful for children's emerging identity.

Parents are in a unique position to help children and young people make sense of these confusing messages. Good sex and relationship education (SRE) informs children and young people about relationships, emotions, sex, sexuality and sexual health. It also enables them to develop life skills and a positive attitude to sexual health and wellbeing.

Why is sex and relationships education (SRE) important for all children and young people?

- research tells us that young people and their parents want better sex and relationships education
- research tells us it improves sexual health and wellbeing and reduces teenage pregnancies and sexually transmitted infections.

Young people have said for many years that their sex education is 'too little, too late and too biological' and that it avoids the broader issues of relationships, emotions, sexuality, contraception, sexually transmitted infections and abortion.

Earlier first sex is most common with those who are more vulnerable. And more vulnerable individuals are more likely not to use contraception or practice safer sex when they first become sexually active.



Almost one in three 16- to 18-year-olds said they had sex under the age of 16 (the legal age of consent). 15 per cent of 16- to 24-year olds had at least two partners in the past year with whom no condom was used, and young people (aged 16 to 24) account for more than half of the diagnoses of sexually transmitted infections (STIs)². Although teenage pregnancy in the UK has been decreasing overall for some time, it is still the highest in Western Europe.

A number of reviews have shown that high quality SRE, when linked to confidential sexual health advice services, can delay the start of sexual activity and can promote an open and accepting attitude towards sex and sexuality.

Much is being done to improve sexual health and SRE in school, in the wider community and at home and to improve sexual health services.

² Young people, sex and relationships the new norms, IPPR, August 2014

Sex and relationships education (SRE) and my disabled child

There is a tendency to think that disabled people, including those with severe disabilities, do not have sexual feelings, sexual needs and sexual capabilities. But they do. Parents sometimes feel uncomfortable about this. They may feel concerned about this for a number of reasons. They may fear that their child will be vulnerable to exploitation, abuse or may become pregnant. They may feel a conflict with their own religious or cultural beliefs about sexual relationships outside marriage, or homosexuality for example. To love, care for and want to protect your child is a natural instinct.

Many parents worry that teaching children about sex will encourage them to become sexually active at a younger age. However, those children who have received sound sex education are likely to become sexually active later than their peers.

Accepting that your child has these sexual feelings and talking about sex will help them to understand the difference between a loving relationship and

abuse. It may also make it easier for your child to discuss difficult and painful feelings with you.

Not knowing and understanding the changes and developments of your body can be frightening and bewildering. Especially as, without 'formal' sex education, learning still takes place in the playground and from the television etc. There are many 'myths' and consequently 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 may cause your child confusion and fear.

You have a right to uphold your own beliefs and to bring your children up with knowledge of where you and your community and your religion stand on moral and religious questions. But children may grow up to believe quite different things and regard as acceptable, relationships and activities that you may not feel comfortable about. Open communication based on respect for your son/daughters own attitudes and beliefs, which may be very different from your own, is key.



1 Sexual awareness

Sexual awareness is the result of all the physical, emotional, intellectual and social factors that have influenced our development throughout our lives. The use of the word sexuality in this booklet refers to awareness as a sexual being, and not just to sexual orientation. Defining sexuality as wider than just a physical function is particularly important for young disabled people. A person who is not able to use part of his or her body still has an equal right to full sexual expression. Similarly, a disabled young person should have the same access to sex education, sexual health care, and opportunities for socialising and sexual expression as other young people.

Having an impairment, health or genetic condition or developmental delay often affects many different aspects of sexual development.

For example, a lack of privacy and independence in daily living can mean a young disabled person often misses out on early sexual experiences such as kissing and flirting. Many other things stop disabled people achieving sexual and emotional fulfilment, including cultural prejudices, professional and parental attitudes, lack of social opportunities and a lack of appropriate services.

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 the many issues surrounding sex and relationships. Others may want their child to have sex education, but are unsure how to go about it. Parents who are not disabled themselves may not have personal experience on which to base their advice to a disabled child and may not know the answers to their questions.

“ At special school it was terrible. The assumption was that we wouldn't have and didn't deserve sexual relationships. ”



All parents – including those with non-disabled children – find talking about sex and relationships difficult, often worrying they may not know enough or have the confidence to talk and listen without embarrassment.

Feelings of isolation

“ 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. ”

Whilst most people can expect to find role models and support from within their community or within the family, a disabled child is more likely to experience isolation when they are the only disabled family member. This can be even more acute if they are unsure of their sexual orientation.

In some cases parents may actively encourage disabled children not to identify with other disabled children. Yet it can be helpful for disabled children to be able to discuss experiences and share difficulties with others who understand because they have been through similar experiences.

Coming to terms with being disabled

“ I definitely went through this stage, perhaps in my teens. I never saw myself as being disabled, I would find it hard to look at photos of myself or see my reflection walking, for example in a shop window. I still find it hard sometimes. ”

For some disabled people accepting their condition can be a difficult journey. Getting support from other disabled teenagers can be vital. It is important that teenagers get support from others who understand the issues, for example by socialising with their peers in different activities or holidays. Social networks (Facebook, Twitter) and safe internet chat rooms with other young people can all be helpful. Children and young people may also benefit from seeing and hearing stories from their peers.

Parents may also have a difficult journey to make, towards accepting their son or daughter as a young adult who may have developed their own, and different, values and opinions.

“ I am me and I am what I am, if people don't accept that it is their hard luck. ”

Body image

Images and attitudes are among the main problems faced by disabled people attempting to assert themselves as independent adults and positive sexual beings. There are many negative images which focus on dependence, guilt, pity and fear. These images can impact upon the self-esteem of the disabled child and young adult.

In the age of 'the body perfect' the media, fashion industry and popular culture generally reinforce stereotypes and promote superficial and skin deep ideas about what is attractive. This in turn can reinforce the view that disabled people are inadequate and unlovable. Expressions such as 'survival of the fittest' and 'body beautiful' are in everyday use.

Sexual orientation

Your child might find that they are attracted to other young people the same sex as them; this is just as common for disabled young people as it is for non-disabled young people. All people are different and a person's sexual orientation is part of who they are, it is not a choice. Your child may feel they can't talk to their friends and family, but still need to talk about their feelings. There are organisations that support disabled lesbian, gay, bisexual and transgender (LGBT) people.

> Switchboard

Helpline open 365 days a year supporting the LGBT community. Also supports friends, parents and family members who are looking for independent advice and support.

 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

“ Top school was harder because we had to go swimming. I'd get myself as close to the pool as possible, a towel covering my skinny legs, and then I'd jump in. ”

The concept of 'physical correctness' is introduced at a very young age, as most toys do not represent an image of anything other than physical 'perfection' demonstrated in quite fantastical proportions on Action Man or Barbie Doll.

Rather than feel their body to be an object of sensuality, some disabled people see their body as an obstacle that impacts negatively on their quality of life, or some even as a source of pain.

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

Privacy

For disabled children who have been taught to be ‘good for the doctor’ and to comply during medical appointments whilst a stranger examines his or her body, the notion of private areas of the body may be a concept difficult to understand.

“ As a child my body was ‘owned’ by doctors. I was treated without respect. My body was treated as a problem. ”

Equally, for any child or young adult who relies upon someone else for intimate care, the concept of private and public areas of the body can be unclear. Not only does this leave them vulnerable to abuse but also to ‘socially inappropriate’ behaviour or language.

For a disabled child or young adult, a lack of privacy can also mean a lack of opportunity to explore his or her own body.

Issues around privacy may also come up if your child is born without an impairment, but becomes disabled whilst growing up – for example if they are injured in a road accident.

“ My daughter went from being very independent to being cared for very closely by us, as the result of a brain injury. It was very hard as she retained a memory that she was too old for her parents to be helping her bathe and dress. As she recovered we had to relearn to let her go and it was even harder the second time around. ”



2 Self esteem

Growing up is about growing into a confident adult with a range of close friendships, including sexual relationships. It 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. These are important issues for all teenagers.

Developing your child's self-esteem

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 from parents and disabled young people may help.

- Reinforce with your child the fact that everyone is different.
- Encourage your child to take interest in their appearance, for example wear fashionable clothes, use make up and so on, if they want to. Make up can be used to camouflage scars and fashionable clothes can be adapted to suit a disabled person's needs.
- 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.
- There are more and more positive role models in the media – point them out to your child without making too much of an issue.
- Encourage them to be assertive.
- 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.
- 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 a wig, but do not feel the need to wear it all the time be proud of that. 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.
- Be aware that disabled people often feel that they are seen as disabled first and as a male or female afterwards.
- Help your child to develop diversion tactics for any questions about their condition that they do not choose to answer, for example by changing the subject.
- Respect their opinions.
- Encourage them to learn about and manage their condition, as they get older.
- Encourage them to make their own decisions about all aspects of their life as far as possible. This will help them to become more assertive, independent and to feel that they have some control over the way they look and their life in general.
- Try not to talk about your child and/or their condition as if they were not present. This often happens in medical appointments.





“ Before the age of about 10 my mum used to dress me in long dresses to cover up my callipers. Only as I got older and expressed myself did I manage to try and dress a bit more trendy. ”

Role models

“ My role models are the late Christopher Reeves, and Stephen Hawkins. 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. ”

“ I think one person who sticks in my mind a lot is Tanni Grey-Thompson. The reason for this is because she has done so well for herself. Winning marathons, and Olympics really shows us disabled people it can be done. You have a disability but it should not stop you from at least trying to do things on your own. ”

“ My parents are my role models as they were both helpful and positive. ”

3 Personal relationships



Having friends is vital for our self-esteem as we grow up. Here are some reasons why friendships may be difficult to develop and suggestions to help your child make friends.

Making friends at school

Schooling can sometimes create additional obstacles to forming friendships:

- attending a school some distance from home can make it difficult to forge friendships within the local neighbourhood
- making the transition from Primary to Secondary often means severing friendships
- where friendships do develop they are sometimes dominated by the assumption that the disabled child needs helping and may not be based upon mutual respect
- a child with a full-time learning assistant may enjoy little opportunity to mix with peers
- facilities and venues for leisure activities and parties may not be accessible to some disabled children and this can make friendships difficult to maintain.

“ The teacher’s aides at school caused me a lot of problems as they would choose who they wanted me to be around and if I had friends they did not approve of they would send them away. ”

The ‘Circle of Friends’ approach was developed to help disabled children, who may be vulnerable to isolation at school, be more included in mainstream settings. A group of the young person’s friends and peers are brought together at their school with the aim of creating a support network for them. Circles of Support is a similar approach to including people in the community, where a group of people meet to help someone achieve their goals in life. You could ask professionals involved in your child’s care about putting these approaches in place as they grow up at school and in the community.

“ School was very hard... not being accepted in groups because I was different. ”

Friendships

If your child goes to a mainstream school where there are few or no other disabled children, find opportunities where they will have the chance of having contact with other disabled children. This might be directly through clubs, or through social networks (Facebook, Twitter).

- If your child goes to a special school find opportunities for mixing with non-disabled peers.
- Try not to be over protective.
- Encourage your child to invite their friends home.
- If it is not possible for your child to go out much, encourage them to keep in telephone or social media contact with friends.
- Enquire about local clubs that your child could go to, whether specifically for disabled people or inclusive.

“ I was lucky to have good friends at school who didn't treat me any differently. ”

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

➤ **Inclusive Solutions** was set up and run by educational psychologists, and uses the Circles of Friends approach, working in schools and local authorities with children and young people. They also offer training and consultancy, and have free resources on their website.

📍 inclusive-solutions.com

➤ **Circles Network** work with people of any age who are isolated or at risk of isolation, they can help in the development of Circles of Support, Independent and Collective Advocacy, Person Centred Planning and Inclusion into the mainstream of life.

📍 www.circlesnetwork.org.uk

➤ **The Foundation for People with Learning Disabilities** has information on developing friendships at school and in the community for children and young people with learning disabilities. They also have information on staying safe when out and about.

📍 www.learningdisabilities.org.uk

➤ **Friendships: a guide to finding friends and building community** by Kay Mills. A collection of personal stories, practical ideas and strategies on how to support people to make friendships, experience new activities and connect them with the community. Aimed at those supporting people with learning disabilities, but with great practical ideas that can be used by everyone, including parents. Available to download free from:

📍 www.centreforwelfarereform.org

Bullying

Bullying takes many forms that may include verbal abuse, physical attacks, and racial and homophobic harassment. All bullying is unacceptable.

Bullying can be teasing or name calling as well as physical assault.

It is not always obvious when a child is being teased as he or she might not tell parents or teachers, but there may be a change in their behaviour. Teasing and name-calling can have a serious impact on a child's self-esteem and self worth and action needs to be taken to deal with and to prevent it.

- Talk about name calling and teasing with your child by creating opportunities. For example, regularly ask how things are going at school, who they like playing with or who they try to avoid.
- Give them lots of praise for coping if they deal with a difficult situation.
- Teach your child some simple sentences about their condition. Encourage them to practice until they can explain their condition confidently.
- Check that they are happy with the explanation that you give to other people about their condition.
- Some families find role-play useful. Work with your child through difficult situations they have encountered or they fear happening. Decide upon appropriate comments and reactions. The more a child is involved in deciding on the best responses the more likely they are to use them.
- Remember that as your child gets older the explanations and responses will need to change.

If your child is being bullied at school

- Speak with the school and explain just what effect bullying has on your child. They may not be aware that it is happening or they may not understand just what an impact it has on your child's self-esteem.
- Try to arrange to have an appointment rather than a quick word in the playground.
- Be specific about what is being said and the effect it is having on your child.
- A teacher might see persistent questioning of your child about their condition as innocent. If it upsets your child it is not acceptable and it needs to be stopped.

All schools should have a policy on bullying to which you should have access as a parent. Schools should look at four key points:


- they should not ignore suspected bullying
- they should listen carefully to all accounts
- they should adopt a problem-solving approach
- they should follow up to make sure that bullying has not resumed.

Further information

For information on what to do if you're concerned your child is being bullied, see our guide to *Dealing with Bullying*. It has lots of useful advice for parents and children including how to approach the school. It's free to parents who call our freephone helpline or to download.

> Anti-Bullying Alliance

Has a range of resources in their Special Educational Needs and Disability (SEND) Information Hub. Plus training for schools and for teachers.

 www.anti-bullyingalliance.org.uk/send-programme/

4 Discussing growing up with your child

What does my child need to know?

Disabled children, like every other child, need to learn about:

- 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
- how to prevent unplanned pregnancy and sexually transmitted infections.

Disabled young people, like everyone else, have a need for:

- a social life with children or young people of a similar age
- friendship
- romance
- exploration of their sexuality
- access to sex education
- privacy for private activity
- understanding of private and public areas of the body.

You should assume that your child will go on to have as independent an adult life as possible and that this will include experiencing sexual desires and taking responsibility for their sexual behaviour.

As puberty approaches you need to prepare yourselves and your son or daughter for a more adult status by allowing them to be as independent as possible. Even if they are very dependent upon the care of others they should increasingly take responsibility for their own decision-making with support from parents and teachers. This will help to have a feeling of control over their life. Giving your child responsibilities will directly affect their confidence, self-esteem and self-worth.



Talking about sex and relationships

“ For me sex education at home was unheard of, but I was no different to my brother or sister.”

Despite a willingness to talk about sex and relationships, many parents are unsure how to go about it. They worry and think they may not know enough and lack the confidence to talk and listen confidently without embarrassment. For some parents of disabled children reluctance to see their children as sexual beings may complicate matters further. These anxieties may peak when a child reaches puberty.



When and how to talk about sex and relationships

Children are more likely to want to talk to you about sex if they are used to talking openly to you, not just about their condition in general, but other things like money, school work, friends, and so on. Showing an interest in what your child does and says will boost their self-esteem. Encourage your children to talk to you about anything that worries them. Even children with severe communication difficulties may be able to indicate to a family member who knows them well that there are things they are worried about or which make them unhappy.

- 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 is not something secretive or to be 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 videos or take advantage for example of a situation that might arise on the television and which might help trigger a conversation.

“ I received sex education at home and my disability was not really discussed as an issue. My mum once said to me that she thought it might take me longer than most to get a boyfriend but she was sure I would eventually and she was right! ”

When talking about sex, take into account your child's condition and be realistic. For example, it might take longer; it might mean experimenting a little.

- 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 really don't know – let's look it up together'.
- Don't bombard your child with questions or talk too much. Many children say it is awful to get a formal lecture on sex or have questions fired at them: 'I asked a question and she immediately came back with, "Are you having sex then?"'
- Try and hold on to your anxieties, answer the question and respect privacy.
- Remember that disabled people have relationships with other disabled people and with non-disabled people.
- Remember that same sex relationships are as common for disabled people as for non-disabled people.

“ The first time I saw other people with arthrogyrosis, with wives, husbands and children, who were driving, working, living independently - I never worried about my future. ”

What words or language should you use?

To begin with, use the words that your child is familiar with and gradually introduce the correct medical names for the genitals and other body parts. These are going to be more consistently used by others. Even if your child chooses to use the original words, they need to understand, and be able to use the correct medical terms in certain situations. This is especially important if your child will have to be in hospital on their own when you may not always be there. Your child may be embarrassed if they cannot explain a problem to a doctor or nurse because they do not know the correct words.

For everyone involved in the personal or intimate care of the child or young person, consistency in the language used to describe the genitals and other areas of the body is also very important.

For the child with a physical impairment who relies on the help of care workers when going to the toilet, or who is used to undressing regularly for doctors or therapists, the concept of private parts of the body may need reinforcing.

> NHS Choices

NHS Choices has a range of resources to help parents overcome difficulties talking about puberty and sexuality issues with their children and also signpost to information on puberty, contraception, STIs for young people with learning disabilities.

📍 www.nhs.uk – search for 'Puberty info for parents'

> BILD (British Institute of Learning Disabilities)

Information and resources for parents and young people growing up with learning disabilities covering all aspects of friendships, sex and relationships. For example consent, rights and informed choice, puberty, masturbation, sexual health – contraception, STIs and more. They also have easy read information about friendships and relationships.

📍 www.bild.org.uk

> Let's Talk about Sex by Robie Harris and Michael Emberley 2010 – *Up-to-date information about all aspects of growing up, sex and sexuality, including contraception, STIs, safe sex, sexual abuse and responsible choices. Inclusive of different sexualities, disabilities, ethnicities and body shapes. Aimed at 10-14 year olds and their parents and carers.*

> Talking together ... about growing up by Lorna Scott & Lesley Kerr-Edwards (2010). *An activity-based workbook for parents of children with learning disabilities. With chapters on body parts, the difference between public and private, keeping safe, feelings, growing up, which words to use and so on.*

> Books Beyond Words

A series of booklets illustrated in full colour and with no words (or very few) to assist people with learning disabilities to understand health issues, personal relationships or life changes. Edited by Professor Sheila Hollins.

📍 www.booksbeyondwords.co.uk



5 Sexual development

Puberty

Disabled children grow up too and they go through the same process as any other child. Although puberty may be early for some and delayed for others it is a biological and emotional process that cannot be stopped, even if some parents would like it to. There are some very rare medical conditions which mean that medication might be needed to bring on puberty and its associated changes.

As much as possible all children and young people need to be prepared for the changes to their body before they take place.

Girls

- Body hair starts to grow.
- Breasts begin to grow.
- Periods begin.
- Mood swings can be more noticeable.

Boys

- Body hair starts to grow.
- Voice starts to break.
- Wet dreams begin.
- Mood swings can be more noticeable.

You may wish to talk to a teacher at school about their sex education programme. Especially if you feel that it might bring up some worries or concerns for your child or you feel that your child might benefit from being prepared for the lessons beforehand at home. Also, it may be that your child would benefit from having certain points reinforced at home afterwards. They may come home with some worries relating to their medical condition or condition 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?



As much as possible, as their parent or carer, you need to be able to allay any fears they may have.

If you do not have the answers it might be useful to contact the support group for your child's condition. As your child becomes a teenager, it might be helpful for him or her to see a genetic counsellor. Also, you may find it helpful to look on the NHS Choices website (see previous page).

As much as possible you need to pre-empt any worries or issues that might arise from lessons.

Changes for girls

Having periods is part of the visual process of growing up. It is 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 that this is a normal process. She needs to know that she is menstruating and that it will stop in a few days. She may have little or no sensation in the vaginal area, and therefore may not be aware when her period has started. It is important to watch out for the start of any bleeding. This will be simpler once a regular cycle is established, and it may be useful to keep a diary of the menstrual cycle, or encourage her to do so.



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

Make sure that 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 these are quite easy for a girl to put in place herself, but sometimes she will need help because of the nature of the condition. There needs to be an emphasis at this time on personal hygiene and cleanliness.

It is important to emphasise that it is a private thing, and she should not talk to everybody about it. Let her know that she can talk to her carer, her teacher, the school nurse or a girl friend.

Changes for boys

Most young disabled men are likely to go through adolescence and puberty at about the same time as anyone else. The voice will change; facial hair, pubic and body hair will start to grow. Tell your son about wet dreams and that they are perfectly normal and may sometimes happen when they are 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 the semen should be wiped up with a tissue, and thrown away. This also is a responsibility, which, along with personal hygiene, is a part of personal care and growing up.

There are a number of very good resources to help you explain to a child with learning disabilities the changes that a boy and girl go through at puberty. See the organisations on page 15 and 22 for more information.

Personal care

Intimate personal care is a necessary part of some disabled people’s lives. As a child grows up and goes through puberty they may find personal care to be more embarrassing and feel more awkward having intimate or private parts of their body touched. They may also feel shy of others seeing their body.

It is very important that parents are respectful and sensitive when delivering intimate personal care to their son or daughter and that they encourage similar behaviour in all care workers. This means:

- knocking before entering a bedroom or bathroom
- asking permission on each occasion before providing intimate care – for example, “Is it OK if I help you take off your pyjamas now?”
- discussing personal care plans and any changes to these with the child or young person as far as possible
- reassessing whether intimate personal care is still necessary and whether it could or should be provided in a different way. Are there aids and equipment which could enable the young person to manage alone?
- reassessing how many different people need to be involved in a young person’s personal care and keeping this to a minimum
- clear communication and explanation of why a procedure is necessary.

Use consistent language for genitals and for bodily functions. Ensure any new care workers are informed of the appropriate language to use.

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 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. 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 coming into a bedroom or bathroom. Encourage others, such as care workers, to be equally respectful.

Parents often assume that their child's physical impairment means that they are unable to explore their body or to masturbate. However, quite often they do find a way.

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 child's doctor whether it would do any harm if occasionally you "forget" to put them on.

Continence wear can be another barrier. If this must be worn at all times, perhaps you could allow your child some 'private time' in the bath – providing that you know they are safe. Even if your child is unable to explore their own body with their hands they may be able to look at themselves and notice any bodily changes as they mature. This may lead naturally to questions on body changes and the opportunity to discuss the wider issues.

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

Some children and young people masturbate because it helps them to feel warm, relaxed and loved.

Young people with learning difficulties sometimes do not understand the difference between private and public. It is important to try and support children to know that what they are doing is natural and not wrong, but that it is only right on their own in a private place, such as their bedroom.

For organisations and resources that can help see pages 15 and 22.

Further information

Many publications on sex and relationships for disabled people are focussed on learning disabilities. There are some publications around physical disability, but these are mostly produced by the relevant specific-condition charity. The Contact helpline will put you in touch with the most relevant organisation.

> The Sexual Advice Association has useful information about all aspects of male and female sexual function and sexual problems, for example help with erectile dysfunction. Callers to the helpline can request general information on the causes and treatment of sexual problems and a list of specialists in their area.

 **Helpline 020 7486 7262**

 **www.sda.uk.net**

6 Contraception and STIs

Contraception

There are many different contraceptive methods available, including the contraceptive pill, male and female condoms, the Intrauterine Device and the diaphragm or cap.

There are also other methods such as contraceptive injections, which contain a slow-release supply of a hormone. These work by stopping the ovaries releasing eggs and by thickening the mucus in the cervix, creating a barrier to sperm. They give 99% protection against pregnancy for 12 weeks. Prescribed medicines such as those for epilepsy and tuberculosis make them less effective. It is also possible to have a contraceptive implant where a small flexible tube

is placed under the skin of the inner upper arm. It releases the hormone progesterone and this stops the ovaries from releasing an egg.

A GP or fpa (formerly the Family Planning Association) will give advice as to which method might be most suitable. Your daughter or son should explain any medication they are already on (because some drugs, for example anti-epileptic drugs may reduce the effectiveness of the pill) and any allergies (for example to latex) which may affect the method chosen. They should also let the clinic staff know about their condition and its features. For example, the insertion of an IUD in a young woman with epilepsy may trigger a reflex seizure.

How effective any contraceptive is depends on how old the young person is, how often they have sex and whether the instructions are followed.

Can a young person obtain contraception without parental consent?

Research findings tell us that many young people fail to get help because they fear that they will not receive a confidential service from health professionals. This is a difficult issue because parents naturally want to know what is happening. Health professionals will always encourage young people to talk with their parents.

Young people have the right to a confidential service and doctors can prescribe contraception and advise them on sexual health matters without their parents' knowledge. But doctors use their professional judgement to decide whether the young person is mature enough to understand the treatment and advice given, and they will break confidence in circumstances where they believe that there is limited understanding or where the young person is being abused.



It is also known that most young people who seek advice will involve their parents either before the first appointment or very soon afterwards. Parents report disappointment when their son or daughter has not involved them initially but also express relief that the young person has been sensible and responsible in getting advice.

Emergency contraception

If your daughter forgets to use contraception or has had an accident, she may be at risk of an unplanned pregnancy. Advise her to contact her doctor or family planning clinic as soon as possible. There are two methods of emergency contraception:

- fitting a coil (IUD)
- one or two doses of a special pill. These are available free from a GP or sexual health service, or can be obtained over the counter at pharmacies for a fee.

Sterilisation and abortion

Some parents are so worried about pregnancy that they consider whether their son or daughter should be sterilised in order to prevent any chance of an unplanned pregnancy. There are substantial ethical, psychological and legal concerns about this and organisations of disabled adults generally regard sterilisation without the informed consent of the disabled person as an act of abuse.

If you are considering this, you need to be aware that under the Mental Capacity Act 2005, all individuals are presumed to have the capacity to make decisions about themselves unless it is proved that they lack the capacity to do so. Decisions about mental capacity are made by the Court of Protection and are made on an individual basis. Doctors will be most reluctant to agree to this drastic step and you will have to go to court.

With newer, more reliable forms of contraception, such as contraceptive injections, it is likely that sterilisation will continue to decline. At present, a handful of parents of young people with learning disabilities do go to court each year to argue that their son or daughter should be sterilised.

It may be better to have a discussion with a family planning specialist about the different methods of contraception available and see if you can find an option which is reliable, but not permanent.

Similarly some parents, on finding that their daughter is pregnant, will try to persuade her that terminating the pregnancy is in her best interests. Some parents may find the prospect of an abortion unacceptable, due to their own religious and cultural beliefs. It is possible that either option may be in your daughter's best interests, but she needs time and your support to help her make her decision, and ultimately The Mental Capacity Act will also apply in these cases. As her parent you may also need support at this difficult time.

Many disabled people form lasting and loving relationships and the mutual desire for a child may be part of this. Disabled people can and do become able and effective parents. The Disabled Parents Network can advise.

Further information

➤ Disabled Parents Network

Support, advice and information for disabled parents.

☎ Helpline 0870 241 0450 (Mon-Fri)

🌐 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.

🌐 <http://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



Sexually Transmitted Infections (STIs)

Anyone can get a sexually transmitted infection, including HIV, the virus which causes AIDS, if they do not have safer sex. There are at least 25 different Sexually Transmitted Infections (STIs). The most common are:

- chlamydia
- gonorrhoea
- genital warts
- genital herpes
- syphilis
- trichomonas vaginalis
- HIV and AIDS.

HIV stands for the Human Immunodeficiency Virus and affects men and women. The virus damages the body's immune system so that over time it becomes vulnerable to illness and infections.

AIDS is caused by HIV. When a person has AIDS it means their immune system is very weak and they have developed certain infections or cancers. These can be fatal.

STIs are most commonly passed on through vaginal, oral and anal sex. You don't need to have a lot of sexual partners to get an STI although the more partners that a person has, the greater the chance is that one of them may pass on an infection. Common symptoms of an STI 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.

Symptoms can vary from infection to infection and many STIs show no symptoms at all. It is not uncommon to have more than one infection at the same time. Most STIs can be completely cured if found early enough and may only require a course of antibiotics. However, if left untreated these infections can be painful and uncomfortable or at worst cause permanent damage to health and fertility.

If your son or daughter is, or may be, sexually active and appears to have any of these symptoms, you should advise them to see a doctor. It is important not to become angry or show your

disapproval, otherwise they may find it harder to confide in you and you may also lose the opportunity to talk openly about safer sex and avoiding these infections in future. Reassurance that you will help them to get treatment and explain how to avoid re-infection is likely to keep better lines of communication open in the long term.

Safer sex – how to avoid sexually transmitted infections

You should advise your son or daughter to:

- use a condom (male or female) correctly and consistently when they have sex to prevent the transmission of most STIs including HIV
- discuss with their partner before they have sex how they will both protect themselves
- have a routine check up at a sexual health clinic.

If your son or daughter or their partner has symptoms, or think they might have an infection, tell them to seek advice before they have any more sex. If they have an infection ask them to tell their partner so they can be treated too.

Sexual health clinics specialise in diagnosing and treating all STIs. Most large hospitals have a sexual health clinic. You can find details of your nearest clinic by:

- visiting the Family Planning Association (fpa) website www.fpa.org.uk/find-a-clinic
- looking in the phone book under genitourinary medicine, STD or VD
- calling the Terrence Higgins Trust on 0808 8021221
- calling NHS 111 (24hrs).

Further help and advice

> Brook

Run free and confidential sexual health and wellbeing centres for young people offering sexually transmitted infection (STI) testing, contraception and emergency contraception, as well as counseling and support in improving general health and wellbeing. You can find your nearest centre on their website.

Ask Brook gives sexual health information and support and for anyone under 25. Includes information on where to go for emergency contraception.

Textchat 07717 989 023

Helpline 0800 0185 023

 www.brook.org.uk

> fpa (formerly the Family planning Association)

Contraception help and advice, plus advice for parents. Find a clinic service. Books, leaflets, advice on most aspects of sexual health including abortion, contraception and sexually transmitted infections. Book for parents who have young people with learning difficulties explaining contraception, STIs.

 www.fpa.org.uk

> Muslim Youth Helpline

Support for young Muslims on any aspect of growing up including sex and relationships.

 Free helpline 0808 808 2008

Live web chat – click on the Need Help icon www.myh.org.uk

Protecting your child from abuse

Disabled children and young adults may 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 with using the toilet and getting dressed
- they may have less understanding about 'personal' and 'private' parts of the body through learning difficulties
- they may also have less understanding about 'personal' and 'private' parts of the body through 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 that you as a parent can protect your child from abuse is to have an open and loving relationship based on honesty. You can reassure your child that there is nothing so awful and embarrassing that they couldn't talk to you about it.

Try to make sure that your child understands as much as they can about love and sex and the difference between wanting to touch and kiss someone and being made to do 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 – their parents, a teacher, a policeman, a bus driver, a lifeguard, depending on where they are at the time.

Don't overestimate the risks yourself and overprotect your child as a result. It is still thankfully very rare for children to experience abuse or assault by a stranger. Arm them with the confidence, knowledge and skills to protect themselves and then let them enjoy exploring all that life has to offer.

Parents are in a good position to start the conversation early and there is information to help you.

Further information

> NSPCC

Information on what is healthy sexual behaviour in children and young people. Includes a guide for parents on keeping children safe without using scary words or even mentioning sex, spotting warning signs and what to do if you're worried. Also has advice on how to react to sexualised behaviour and talk to your child about topics, including sexting and online porn.

 www.nspcc.org.uk/preventing-abuse/keeping-children-safe


> Thinkuknow

Information for parents on how to keep children safe online. It takes parents through technical tools and how to set parental controls from different TV and gaming providers. It also features games and videos you can play with your children from age 5 to help them learn to stay safe online and how to get out of bad situations. Parents of children with learning disabilities may find using the games and videos for the younger age groups helpful.

 www.thinkuknow.co.uk/parents

> 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

7 Sex and relationship education at school



A false debate is often presented as to whether parents or schools should be responsible for sex and relationship (SRE) education. In reality both have an important role.

Whilst special schools usually have considerable expertise in teaching SRE in a way that is inclusive and sensitive to the needs and experience of disabled pupils, disabled children increasingly attend mainstream schools.

Young disabled people have the same rights to education and information, to dignity and respect, as their non-disabled peers. All children and young people have a legal right to education and support that will prepare them for the responsibilities and experiences of adult life.

“ Sex and Relationship Education at school was non-existent, they didn't think disabled people should be having sexual relationships. ”

Sex and relationship education

There are new requirements for relationships and sex education (RSE). These came into force in September 2020 and apply to all schools in England, both state-funded and independent. All schools must have regard to statutory guidance on RSE

Relationships education is compulsory for all primary school children. Primary schools do not have to teach sex education though some may choose to do so.

Relationships and sex education is compulsory for all secondary school children.

Health education is compulsory in all state-funded schools, but not independent schools. Health education includes both physical health and mental wellbeing. Independent schools must still teach personal social and health education (PSHE).



What will be taught

There is no set curriculum for particular year groups, but government guidance sets out what children are expected to have learned by the end of primary or secondary school. Relationships and sex education does not have to be taught in separate lessons but can be embedded in the wider curriculum.

Primary school

Relationships education in primary school will cover:

- family in its different forms
- friendships
- respectful relationships including online
- personal space and how to keep safe.

As part of the science curriculum from year 5 upwards children will be taught about puberty and body changes.

Primary schools do not have to teach any sex education beyond this, but some schools may choose to.

Secondary school

In secondary school the topics covered in primary will be explored in greater depth and new ones introduced including:

- different legal types of relationships
- responsibilities of parents
- intimate sexual relationships and choice
- pregnancy and contraception
- protections under the Equality Act
- bullying, sexual harassment and coercive relationships
- more detailed info about keeping safe online including pornography.

The content will be adapted to the age and development of the children. RSE must be accessible to children with special educational needs and disabilities and differentiated and personalised where needed.

All schools must publish a policy on relationships and sex education and consult with parents when drawing up or revising the policy. It is important for parents of children and young people with SEND to be involved in this.

Does my child have to take part in these lessons?

You cannot withdraw your child from relationships education or health education. These are compulsory.

You cannot withdraw your child from any sex education that is taught as part of the science curriculum, for example the facts of human reproduction.

You can ask for your child to be excused from sex education taught as part of RSE. You can do this until your child turns 15. Young people aged 15 and older may choose to receive sex education even if their parents disagree.

Before you decide to withdraw your child, you should consider carefully whether this is best for your disabled child. Disabled young people are sexual beings like everyone else and have the same rights and needs for good sex education and sexual health care, and the same opportunities for socialising and sexual expression as their non-disabled peers. Schools have a duty to discuss your concerns with you and help you to decide what is best.

Preparing your child for sex education and relationship

It might be very useful if you could discuss with the teacher beforehand the content of lessons and how it might affect your child. The following is a checklist of questions you might want to ask the teacher:

- are they aware that they have a disabled pupil in the class?
- do they know the nature of your child's condition and what issues may arise for them from the lesson content?
- will your child have an opportunity to speak with a member of staff about any concerns they may have before the lesson?
- is there an identified member of staff your child can approach, if they need to speak to someone, after the lesson?

You may wish to make the teacher aware of:

- your child's thoughts and anxieties about the lessons

- your child's thoughts and anxieties about a specific area of SRE relating to their condition
- any support group for your child's condition which might give them more specific information.

Consistency in language being used by parents, care workers, teachers and learning assistants is very important where a child needs intimate care and their 'private' parts are 'public' property. It may be especially important for pupils with learning disabilities.

It may be worth asking the teacher if any particular words are to be used. If your child normally uses a different word, explain to him or her that these words refer to the same part of the body.

Following up SRE at home

For some pupils it may be necessary to have some SRE issues reinforced at home, for example:

- the difference between 'public' and 'private' parts of the body
- reproductive functions of the body
- relationships and responsibility
- realistic expectations/aspirations.

If a parent has prior knowledge of what is being taught in PSHE and SRE they are better able to support their children. The following are just some of the personal and individual worries that a child might take home:

- sexual function – how will I be able to have sex?
- sexual orientation – maybe I am gay
- body image – will anybody want to have sex with me?
- future relationships – will I ever get a boy/girlfriend?
- getting married – will I ever get married?
- having children – will I be able to have children?

If you know that your child has covered a topic at school which they may have found difficult or worrying, you may like to ask them how it went and whether they have any follow up questions that they need answering. If you do not have all the answers, don't worry – the organisations in this guide may be able to help (see pages 15 and 22). The fact that you are seen to be taking your child's

worries seriously and trying to find answers will be very reassuring.

How can you be involved in setting the school agenda?

It is very important that there is a strong partnership between the school, parents and the disabled pupil in all areas of school life and this is especially true with SRE and PSHE issues.

It is essential that the governing bodies involve parents, especially parents of disabled pupils if there are children or young people with disabilities at the school, in developing and reviewing their SRE policy. It is important that communication with them be ongoing. Parents can also look at the resources that are used and test out leaflets and videos at home.

If good communication does not happen, parents may assume that SRE is being covered at school and teachers may assume that it is being covered at home. Parents are far less likely to withdraw their children from SRE if they know how it is being approached and they have been involved in working on, and are aware of, the content.

If your child's school does not appear to involve parents in this part of the curriculum, you could try contacting the special needs co-ordinator at the school (sometimes referred to as the SENCO) to see if they would like some parental input. Parents have a lot of experience of their child's worries and concerns and if staff and governors understand these, they will be able to better plan a curriculum that is inclusive.

Partnership with other agencies

Most disabled children have professionals from several agencies involved in their lives, for example social workers, doctors, therapists, community nurse. A good working relationship with all these agencies is important to ensure a consistency of language, expectations and understanding of the child's needs.

All staff including ancillary staff, physiotherapists, nurses and care workers as well as teachers should follow the school's sex and relationship education policy when working with disabled pupils.

Finally...

We hope you have found this guide helpful. Being a parent of a disabled teenager can be a huge challenge. Although it is not always easy talking to your children about growing up or about sex and relationships it is an essential part of parenting and can be highly rewarding for you and your child (even a teenage one!). Attitudes to issues such as contraception, masturbation, homosexuality and sex outside of marriage vary widely. The needs of the young person will be different for many reasons including culture and values, religious beliefs, age, and the nature of their condition.

As young disabled people enter adulthood they need to explore their own needs and voice their own opinions and become themselves rather than their parents' children. To do this they need your continuing love, support, advice, encouragement and understanding.

This resource was originally developed by Contact together with:

> The PROUD Consortium

PROUD was the name of a group of individuals and organisations brought together by Sharon Baker of The Arthrogyposis Group. Sharon Baker developed the initial idea for the resource and is the lead author. Working with Contact, the consortium came together to raise awareness of the many issues of growing up with a disability. Members of PROUD included disabled adults, parents of disabled children and young people, professionals from Worcestershire's Health and Education Authorities working with young people with disabilities and representatives from the Association for Spina Bifida and Hydrocephalus and Disability Awareness In Schools. PROUD consulted widely with disabled adults and parents and carers of young disabled people and children and thanks them for their help in developing this pack. The quotes in this booklet are taken from a survey conducted by The Arthrogyposis Group on growing up with a disability and caring for a disabled child. Lead author: Sharon Baker. Sponsored by the Teenage Pregnancy Unit Original editor: Helen Christophers.

Original contributors also included

> 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



8 Further information

> The Arthrogyrosis Group

 Helpline 0800 028 4447

 www.tagonline.org.uk

> Association for Spina Bifida and Hydrocephalus

 01733 555988

 www.shinecharity.org.uk/

General health issues

> NHS 111

the NHS non-emergency number. They can assess any symptoms and direct you to medical care. Also put you in touch with clinics in your area.

 <http://www.nhs.uk/>

Growing up

> The Transition Information Network (TIN)

An alliance of organisations and individuals who come together with a common aim: to improve the experience of disabled young people's transition to adulthood. TIN is a source of information and good practice standards for disabled young people, families and professionals.

 www.transitioninfonetwork.org.uk/

> Disabled Living Foundation

Advice on equipment for independent living, including clothing and equipment for children.

 Helpline 0300 999 0004

 www.dlf.org.uk

> The Preparing for Adulthood programme (Pfa)

Programme to support young people into adulthood with paid employment, good health, independent living and friends, relationships and community inclusion. It has blogs, stories and videos from young people as well as information to support young people with complex care needs.

 www.preparingforadulthood.org.uk

Counselling

> Relate

Counselling on relationship difficulties, children and young people's counselling, psychosexual therapy, and book shop on relationship issues.

 Helpline 0300 100 1234

 www.relate.org.uk

> Relationships Scotland

Supports individuals, couples and families experiencing relationship difficulties.

 InfoLine 0845 119 2020

 www.couplecounselling.org

How Contact can help

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



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@contact.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.contact.org.uk/publicationslist**

 **0808 808 3555**

Get in contact with us

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 020 7608 8700

 info@contact.org.uk

 www.contact.org.uk

 www.facebook.com/contactfamily

 www.twitter.com/contactfamily

 www.youtube.com/contact

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 **0808 808 3555**

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 helpline@contact.org.uk



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Updated by Karin Beeler

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