Puberty and RSE

Children with chromosome and gene disorders grow up too. They go through the same process as any child. All children need to be prepared for the changes that will happen to their body before they take place. Children usually receive their first lesson about puberty at school in Year 5 (Science).

Relationships and sex education is the right of every child and young person. Your child has the right to an education that helps them to understand themselves, their development and the choices open to them. This understanding will help to protect them.

Social learning means relationships with families and friends, emotions and feelings, acceptable expressions of love and affection, age-appropriate behaviour, cultural normalities and moral values. Health education means growth and development, personal hygiene and presentation, self-esteem, keeping healthy and keeping safe. Learning about sexuality has its proper place, it shouldn’t be singled out as something mysterious or embarrassing.

Despite a willingness to talk to their children about sex and relationships, many parents and carers are unsure about how to get started. For some parents and carers of disabled children, fears of exploitation and pregnancy or a reluctance to see their children as sexual beings may complicate matters further. Parents and carers’ anxieties often peak when a child reaches puberty. Their concerns can be reduced if the child’s sexual development is addressed as a natural part of home and school, rather than just at crisis points. They appreciate the openness and support given by schools and health professionals. Schools can help support parents and carers by lending RSE books and resources.

As a parent you can help to prepare your child for what is to come, so that changes to their bodies do not come as a shock. Many children are often scared of changes that occur and it is important - particularly for those that have some degree of understanding, that they know from a young age that these changes will happen to them.

There are lots of resources available to help parents to discuss this with their children. Many of which are mentioned in this guide. If this subject is difficult for parents to comprehend, there is help available, whether it is reading from a book, or talking to someone that is experienced in this subject.
“We're in the thick of it, and one thing I will say, is that while we are trying to cope with all the obvious physical stuff, the dentist reminded me that wisdom teeth also come in at this point, and might be painful. I had completely forgotten this. Something is really bothering my son and I can’t tell what it is, it might be wisdom teeth (can't tell, can't get a dental x-ray but still good to know about it).”

Index

Relationships and Sex education (RSE) ......................page 4
Body changes........................................................................page 6
Periods.....................................................................................page 6
Precocious (early onset) puberty.................................page 7
Delayed puberty.................................................................page 7
Difficult sexual behaviour...................................................page 9
Links......................................................................................page 10
Books....................................................................................page 12
DVD’s....................................................................................page 14
Sex Education in the UK

Known as SRE (sex and relationship education) by many professionals. In the Children and Social Work Act 2017 the government changed the name of this subject area from SRE to RSE to ensure the ‘relationship’ element comes before the ‘sex’, as we would hope it would in practice.

Relationship and Sex education (RSE) is compulsory in local authority maintained schools from age 11 onwards. Pupils in schools in England are currently taught about relationships, health and the wider world through sex and relationship education (SRE) and personal, social, health and economic education (PSHE) lessons. It involves teaching children about reproduction, sexuality and sexual health. All schools must have a written policy on sex education, which they must make available to parents for free. Academies and free schools are not under this obligation. If they do decide to teach SRE, they also must have regard to the guidance. The Department for Education is considering how to update the existing Sex and Relationship guidance which was last updated in 2000, and is therefore now out of date. The updated guidance will support schools in delivering the new subjects of Relationships Education at primary level and Relationships and Sex Education (RSE) at secondary level, as well as, potentially, Personal, Social, Health and Economic Education (PSHE).

This guide has been compiled mainly as a signposting guide to help parents to find the best available information on puberty, relationships and sex education.

From September 2020: statutory RSE

On 1 March 2017, the then Education Secretary, Justine Greening, announced her intention to put ‘Relationships and Sex Education’ on a statutory footing. She also announced her intention to create a power to make personal, social, health and economic education (PSHE) statutory in future. Section 34 of the Children and Social Work Act 2017 provides for relationships and sex education to be taught in all schools in England. Following consultation, the RSE proposals are intended to be in place for teaching to start in September 2020, with schools able to begin with the relevant teaching a year earlier if they wish. The proposals involve:

- all primary schools in England teaching ‘Relationships Education’
- all secondary schools teaching ‘Relationships and Sex Education’
- reformed statutory guidance, following consultation
- retaining the parental right of withdrawal from sex education, with new rights for children to ‘opt-in’ as they approach the age of 16 years.
- flexibility for schools in their approach, including for faith schools to teach within the tenets of their faith

A consultation was opened and has now concluded. New guidance is due to be published soon.
RSE AT HOME
For some children with a chromosome or genome disorder it may help to also have RSE at home. Helping them to understand..............
- 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
- personal intimate care
This information and more can be found in the charity ‘Contact’s’ guide for parents.

Growing up, sex and relationships
https://contact.org.uk/media/1160021/growing_up_parents.pdf
Alternatively, if you can’t access online guides, you can contact them by Freephone helpline 0808 808 3555
email: helpline@cafamily.org.uk

“I have found that answering any questions my daughter has clearly and in a matter of fact way, has helped with her understanding. With mood swings, it’s just grin and bear it, as it’s very much out of her control!”
Changes in females
The average age for girls to begin puberty is 11 years. But it is different for everyone. It's completely normal for puberty to begin at any point from the ages of 8 to 14 years. The process can take up to 4 years. The first sign of puberty in girls is usually that their breasts begin to develop. It's normal for breast buds to sometimes be very tender or for one breast to start to develop several months before the other one. Pubic hair also starts to grow, and some girls may notice more hair on their legs and arms; underarm hair begins to grow. Around 2 years after beginning puberty, girls usually have their first period (Menstruation). Hips will become wider and there may be some deepening of the voice. Whatever the age and ability of your daughter; as well as having menstruation explained, she will need guidance on how to cope with periods. You could use a social story with pictures to help her understand. Show her a pack of sanitary towels and explain how they are used, when they should be changed and how to dispose of them. You will also need to explain that they will probably get tummy pain, so they might need to take some pain medication to help relieve the symptoms. Explain to them how often periods occur and how long one might last. For some girls, using pads might cause sensory issues or make them sore, it may suit them better to wear ‘period pants’ or reusable cloth pads, which have become widely available in recent years. Have a look at: https://www.modibodi.co.uk/periods-underwear/ and www.earthwisegirlsuk.co.uk/reusable-sanitary-towels-c-1.html These type of products can also be purchased from a variety of people that make them to sell on sites like Etsy and on Facebook. If your daughter wears continence pads already, the use of additional sanitary towels will be unnecessary, but her pad will need changing more frequently during her period flow. She will need washing or the use of wet wipes to clean her genital area during personal care.

Changes in males
The average age for boys to begin puberty is 12 years. The first sign of puberty in boys is usually that their testicles get bigger and the scrotum begins to thin and redden. Testicles begin to make and store sperm. Pubic hair also starts to appear at the base of the penis. The penis can become erect and can ejaculate semen. They will experience ‘wet dreams’. They will develop a deeper voice and grow facial hair; chest hair may also start to appear. The “Adams apple” will appear (bony lump at the front of the throat).

Puberty - changes in both sexes
♦ general growth of the whole body
♦ development of muscles
♦ growth of pubic hair
growth of underarm hair
- body hair appears on legs
- glands in the skin may become overactive, causing spots and sometimes acne
- hair can become greasier
- emotional changes occur, often with mood swings.

Some children with a learning difficulty might not cope well with these changes and may even self-harm, i.e. try to pull out body hair.

**Precocious (early onset) puberty**

*Causes of early puberty*

It's not always clear what causes early puberty. It may just be a tendency that runs in your family.

Precocious (early) puberty refers to the appearance of secondary sexual characteristics before the age of 8 in girls and age 9 in boys. It may result in tall stature in childhood, but short stature in adulthood. If puberty starts before the age of 8 then it is a good idea to speak to your GP for advice. In some cases, early puberty could be a sign of an underlying condition that may need to be treated. There are different forms of precocious puberty:

- **Central precocious puberty (CPP)** is caused by early activation of the hypothalamic-pituitary-gonadal (HPG) axis. Controlled by the hypothalamus and the pituitary gland (the structures in the brain responsible for hormone secretion) that release hormones, the reproductive organs (testicles and ovaries) secrete sexual hormones that trigger puberty.

- **Precocious pseudo puberty** is brought about by production of sex hormones independently of the maturation of the (HPG) axis.

```
"My daughter was diagnosed aged 7 with precocious puberty and we decided to delay the process in consultation with the hospital's endocrinologist. My daughter is also developmentally delayed and so would not absorb any education on the subject."
```

**Delayed puberty**

Delayed puberty is when:
- boys have no signs of testicular development by 14 years of age
- girls have not started to develop breasts by 13 years of age, or they have developed breasts but their periods have not started by 15

*Causes of delayed puberty*

It's not always clear what causes delayed puberty. It may just be a tendency that runs in your family. Delayed puberty is generally more common in boys.
Occasionally it can be caused by:
- a long-term illness, such as cystic fibrosis, diabetes or kidney disease
- malnutrition, possibly from an eating disorder or a condition such as cystic fibrosis or coeliac disease
- a problem with the ovaries, testes, thyroid gland or pituitary gland
- a disorder of sexual development, such as androgen insensitivity syndrome
- a genetic condition, such as Kallman syndrome and Klinefelter syndrome

Tests and treatments for delayed puberty
Your GP may refer you to a specialist if they think there could be an underlying cause of delayed puberty that needs to be investigated. Tests that may be carried out include a blood test to check hormone levels, a hand X-ray to help determine likely adult height, and an ultrasound or MRI scan to check for problems with glands or organs.

Delayed puberty can be treated by:
- treating any underlying cause
- using medication for a few months to increase hormone levels and trigger the start of puberty

Treatment with medication is usually recommended if the lack of development is causing problems, such as significant distress.
Difficult sexual behaviour
An information sheet about ‘Difficult sexual behaviour amongst men and boys with learning disabilities’ is available from the Challenging Behaviour Foundation. The information sheet gives some suggestions about understanding and responding to difficult sexual behaviour displayed by men and boys with learning disabilities, including masturbation and unwanted sexual contact with other people. A wide range of issues are discussed, including: what is difficult?, sexual contact with other people with learning disabilities, pornography and other sexual stimuli, sexual suppressant medication, and access to a sexual partner. The information sheet also considers difficult sexual behaviour and the possibility of the man having been sexually abused. The information sheet has been written by David Thompson who has a spent over ten years working directly with men with learning disabilities, on sexual issues. The information sheet can be downloaded free of charge from the Challenging Behaviour Foundation website: https://www.challengingbehaviour.org.uk/information/information.html For further information and a full list of resources contact the Challenging Behaviour Foundation: 01634 838739 Email: info@thecbf.org.uk

Sexual abuse and Grooming
Without going into great detail in this guide, there is a very interesting and usual article that has been written by a US paediatrician on this subject, which parents might find helpful to read: https://bit.ly/2KazP5S

The NSPCC has lots of useful resources on Emotional, Online, Physical and Sexual abuse, grooming, bullying, etc.
0808 800 5000
Email: help@nspace.org.uk

“ We watched a very moving, informative and thought-provoking short film called “Sanctuary” that approached the subject of relationships and love and sex from the perspective of adults with learning disabilities living in Galway. The legal situation highlighted no longer applies but I would highly recommend a watch of this film to parents, carers and professionals – the full 1 hour 25 minutes 2018 movie (classification 15) is available for download from YouTube for £2.49 https://www.youtube.com/watch?v=Xt2NFvMlnFg ”
**Links**

Helping your relative to understand changes to their body using **Easy read guides** (pictures and minimal text)

- [www.easyhealth.org.uk/sites/default/files/Lets_Talk_About_Puberty.pdf](http://www.easyhealth.org.uk/sites/default/files/Lets_Talk_About_Puberty.pdf)

- **The Brook Advisory Centre** [www.brook.org.uk](http://www.brook.org.uk)
  0808 802 1234 (11am-3pm Mon-Fri)
  Brook is the only national voluntary sector provider of free and confidential sexual health advice and services specifically for young people under 25. Brook give confidential advice to young people. You can also text to: 07717 989 023 (standard SMS rates apply).

- **Foundation for people with learning difficulties**
  Talking about difficult subjects resources [https://bit.ly/2HbCP3g](https://bit.ly/2HbCP3g)
  020 7803 1100 Email: fpld@fpld.org.uk

- **Teenage Health Freak** [www.teenagehealthfreak.org/topics/body](http://www.teenagehealthfreak.org/topics/body)
  a website for all sorts of teenage worries and questions.

- **Autism** [https://www.autism.org.uk/sexeducation](https://www.autism.org.uk/sexeducation)
  The National Autistic Society (NAS) has some useful information on their website about sex education and children and young people living with an ASD.

- **Oak Field School & Sports College. Wigman Road, Bilborough, Nottingham. NG8 3HW**
  0115 9153265
  Email: admin@oakfield.nottingham.sch.uk
  [www.oakfieldsportscollege.org.uk/](http://www.oakfieldsportscollege.org.uk/)
  Children and young people with special educational needs require an education, which will support and guide them as they get older. A lack of clear sex and relationship education could leave them ignorant and vulnerable. At Oak Field School in Nottingham, staff, parents and students have worked over many years to address this area of education. The school produces many resources for students and their families. Oak Field school has some great booklets on a vast range of subjects including masturbation, menstruation, smearing, sexting, internet safety, use of public toilets etc. for parents and young people. Bodyworks is a programme particular aimed at those young people with profound physical and learning disabilities. If you would like more information, please contact Oak Field school and sports college. Oak Field caters for children and young people with severe and profound and complex intellectual and physical disabilities, aged 3-19. David Stewart OBE, the head teacher has
run workshops on Sex and the three R's (Rights, Relationships and Responsibilities) at past Unique family conference weekends. The booklets are available from the school. There is a list on the website under the tab About Oak Field/Other Policies.

- **Living your Life 2011 – Brook** [www.brook.org.uk](http://www.brook.org.uk)
  This is a detailed RSE programme for young people and adults with learning disabilities written by staff at Oak Field School, Nottingham.

- **Me-and-Us/Bodysense** [www.bodysense.org.uk/](http://www.bodysense.org.uk/)
  Me-and-Us is no longer trading, however, Bodysense has continued to publish some of their guides, which are available as educational resources. They have a really good guide called ‘Periods – a practical guide’ by Mai Rees, Charlotte Carter and Lindsay Myers, produced in collaboration with Conwy and Denbighshire NHS Trust, 2008. Bodysense make 3D anatomically correct models and teaching resources that enable young people to develop relationships that bring them acceptance, love and pleasure.

- **NHS choices** page has information on changes during puberty

- **Ready to Shine** [https://www.ready2shine.co.uk/](https://www.ready2shine.co.uk/)
  Ready2Shine is a Service for Adults and children with Learning Disabilities to access Education in relation to Sexual Health, Emotions, Relationships and Self Care. This is not just about sexual activity; this will include aspects such as boundaries with staff, peers, family and strangers. Other topics will include managing menstruation, self-care for males and females and appropriate masturbation. Understanding and managing emotions and recognising different types of relationships will also be key themes during the sessions.

- **Sex education forum** [www.sexeducationforum.org.uk/](http://www.sexeducationforum.org.uk/)
  020 7843 600 General enquiries 0207 843 6000
  Email: sexedforum@ncb.org.uk
  The Sex Education Forum is a group working together to achieve quality relationships and sex education (RSE) for all children and young people.


- **Video clips** about what is appropriate and inappropriate behaviour [https://bbc.in/2YFQI5m](https://bbc.in/2YFQI5m)
There are many books available on puberty related changes, here are just a few.................

- Asking About Sex & Growing Up: A Question-and-Answer Book for Kids by Joanna Cole
- Usborne Facts of Life, Growing Up (All about Adolescence, body changes and sex) by Susan Meredith
- What's Happening to Ellie? A book about puberty for girls and young women with autism and related conditions (Sexuality and Safety with Tom and Ellie) by Kate E. Reynolds
- What's Happening to Tom? A book about puberty for boys and young men with autism and related conditions (Sexuality and Safety with Tom and Ellie) by Kate E. Reynolds
- What's Happening to Me? (Girls Edition) (Facts of Life) by Susan Meredith and Nancy Leschnikoff
- What's Happening to Me? (Boys edition) (Facts Of Life) by Alex Frith and Nancy Leschnikoff
- What's Happening to Me? by Peter Mayle

All available from Amazon and other booksellers.

**Books Beyond Words**
https://booksbeyondwords.co.uk/bookshop

Aimed at parents/carers or those working with people with moderate or severe learning disabilities. Each book tells a story in pictures only. Amongst the titles is ‘Susan's Growing Up’ by Sheila Hollins and Valerie Sinason.

**The FPA (formerly known as the Family Planning Association)**
www.fpa.org.uk/relationships-and-sex-education/parents-and-carers

Has a selection of books available to purchase, including the titles..............

**Talking together ... about growing up:** A workbook for parents of children with learning disabilities FPA (2010) Scott, L & Kerr-Edwards, L.

A practical activity-based workbook for use in home and school settings. Fully illustrated exercises related to everyday life. Provides advice on how
to adapt the tasks to different levels of ability and in different family settings, and information on public and private behaviour; menstruation and masturbation; feelings and looking ahead to relationships. There is also clear advice on assertiveness training and keeping safe. Children and young people with learning difficulties - all ages workbook.

- **Talking together...and sex and relationships:** A practical resource for schools and parents working with young people with learning disabilities FPA (2010) Scott, L & Kerr-Edwards, L
  Uses illustrated stories and activities for use in the classroom to explore a range of situations that young people with learning disabilities face as they grow up. Also has pages for parents/carers so that home and school can work in partnership. Young people with learning disabilities aged 13 and above.

- **Talking together... about contraception** FPA (2010) Scott, L & Kerr-Edwards, L
  This two-book pack supports young people with learning disabilities who wish to access contraception. Book one contains a guide to the methods of contraception available. Book two has been written for young people and has clear pictures, easy-to-read stories and picture posters. Young people with learning difficulties, aged 13 and older.


- **Pavilion Publishing (Brighton) Ltd** [www.pavpub.com](http://www.pavpub.com)
  Telephone customer services: 0844 880 5061
  Opening hours are 9am-5.30pm (Mon-Thurs), 9am-5pm (Fri)
  Email: info@pavpub.com
  Pavilion publish many books on sexual health and mental health.

- **Vanderbilt university**
  [https://vkc.mc.vanderbilt.edu/healthybodies/](https://vkc.mc.vanderbilt.edu/healthybodies/)
  They have boys and girls healthy bodies' toolkits and are symbol supported. They have a pain scale which may also be helpful.

- **Condom Cards** [www.bodysense.org.uk/](http://www.bodysense.org.uk/)
  Me-and-Us (2008) Eleven line drawings on laminated cards showing how to use a condom, together with a guidance card. For use by educators of people with learning disabilities or limited reading skills.
  Age 14+ Set of 12 Cards

- **Songs for your body**
  A CD of twelve songs designed to help a person with a learning disability learn about personal, social and sexual health, together with a book of guidance and activities for the educator to use. Primary and secondary CD.
DVD’s

♦ Life Support Productions
  www.lifesupportproductions.co.uk/ys.php
  PO Box 2127, London NW1 6RZ
  020 7723 7520
  Email: wilf@lifesupportproductions.co.uk
  DVD’s to aid in the teaching of RSE/PHSE.
  Each of their titles offers a comprehensive guide to the main issues in a
clear and friendly way, using animated characters (2D and 3D animation) to
narrate and illustrate each topic. Accessible and user-friendly with easy to
use menu choices, our DVDs are highly recommended as educational
resources for children and young people including those with learning
disabilities. Each of their DVDs can be previewed online.

♦ Jason’s private world (released as DVD 2007)) A male orientated
  Sex Education DVD with special value to those with learning
disabilities. Suitable for: Primary and secondary Primary and secondary
  DVD. www.fpa.org.uk

♦ Kylie’s private world (released as DVD 2007)) A female orientated
  Sex Education DVD with special value to those with learning disabilities.
  Primary and secondary DVD. www.fpa.org.uk

♦ You, your body and sex (2007) A comprehensive Sex Education
  guide for people with learning disabilities/special needs. Based on Jason's
  Private World and Kylie's Private World with additional material, Primary
  and secondary Online Resources.
  www.lifesupportproductions.co.uk/onlineresources.html
NOTES
Our thanks to all of the parents that contributed towards this guide.

Our grateful thanks to David Stewart, OBE, Head Teacher of Oak Field School & Sports College. Wigman Road, Bilborough, Nottingham. NG8 3HW
0115 9153265 Email: admin@oakfield.nottingham.sch.uk
www.oakfieldsportscollege.org.uk/
for his support and reviewing this guide.

Version 1 (MM)
Copyright © Unique 2019