Understanding Chromosome & Gene Disorders

Puberty





rarechromo.org

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.

Parents and carers' anxieties often peak when a child reaches puberty. They can appreciate 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 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). ”*

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SRE & RSE

Sex Education in the UK

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 gene 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 this guide:

Growing up, sex and relationships

https://contact.org.uk/wp-content/uploads/2021/03/growing_up_parents_new_logo.pdf

Alternatively, if you can't access online guides, you can contact them by Freephone helpline 0808 808 3555

email: helpline@cafamily.org.uk

Choice Support - Supported Loving

https://www.choicesupport.org.uk/about-us/what-we-do/supported-loving

01622 722400

Supported Loving has produced a series of guides which provide clear advice for carers who may not know how to support their relative appropriately with sensitive issues concerning sex and relationships.

> *"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 age of puberty can begin at any age between 8 and 14 years. For more information please see the NHS website: https://cambspborochildrenshealth.nhs.uk/child-development-and-growing-up/hormones-puberty-and-sexuality/



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 her 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
Modibodi: https://www.modibodi.co.uk/periods-underwear/
and Earthwise:
https://earthwisegirls.co.uk/product-category/reusable-sanitary-pads/
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, the use of additional sanitary towels will be unnecessary, but her pad might need changing more frequently during her period.

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. More information can be found on the NHS website: https://cambspborochildrenshealth.nhs.uk/child-development-and-growing-up/hormones-puberty-and-sexuality/

Puberty - changes in both sexes

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

Precocious (early onset) puberty and Delayed puberty

Information on these can be found on the NHS UK website
https://www.nhs.uk/conditions/early-or-delayed-puberty/

> *“ 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. ”*

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 sexual behaviour displayed by men and boys with learning disabilities. 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/wp-content/uploads/2021/02/008-Difficult-sexual-behaviour-.pdf

For further information and a full list of resources contact the Challenging Behaviour Foundation visit:
https://www.challengingbehaviour.org.uk/contact-us/

For general enquiries: phone 01634 838739 or email info@thecbf.org.uk

For Information and support about the needs of a family member with a severe learning disability: phone 0300 666 0126 or email at support@thecbf.org.uk

Sexual abuse and grooming

Without going into great detail in this guide, there is a very interesting 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@nspcc.org.uk
https://www.nspcc.org.uk/what-is-child-abuse/types-of-abuse/

Links

- **Autism**

https://www.autism.org.uk/advice-and-guidance/topics/family-life-and-relationships/sex-education/parents-and-carers
The National Autistic Society (NAS) has some useful information on their website about sex education and children and young people living with an ASD.

- **BigTalk Education**

BigTalk aims to ensure as many children and young people as possible receive high quality Relationship & Sex Education, to help keep them safe, healthy & happy. They have resources on their website for parents, for example:
https://www.bigtalkeducation.co.uk/parents/how-to-talk-about-sex/

- **Brook** https://www.brook.org.uk/

Brook offers help and advice on sex and relationships for young people, including an interactive chatbot here: https://www.brook.org.uk/help-advice/
And information for parents: https://www.brook.org.uk/parents-and-carers/

- **Easyhealth Let's Talk About Puberty**

Helping your relative to understand changes to their body using
These guides from EasyHealth can be accessed by creating a free account:
https://www.easyhealth.org.uk/resources/341-let-s-talk-about-puberty
https://www.easyhealth.org.uk/resources/346-love-sex-and-you
https://www.easyhealth.org.uk/resources/340-i-am-growing-into-a-woman

- **Health for teens** https://www.healthforteens.co.uk/

A website for all sorts of teenage worries and questions.

- **Learn and Thrive: Learning for Life**

Video resources covering personal health, emotions, relationships, and appropriate behaviour. You will need to sign up to access the resources.
https://www.learnandthrive.org.uk/learning-for-life?gad_source=1&gclid=CjwKCAjwxNW2BhAkEiwA24Cm9HG8ejjaAZ52eT7OoUePnfgm1UrTruFI59Y_tOKXAkA0dSar6aDSyxoCpSoQAvD_BwE

- **Oak Field School & Sports College. Wigman Road, Bilborough, Nottingham. NG8 3HW**

0115 9153265
Email: admin@oakfield.nottingham.sch.uk
https://www.oakfieldschool.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. You can order the PSHE resources at:
https://www.oakfieldschool.org.uk/pshe-resources/
David Stewart OBE, the former 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.

- **Sex education forum** info@sexeducationforum.org.uk

020 7843 600 General enquiries 07523 911016
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.

- **Sex education resource list for children and young people with Profound and Multiple disabilities (PMLD)** https://bit.ly/2OPKshl

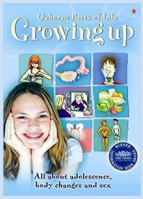
- **Video clips** about what is appropriate and inappropriate behaviour https://www.bbc.co.uk/programmes/b00l7r13/clips

BOOKS

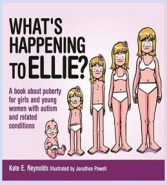
There are many books available on puberty related changes, here are just a few.....

- **Asking About Sex & Growing Up:** A Question-and-Answer Book for Kids by Joanna Cole



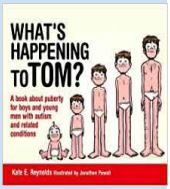


- **Usborne Facts of Life, Growing Up** (All about Adolescence, body changes and sex) by Susan Meredith
- **What's Happening to Ellie?** A book about puberty for girls and young women with autism and related conditions (Sexuality and Safety with Tom and Ellie) by Kate E. Reynolds



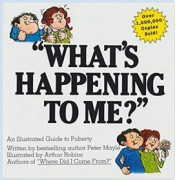
- **What's Happening to Tom?** A book about puberty for boys and young men with autism and related conditions (Sexuality and Safety with Tom and Ellie) by Kate E. Reynolds





- **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



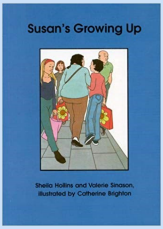


All available from Amazon and other booksellers.

- **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.



- **Easy Ready Condom Guide from SouthWest NHS 'A Picture of Health'**

https://www.apictureofhealth.southwest.nhs.uk/wp-content/uploads/sexual-health/contraception/Easyreadhowtouseacondom.pdf

- **The FPA (formerly known as the Family Planning Association)**

Has a selection of books available to purchase.

- **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.

All of the above titles are available in a bundle from Waterstones.
https://www.waterstones.com/book/talking-together-about-growing-up-talking-together-about-sex-and-relationships-talking-together-about-contraception/lesley-kerr-edwards/dr-lorna-scott/9781905506507

- **Pavilion Publishing (Brighton) Ltd**

Telephone customer services: 44 (0)1273 434 943
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.vumc.org/healthybodies/
They have boys and girls healthy bodies' toolkits and are symbol supported. They have a pain scale which may also be helpful.

- **Easy Ready Condom Guide from SouthWest NHS 'A Picture of Health'**

https://www.apictureofhealth.southwest.nhs.uk/wp-content/uploads/sexual-health/contraception/Easyreadhowtouseacondom.pdf

DVD's

- **Life Support Productions**

https://www.lifesupportproductions.co.uk/
PO Box 2127, London NW1 6RZ
020 7723 7520
Email: info@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. And **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. Both available from: http://www.fpa.org.uk/shop-products-and-training

> *"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"*

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Inform Network Support

Understanding Chromosome & Gene Disorders

Rare Chromosome Disorder Support Group
The Stables, Station Road West, Oxted, Surrey RH8 9EE,
United Kingdom
Tel: +44(0)1883 723356
info@rarechromo.org I www.rarechromo.org

Join Unique for family links, information and support.

Unique is a charity without government funding, existing entirely on donations and grants. If you can, please make a donation via our website at www.rarechromo.org
Please help us to help you!

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 years of support and for reviewing this guide.

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