

## INFORMATION FOR PATIENTS, PARENTS, GUARDIANS AND CARERS

# Down's syndrome

## Frequently asked questions

### Useful websites

Local Services

[Notts Help Yourself](#)

Down's Syndrome Association

<http://www.downs-syndrome.org.uk/>

Down's Syndrome - NHS website

<https://www.nhs.uk/conditions/downs-syndrome/>

Foundation for People with Learning Disabilities

<http://www.learningdisabilities.org.uk>

Communication skills

<https://www.nottinghamshirehealthcare.nhs.uk/language-for-life>

Makaton

[What is Makaton? - About Makaton](#)

Youth Access – provider of young people's advice and counselling services

<http://www.youthaccess.org.uk/>

Mencap

<http://www.mencap.org.uk>

National Association of Special Schools

<http://www.nasschools.org.uk>

Nottinghamshire County Council

<http://www.nottinghamshire.gov.uk/>

Citizens Advice Bureau

<http://www.citizensadvice.org.uk/>

Disability Rights UK

<http://www.disabilityrightsuk.org/>

Department for Work and Pensions

<http://www.dwp.gov.uk/>

Contact a Family

[Contact - for families with disabled children](#)

Helpline: 0808 808 3555

Easy Health - downloadable leaflets and videos

<http://www.easyhealth.org.uk/>

APTCOO (A place to call our own)

<http://www.aptcoo.co.uk/>

Exploring relationships with young people with SEND

<https://learning.nspcc.org.uk/news/2019/april/exploring-emotions-relationships-young-people-send/>

Relate – support for the parents of children and young people experiencing difficulties

<https://www.relate.org.uk/relationship-help/help-family-life-and-parenting>

### **Benefits/grant funding information**

<https://www.downs-syndrome.org.uk/for-families-and-carers/>

Disability Grants for Children and Young People

<http://www.disability-grants.org/grants-for-children.html>

Personal Independent Payment (replaces Disability Living Allowance for those over 16 years of age)

<https://www.disabilityrightsuk.org/personal-independence-payment-pip>

Family Fund – grants to low income families with disabled or seriously ill children

<http://www.familyfund.org.uk/>

### **Sleep**

[Sleep | Downs Syndrome Association \(downs-syndrome.org.uk\)](Sleep | Downs Syndrome Association (downs-syndrome.org.uk))

One free copy available to registered members.

### **Adolescence – Royal College of Psychiatrists**

Surviving adolescence - a toolkit for parents, teachers, young people and anyone who works with young people

<http://www.rcpsych.ac.uk/healthadvice/parentsandyouthinfo/parentscarers/adolescence.aspx>

### **Toilet training**

<https://www.downs-syndrome.org.uk/download-package/talk-about-going-to-the-toilet/?highlight=toilet>

<https://www.healthychildren.org/English/ages-stages/toddler/toilet-training/Pages/Toilet-Training-Children-with-Special-Needs.aspx>

## **Sexuality**

<http://www.childline.org.uk/explore/sexual-identity/pages/sexual-orientation.aspx>

## **Blogs by families who have a child with Down's syndrome**

The Future's Rosie

<http://www.thefuturesrosie.com/>

Down's with the kids

<http://downswiththekids.blogspot.co.uk/>

Orange Juice Flavour Sky

<http://orangejuiceflavoursky.blogspot.co.uk/>

Down's Side Up

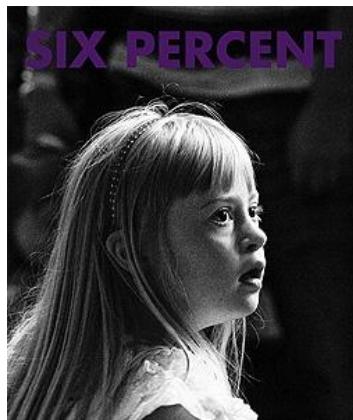
<http://www.downssideup.com/>

## **Nottinghamshire Down's Syndrome Support Group**

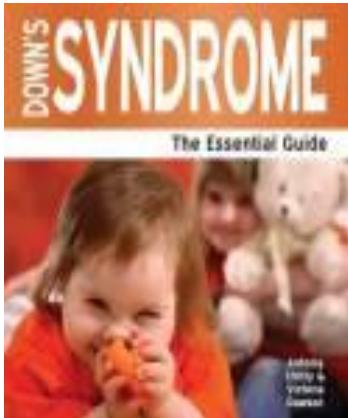
Offer support and activities to Down's Syndrome families living in and around the Nottinghamshire area.

<https://www.nottshelpyourself.org.uk/kb5/nottinghamshire/directory/service.page?id=nh0ChWE-tek&newdirectorychannel=9-6-6>

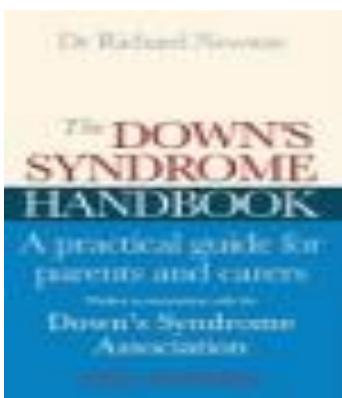
## **Books available to loan**



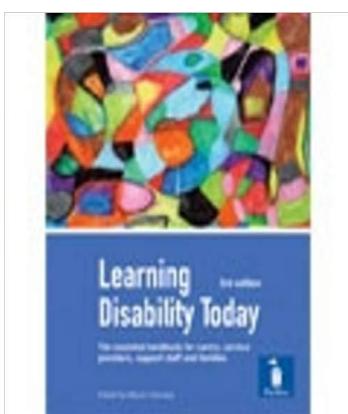
Six per cent Down's Syndrome: My photographs, their stories, by Graham Miller



Down's Syndrome: The Essential Guide



The Down's Syndrome Handbook: A practical guide for parents and carers



Learning Disability Today: The essential handbook for carers, service providers, support staff and families, by Steven Carnaby

You can search the library catalogue at <https://koha.healthlibrariesmidlands.nhs.uk/> - click on 'All libraries' on the right hand side and select King's Mill Hospital. Contact email [library.sfht@nhs.net](mailto:library.sfht@nhs.net) or telephone 01623 622515, extension 4009 for more information.

## Public Libraries

Search the collection and find your nearest library:

<https://www.inspireculture.org.uk/reading-information/find-a-library/>

## **Further sources of information**

NHS Choices: [www.nhs.uk/conditions](http://www.nhs.uk/conditions)

Our website: [www.sfh-tr.nhs.uk](http://www.sfh-tr.nhs.uk)

### **Patient Experience Team (PET)**

PET is available to help with any of your compliments, concerns or complaints, and will ensure a prompt and efficient service.

**King's Mill Hospital:** 01623 672222

**Newark Hospital:** 01636 685692

**Email:** [sfh-tr.PET@nhs.net](mailto:sfh-tr.PET@nhs.net)

If you would like this information in an alternative format, for example large print or easy read, or if you need help with communicating with us, for example because you use British Sign Language, please let us know. You can call the Patient Experience Team on 01623 672222 or email [sfh-tr.PET@nhs.net](mailto:sfh-tr.PET@nhs.net).

This document is intended for information purposes only and should not replace advice that your relevant health professional would give you. External websites may be referred to in specific cases. Any external websites are provided for your information and convenience. We cannot accept responsibility for the information found on them. If you require a full list of references for this leaflet, please email [sfh-tr.patientinformation@nhs.net](mailto:sfh-tr.patientinformation@nhs.net) or telephone 01623 622515, extension 6927.

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