

My Planned Care Patient Information Platform

Paediatric Complex Movement Disorder Service – Waiting Well

Introduction

Complex Movement Disorder Service is a multi-professional team that provides diagnosis and treatment for children with complex neurological conditions. Each child is assessed in an outpatient appointment to review current treatment and discuss potential treatment options. The two most common treatments are:

- Deep brain stimulation
- Intrathecal Baclofen therapy

If your child is on a waiting list, awaiting a procedure date by a Neurosurgeon, there are some things you can do in the intervening period to prepare for your child's admission to the hospital. More information about the complex movement disorder service, Deep Brain Stimulation and Intrathecal Baclofen therapy can be found on the Complex Movement Disorder page on the University Hospitals Bristol and Weston Hospitals Trust website: <http://www.uhbristol.nhs.uk/patients-and-visitors/your-hospitals/bristol-royal-hospital-for-children/what-we-do/paediatric-physiotherapy/complex-movement-disorder-service/>

You can also learn about the Deep Brain Stimulation passport by watching a short video that has been created by the staff at Bristol Royal Hospital for Children and find out how it can improve your child's visits to the hospital, after they have the device fitted:

[Deep Brain Stimulation \(DBS\) Passport - YouTube](#)

Guidance for Patients

Whilst you are waiting for your child's operation, the Bristol Royal Hospital for Children website also has useful information leaflets and videos available online via the following link:

<http://www.uhbristol.nhs.uk/patients-and-visitors/your-hospitals/bristol-royal-hospital-for-children/childrens-website/>

If your child has additional needs and requires support during their admission to the hospital, you may find the below link to our "Hospital Passport" useful:

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Bristol Royal Hospital
For Children

University Hospitals Bristol **NHS**
NHS Foundation Trust

Hello, my name is

I like to be called

and I can respond to it.
Please use my name when
you speak to me.

Who are you?
#hello my name is...

Insert photo
of your child
here

See instructions on the main webpage or
in our leaflet

My Hospital Passport

PREFERABLE INFORMATION
Information about my likes, dislikes and comfort issues

Things I like

Things I don't like

Things that make me feel safe and comfortable

Things that will make my time in hospital better

Web Link to Passport:

<http://www.uhbristol.nhs.uk/patients-and-visitors/your-hospitals/bristol-royal-hospital-for-children/patient-and-family-support-services/disability-support-team/hospital-passport/>

What should I do if my child's health is deteriorating?

GP surgeries are still open

Please contact your GP surgery for advice if you feel that your child's condition is deteriorating. GP surgeries are still open but may be working differently to how they did before the COVID-19 pandemic.

GP surgeries can contact the Children's Hospital for advice if needed.

Contact your Clinical Team at BRHC

Please do contact your child's clinician if you are concerned their condition is deteriorating or you have any questions relating to their care under that service.

Urgent Health Advice

For urgent health advice, when it's not an emergency, please call 111 from any landline or mobile phone. You can also visit www.nhs.uk. The NHS 111 service is available 24 hours a day, seven days a week.

Life Threatening Emergencies

For anything life threatening – please dial 999.