WOLFRAM SYNDROME UK

*Inform, Support, CURE*

www.wolframsyndrome.co.uk

# Parent's Pack

WOLFRAM SYNDROME UK
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This QR code will take you to the Wolfram Syndrome UK website.

This pack has been produced by Wolfram Syndrome UK in support with Birmingham Children's Hospital.

The medical information was produced with guidance by Prof Timothy Barrett Wolfram Syndrome Children's Professional at Birmingham and Dr Renuka Dias Wolfram Syndrome Children's Clinical Lead at Birmingham Children's Hospital.

**Family Support Co-Ordinator's (FSC) Details**

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This QR code will take you to the Family Support Co-Ordinator's page on the WSUK website or you can use the link - https://wolframsyndrome.co.uk/family-support-coordinator/

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# SECTION 12

## Examples of Forms for Clinic

# CHILD AND ADOLESCENT MENTAL HEALTH SERVICES

**DEPARTMENT OF CLINICAL PSYCHOLOGY**
*DIRECT DEPARTMENT LINE: TEL: 0121 333 8046*

Birmingham Children's Hospital has a Paediatric Psychology Team delivering psychological care and consultation across the hospital. As part of the Wolfram multi-disciplinary clinics you will be offered a thirty minute appointment with a member of the team. Our role is to work with children, young people and their families where emotional factors are impacting on a child's health condition and/or its treatment.

The aim of the screening appointment is for us to assess the psychological needs of your child/young person. It will be possible for you to have some time together as a family, for you as parents/carers to have some time alone, for your child/young person to have some individual time, or a combination of the three options, whichever you feel would suit your family best.

Some families find it useful to discuss a wide range of different things, including areas such as how to discuss their child's diagnosis with them, adjustment to life with Wolfram Syndrome, the emotional aspects of adjustment to visual or auditory impairment and thoughts about their appearance. Other areas that parents have chosen to discuss include coping with medical procedures, difficulties with learning and peer relationships. Every child and family is unique and as such there may be different things that you would like to talk about.

If you would like the opportunity to talk to us about what psychology we may be able to offer or discuss issues regarding your child prior to your appointment at the clinic, please contact us on the telephone number above.

**We would be grateful if you would complete the enclosed questionnaire prior to coming to clinic and send it back to us. We look forward to seeing you in clinic.**

Birmingham Children's Hospital NHS
NHS Foundation Trust

**CHILD AND ADOLESCENT MENTAL HEALTH SERVICES**
**DEPARTMENT OF PAEDIATRIC PSYCHOLOGY**

Birmingham Children's Hospital
Steelhouse Lane
Birmingham
B4 6NH

Tel: 0121 333 8048

## Young Person's Questionnaire

The rare diabetes team here at Birmingham Children's Hospital is made up lots of different professionals including Clinical Psychologists.

We often work with young people and their families to think about the emotional side of their condition. This might include weight management, visual impairment and the social difficulties.

Some things that young people have talked about are below. Please let us know if you have had a similar experience and would like to talk more about this:

1. Feeling different to other people my age

   I'm OK with this ☐ I would like to chat about this ☐

2. Not being able to do things that other people my age do

   I'm OK with this ☐ I would like to chat about this ☐

3. Finding it difficult to talk to people my age (e.g. feeling shy or self conscious)

   I'm OK with this ☐ I would like to chat about this ☐

4. Unwanted attention or bullying from others

   I'm OK with this ☐ I would like to chat about this ☐

5. Feeling unhappy, low in mood or anxious

   I'm OK with this ☐ I would like to chat about this ☐

- Some young people find that their difficulties can be hard to think about or they worry that their parents will become upset (it's normal to feel like this, but it is good to talk about it)
- Your appointment with the Psychologist is a safe place to talk about how you feel
- You can choose to attend this appointment on your own or with your parents
- The Psychologist will think with you about ways you can cope with any problems you may be experiencing

A. Please list any other concerns that you would like to discuss

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.....
.....
.....

B. On a scale of 1-10 how would you rate your mood




***Thank you for completing this questionnaire and we look forward to meeting you***

**Date:** _____

**On waking**: _____

| Time | Drink (mls) | Amount of urine | State of pants/pad | Bowel action |
|---|---|---|---|---|
| 07am | | | | |
| 08 am | | | | |
| 09am | | | | |
| 10am | | | | |
| 11am | | | | |
| 12pm | | | | |
| 1pm | | | | |
| 2pm | | | | |
| 3pm | | | | |
| 4pm | | | | |
| 5pm | | | | |
| 6pm | | | | |
| 7pm | | | | |
| 8pm | | | | |
| 9pm | | | | |

# Urodynamics Department

## Frequency Voiding Chart

NAME:_____

UNIT NUMBER: _____

**So we can understand your child's problem, please complete the chart with care and bring it along to your appointment**

- Complete the chart for 2 days. Avoid school days – use weekends and holidays
- Measure in millilitres all of the drinks which are drunk.
- Measure in millilitres the amount your child voids (wees) by using a plastic jug with millilitres on the side.
- Record the state of the pants – whether damp or wet.
- Record any bowel actions.

**If you have any queries please contact the Urodynamics Department on 0121 333 9222**

**Date Monday**: 1st January 2010
**On waking**:7.00 Wet pyjamas and pants

| Time | Drink (mls) | Amount of urine | State of pants/pads | Bowel action |
|---|---|---|---|---|
| 7am | | 200mls | Wet | |
| 8am | Milk 200mls | | | |
| 9am | | | | |
| 10am | Ribena 22o mls | 120mls | Damp pants | |
| 11am | | | | |
| 12pm | | | | |
| 1pm | | | | |
| 2pm | | 90mls | Slightly soiled | |
| 3pm | | | | |
| 4pm | Lemonade 150mls | | Wet pants & trousers | |
| 5pm | | | | |
| 6pm | | 160 mls | Damp | Bowels open |
| 7pm | Water 180mls | | | |
| 8pm | | 100mls | Dry | |
| 9pm | | | | |

EXAMPLE

**Date:** _____
**On waking**: _____

| Time | Drink (mls) | Amount of urine | State of pants/pad | Bowel action |
|---|---|---|---|---|
| 07am | | | | |
| 08 am | | | | |
| 09am | | | | |
| 10am | | | | |
| 11am | | | | |
| 12pm | | | | |
| 1pm | | | | |
| 2pm | | | | |
| 3pm | | | | |
| 4pm | | | | |
| 5pm | | | | |
| 6pm | | | | |
| 7pm | | | | |
| 8pm | | | | |
| 9pm | | | | |