WOLFRAM SYNDROME UK

Inform, Support, CURE

www.wolframsyndrome.co.uk

Parent's Pack

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CONTENTS OF PACK:

1. Wolfram Infographic
2. Why should I attend the WS clinic?
3. Clinic Information
4. Benefits/Financial Help
5. Helpful organisations
6. Facilities at the hospital and Floorplans
7. Frequently asked questions
8. Claiming travel costs
9. Meet the Expert
10. The Wolfram Syndrome child at school: give this sheet to your child's teacher.
11. Wolfram Syndrome Variants
12. Forms for Clinic

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.

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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 4

Benefits/Financial Help

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BENEFITS/FINANCES/CONCESSIONS

DISABILITY LIVING ALLOWANCE (DLA):

DLA is the main benefit available for children under 16 with a condition or disability and is not means tested. DLA cannot be backdated; the date of your claim will usually be when the form was received by the DLA office or the date you call the enquiry line. It usually takes 40 working days to deal with a DLA form.

DLA is made up of 2 parts:

Care Component:

This is for children who need extra attention or supervision. When the DLA unit consider whether your child qualifies, they will compare your child's needs with those of a child of the same age who has no disabilities. For example, needing to provide extra care during the night for as little as 20 minutes (in total) could mean your child qualifies.

Mobility Component:

This is for children who need help with getting around.

Care Component	Weekly Rate (as at April 2025)	Examples of the level of help you need for your child
Low Rate	£29.20	Help for some of the day or with preparing cooked meals
Middle Rate	£73.90	Frequent help or constant supervision during the day, supervision at night.
High Rate	£110.40	Help or supervision throughout both day and night.
Mobility Component	**Weekly Rate (as at April 2025)**	**Examples of the level of help you need for your child**
Low Rate	£29.20	Needs extra guidance or supervision outside.
High Rate	£77.05	Child is deafblind or severally visually impaired

Rates:

DLA is paid at different rates made up from the care component and the mobility component. Your child may be eligible for just one component **or** both.

Extra help because your child gets DLA:

Getting DLA can help you qualify for extra amounts of other means-tested benefits and tax credits. It may also help you qualify for Carer's Allowance (see below).

Help with filling out the form

To claim DLA, you will need to fill in a DLA 1A Child form. You can order one by calling the DLA helpline- 0800 121 4600 or by printing and filling in the form from this link https://www.gov.uk/government/publications/disability-living-allowance-for-children-claim-form.

It is a large form to fill out, and can be off-putting, but there are organisations who can help you to complete it: Contact will be able to find organisations local to you – their number is 0808 808 3555.

For more information about DLA, visit the website at: https://www.gov.uk/disability-living-allowance-children call 0800 121 4600

Universal Credit (UC)

You may be entitled to Universal Credit (UC) if your child receives DLA. If they do, the rates for the disabled child elements are as follows:

Rate	Amount per month (as at April 2025)
Higher	£495.87
Middle and Low	£158.76

You are able to claim the carer's element if you care for your child for more than 35hrs per week.

Carer's element	£201.68

Carer's element on UC is separate to Carer's Allowance (CA). Please be aware that when claiming CA on UC it is reduced **£ for £** from your total award.

You can use the following calculator to work out your rates https://benefits-calculator.turn2us.org.uk/.

These rates are subject to change based on government inflation.

CARER'S ALLOWANCE (CA):

Carer's Allowance (CA) is **£83.30** per week (as at April 2025) to help you look after someone with substantial caring needs. You need to be age 16 or over and spend at least **35** hours a week caring for them. CA allowance is not means tested so it doesn't matter what savings you have, but it is only payable if you earn **£196** or less per week after tax, National Insurance and expenses.

For more information visit the website at www.gov.uk/carers-allowance or call 0800 731 0297

PERSONAL INDEPENDENCE PAYMENTS (PIP)

Personal Independence Payments (PIP) is the adult benefit that replaces DLA when a child turns 16. PIP is available for adults 16-64. For more information about how this could affect you or your child visit https://www.gov.uk/pip.

If you live in Scotland, then you need to apply for the Adult Disability Payment instead. Those receiving PIP in Scotland will be automatically transferred over to ADP by Summer 2024. You can apply by using this link https://www.mygov.scot/adult-disability-payment.

DIRECT PAYMENTS (DP)

If you or someone you care for gets help from social services, you can apply for Direct Payments(DP). These payments allow you to arrange care and services yourself, instead of receiving them directly from your local council, and can be made to parents and carers aged 16 or over. Following an assessment, DP can be used for a variety of services which offer your child or young person stimulation, new experiences and independence.

These include:

- Short breaks,
- Nursery placement providing specialist support for your child,
- Assistance to attend an activity, for example, a youth club.
- Personal care

For more information visit: https://www.gov.uk/apply-direct-payments.

If you live in Scotland or Wales, you will need to contact your local council directly about DP.

OTHER FINANCIAL ASSISTANCE AVAILABLE:

TV LICENCING:	You can claim a **50% discount** on TV Licence fees if anyone in your household (including children) is registered blind or severely sight impaired (**not** partially sighted). The TV Licence must be transferred into that person's name. For more information visit the website: https://www.tvlicensing.co.uk/check-if-you-need-one/for-your-home/blindseverely-sight-impaired-aud5 or call 0300 790 6087.
CINEMA DISCOUNT CARD:	The Cinema Exhibitors Association Card (CEA Card) is a national card that can be used to verify that the holder is entitled to one FREE ticket for a person accompanying them to the cinema. For more information, visit the website at: https://www.ceacard.co.uk/ or call 01244 526016.
DISABLED PERSON'S BUS PASS:	You are eligible for free bus travel if you are visually impaired or profoundly deaf. The scheme is operated differently in parts of the UK – for example, in England they are valid for off-peak travel only. You can also ask for a companion (unnamed) to be included on the pass. Contact your local authority for more information.

BLUE BADGE SCHEME:	Blue Badge parking permits allow disabled drivers and passengers to park nearer to where they're going. The badge is transferable between cars, but the disabled person must be a passenger in the car. Visit www.gov.uk/browse/driving/blue-badge-parking for more information.
SOCIAL SERVICES:	Your local Social Services can help with providing gadgets such as hearing loops, vibrating alarm clocks and smoke alarms. They also help with mobility training and living skills. Contact your local council for more information.
DISABLED PERSON'S RAILCARD:	If you receive disability related benefits, are registered visually impaired or registered deaf or use a hearing aid, you could be eligible for a Railcard which will save you and a companion 1/3 on most adult rail fares. Visit the website for more information: www.disabledpersons-railcard.co.uk.
THEATRE/CONCERT TICKETS/PLACES TO VISIT:	Remember it's always worth mentioning that you/your child has a disability. You may be entitled to reduced payments for a companion, or you may be given better seats.
COLD WEATHER PAYMENTS:	You may get a Cold Weather Payment if you receive certain benefits, particularly Universal Credit with the disabled child element in your claim. Payments of £25 are made when your local temperature is either recorded as, or forecast to be, an average of zero degrees Celsius or below over 7 consecutive days between 1st November and 31st March: https://www.gov.uk/cold-weather-payment.