WOLFRAM SYNDROME UK
Inform, Support, CURE
www.wolframsyndrome.co.uk

YP and Adult’s Clinic Pack

CONTENTS OF PACK:

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

This pack has been produced by Wolfram Syndrome UK in support with Queen Elizabeth Hospital.

The medical information was produced with guidance by Prof Timothy Barrett Wolfram Syndrome Children's Professional at Birmingham.

Adult Support Co-Ordinator (ASC) Details

- Mobile 07752 193635

Email: admin@wolframsyndrome.co.uk

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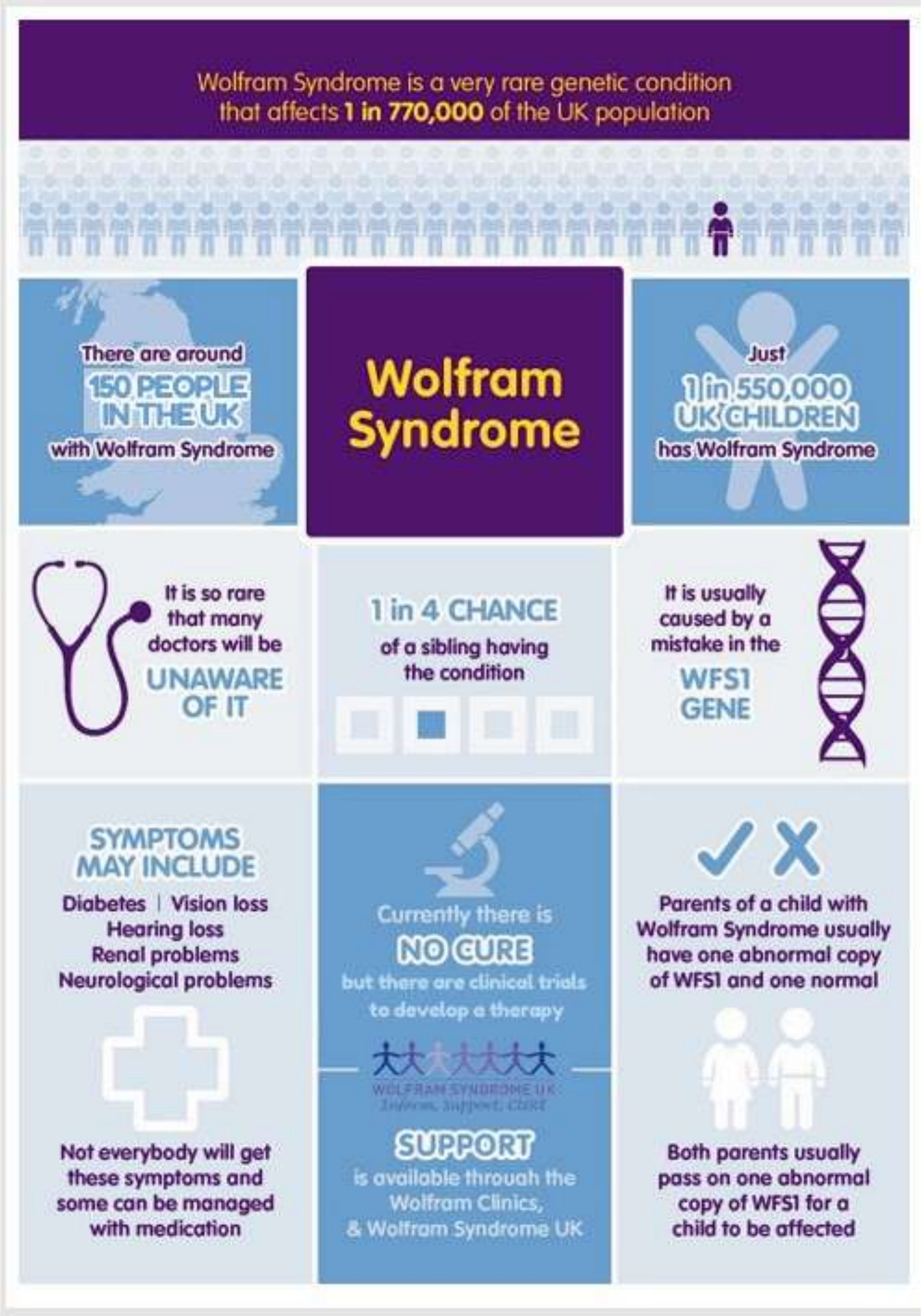
SECTION 1

Wolfram Infographic



Wolfram Syndrome is a very rare genetic condition
that affects **1 in 770,000** of the UK population

There are around
150 PEOPLE IN THE UK
with Wolfram Syndrome

Wolfram Syndrome

Just
1 in 550,000 UK CHILDREN
has Wolfram Syndrome

It is so rare that many doctors will be **UNAWARE OF IT**

1 in 4 CHANCE
of a sibling having the condition

It is usually caused by a mistake in the **WFS1 GENE**

SYMPTOMS MAY INCLUDE

Diabetes | Vision loss
Hearing loss
Renal problems
Neurological problems

Not everybody will get these symptoms and some can be managed with medication

Currently there is
NO CURE
but there are clinical trials to develop a therapy

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SUPPORT
is available through the Wolfram Clinics, & Wolfram Syndrome UK

Parents of a child with Wolfram Syndrome usually have one abnormal copy of WFS1 and one normal

Both parents usually pass on one abnormal copy of WFS1 for a child to be affected

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SECTION 2

Why should I attend the WS Clinic at QEH?

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Why should I attend the WS clinic at Queen Elizabeth Hospital?

1. You will be seen by medical professionals who have expert knowledge of Wolfram Syndrome ~ knowledge which is usually lacking locally.

2. You'll get an update on the latest research into potential therapies to slow the progression of the condition.

3. You will have the opportunity to take part in this research, and be invited to take part in clinical trials when they take place.

4. You will typically see the same consultants each time you attend, which means they really get to know you and your health needs.

5. The team at the Wolfram clinic will provide information to your local health team to support them in delivering high quality care.

6. By attending, you are providing the team with invaluable knowledge about Wolfram Syndrome.

7. Having you and other individuals come together at the Queen Elizabeth Hospital provides a vital focal point for undertaking research.

8. You get to meet other adults/young people who understand what you are going through.

9. You'll be supported by the Adult Support Co-ordinator, who will not only be there for you during the clinic, but can also provide support and information for issues you may be experiencing outside of the clinic.

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SECTION 3

Clinic Information

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Wolfram Multi-Disciplinary Clinic—Queen Elizabeth Hospital

Queen Elizabeth Hospital (QEH) received NCG (National Commissioning Group) funding in 2010 to support multi-disciplinary clinics for patients who have been diagnosed with Wolfram Syndrome

What does this mean?

We know from talking with those with the syndrome, and those who are undergoing diagnosis, how difficult it is to find doctors at a local level with knowledge of Wolfram, its many different aspects, and the impact that this has on their health care.

Experts have been gathered from across the fields of Ophthalmology, Neurology, Endocrinology and Genetics amongst others, which should bring about a major change in how Wolfram is managed, with a focus on Diagnosis, early intervention and good health management.

Which Clinicians will be available?

On the day you **may** be seen by an:

Ophthalmologist

Speech and Language Therapist

Endocrinologist

Neurologist

Geneticist

Clinical Psychologist

Audiology

In addition, there will be a WSUK Adult Support Co-ordinator available to help you with any support needs. She is also available to help at other times.

What happens at an appointment?

You will be invited to spend the afternoon at the QEH. During the afternoon you will meet several health professionals in the Centre for Rare Disease situated in the Heritage Building.

Consultations with each clinician will last approximately 25 minutes. If any further action is required, each clinician will advise you what will happen next.

What tests may be done?

You will have your vision and visual field checked. You will also have a blood test and will be asked for a urine sample (you may wish to bring this with you).

If any other tests are required, you will be informed about these on the day.

Please bring any recent test results or clinic letters with you.

Following your appointment, information and test results will be sent to your local health care team to ensure you receive optimum care locally. You will also receive a letter outlining your consultation with each clinician.

If you have any questions or concerns about attending the clinic please contact the WS clinic secretary at QEH – 07442 831118 or the WSUK Adult Support Co-ordinator. Contact details are at the front of the pack.

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SECTION 4

Benefits/Financial Help

BENEFITS/FINANCES/CONCESSIONS

PERSONAL INDEPENDENCE PAYMENTS (PIP):

PIP is the main benefit for young people and adults aged 16-64, with a condition or disability and is not means tested. PIP cannot be backdated; the date of your claim will usually be when the form was received by the DWP office or the date you call the enquiry line. It usually takes 40 working days to deal with a PIP form.

PIP is made up of 2 parts:

Daily Living Part:

This is for those who need help with everyday tasks.

Mobility Part:

This is for those who need help with getting around. You do not have to have a physical disability to get the mobility part. You might also be eligible if you have difficulty getting around because of a cognitive or mental health condition, like anxiety.

The Department for Work and Pensions (DWP) will assess how difficult you find daily living and mobility tasks. For each task they'll look at:

- Whether you can do it safely
- How long it takes you
- How often your condition affects this activity
- Whether you need help to do it, from a person or using extra equipment.

Your carer could get Carer's Allowance if you have substantial caring needs.

Rates:
PIP is paid at different rates made up from the care component and the mobility component. You may be eligible for just one component or both.

Daily Living Component	**Weekly rate (as at April 2026)**	**Examples of the level of help you need**
Low rate	£76.70	Help for some of the day or with preparing cooked meals. Frequent help or constant supervision during the day, supervision at night.
Enhanced rate	£114.60	Help or supervision throughout both day and night
Mobility Component	**Weekly rate (as at April 2026)**	**Examples of the level of help you need**
Low rate	£30.30	Needs extra guidance or supervision outdoors.
Enhanced rate	£80.00	You are deafblind or severely visually impaired.

Help with filling out the form

To claim PIP, you will need to fill in a form. You can order one by calling the ‘PIP new claims’ helpline-0800 917 2222; Textphone- 0800 917 7777 or by printing off and filling in the form from this link - https://www.apply-for-pip.dwp.gov.uk/eligibility/check-if-eligible. You can apply by post but this will take longer. Send a letter to Personal Independence Payment New Claims, Post Handling Site B, Wolverhampton. WV99 1AH.

It is a large form to fill out, and can be off-putting, but there are organisations who can help you fill it out. You can read Citizens Advice’s help on filling in the form. For more information about PIP please visit the website at: https://www.gov.uk/pip

If you live in Scotland:

You need to apply for Adult Disability Payment (ADP) instead of PIP.

If you currently get PIP, you'll be automatically moved to ADP by summer 2024. When the move begins, you'll get letters from DWP and Social Security Scotland. Read More about the moving process.

You can apply by using this link https://www.mygov.scot/adult-disability-payment.

Universal Credit (UC)

Universal Credit is a payment to help with your living costs. It's paid monthly - or twice a month for some people in Scotland.

You may be able to get it if you're on a low income, out of work or you cannot work. You might get an extra amount of UC if you have a health condition or disability that limits how much work you can do. The Department for Work and Pensions (DWP) refers to this as your 'capability to work'.

How much you'll get	Monthly standard allowance (as at April 2026)
If your single and under 25	£338.58
If your single and 25 or over	£424.90
If you live with your partner and you are both under 25	£528.34 (for you both)
If you live with your partner and either of you are 25 or over	£666.97 (for you both)

You'll continue getting any other benefits you already receive, such as Personal Independence Payment (PIP) or Carer's Allowance.

Find out more about Universal Credit by using this link https://www.gov.uk/universal-credit/what-youll-get

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

CARER’S ALLOWANCE (CA):

Carer’s Allowance is £86.45 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 is not means tested so it doesn’t matter what savings you have, but it is only payable if you earn £204.00 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

SCOTTISH CARER PAYMENT

From March 2026 carers in Scotland may be eligible to receive Carer Support, a new benefit combining three components:

- **Carer Support Payment (CSP)** – the Scottish equivalent of Carer’s Allowance (£86.45 per week from April 2026). In addition, carers will be able to claim CSP for 12 weeks following the death of the person they care for, an extension from the current 8-week period.
- **Scottish Carer Supplement** – this replaces the Carer’s Allowance Supplement with a regular payment of £11.70 per week for carers in Scotland who already receive the Carer Support Payment.
- **Carer Additional Person Payment** – this is an additional payment of £10.40 per week, available to those in receipt of Carer Support Payment who care for more than one person. Carers may be eligible for more than one Carer Additional Person Payment if they are caring for more than one additional person.

DIRECT PAYMENTS (DP)

You can only get Direct Payments if you’ve been assessed by social services as needing care and support services.

DP can be made to:

- Disabled people aged 16 or over (with short or long-term needs)
- Disabled parents for children’s services
- Carers aged 16 or over (including people with parental responsibility for a disabled child)
- Elderly people who need community care services

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

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

The WSUK ASC can assist you where possible with some of the forms. Contact details available at the front of the pack.

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 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.
COLD WEATHER PAYMENTS	You may get a Cold Weather Payment if you're getting certain benefits, particularly if you receive UC with the disabled 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 Celsius or below over 7 consecutive days between 1st November and 31st March: https://www.gov.uk/cold-weather-payment.

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SECTION 5

Helpful Organisations

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ORGANISATIONS THAT CAN HELP YOU AND YOUR FAMILY

This isn’t a comprehensive list of organisations that can be of use to you. Many more that include links to holidays and activities can be found on the WSUK website - https://wolframsyndrome.co.uk/helpful-organisations/ and in the WSUK Handbook, also available on the website - https://wolframsyndrome.co.uk/ws-handbooks/

Wolfram Syndrome UK (WSUK)

WSUK aims to raise as much awareness of this syndrome as they can whilst supporting individuals and families affected.

The WSUK Adult Support Co-ordinator (ASC) works with young people and adults affected by WS, to provide information, support and advice. The ASC also helps individuals attend the multidisciplinary clinic at the Rare Disease Centre at the Queen Elizabeth Hospital, Birmingham.

The ASC works alongside the FSC during the transition of young people from the paediatric to adult service to ensure a smooth change over.

Website - https://wolframsyndrome.co.uk/

Office email – admin@wolframsyndrome.co.uk

Telephone – 01903 211358

RNIB

Offers practical and emotional support to help people with a visual impairment face the future with confidence.

https://www.rnib.org.uk/

Helpline: 0303 123 9999

RNIB SIGHTLINE DIRECTORY

An online directory of services and organisations that help blind and partially sighted people in the UK.

https://www.rnib.org.uk/sightline-directory/

VICTA

Provides support, information, activities, breaks and holidays for families with blind or visually impaired children or young people up to the age of 29.

https://www.victa.org.uk/

01908 240831

LOOK

Provides support, information and activities for families with visually impaired children and young people, to help them gain the best outcomes and reach their full potential.

https://www.look-uk.org/

07464 351 958

ACTION FOR BLIND PEOPLE

Action for Blind People merged with RNIB in 2017. This allows us to help more blind and partially sighted people by combining our services, knowledge and expertise within one charity

https://www.rnib.org.uk/who-we-are/action-for-blind-people

SIBS

Support and information for siblings of disabled people.

https://www.sibs.org.uk/

DIABETES UK

Self-help charity for diabetics. Information, diet advice, Teenzone.

https://www.diabetes.org.uk/ Tel:0345 123 2399

ACTION ON HEARING LOSS

The UK's leading charity supporting people with hearing loss, deafness and tinnitus.

https://rnid.org.uk/

THOMAS POCKLINGTON TRUST

Thomas Pocklington Trust is a national charity which supports blind and partially sighted people with a focus on Education, Employment and Engagement.

https://www.pocklington-trust.org.uk/

DISABILITY GRANTS

A directory that allows you to search for national and local organisations that can provide a grant for things like equipment, holidays, housing, days out… anything above and beyond the normal costs of everyday living.

https://www.disability-grants.org/

TURN 2 US

Helps people in financial need to access welfare benefits, charitable grants and other financial help.

https://www.turn2us.org.uk/

BRITISH BLIND SPORT (BBS)

The work of the charity enables visually impaired people to have the same opportunities as sighted people to access and enjoy sport and recreational activities in the UK.

https://britishblindsport.org.uk/

01926 424247

BLIND CRICKET IN ENGLAND AND WALES

The BCEW have been working in partnership with BBS and the England and Wales Cricket Board since 2006 to deliver competitive cricket for those who are blind or partially sighted, running national and international competitions.

https://bcew.co.uk/

0208 2794642

CALVERT TRUST

The Calvert Trust enables people with disabilities, together with their families and friends, to achieve their potential through the challenge of outdoor adventure in the countryside. Bases in Exmoor, Northumberland and the Lakes.

https://calvertexmoor.org.uk/. Tel: 01598 763221

https://calvertlakes.org.uk/. Tel: 017687 72255

https://www.calvertkielder.org.uk/. Tel: 01434 250232

SUPPORT, INFORMATION AND ADVICE	LEISURE AND ACTIVITY BREAKS	GRANTS, BENEFITS AND FINANCES	DAY EVENTS
WSUK	Calvert Trust	Disability Grants	LOOK
RNIB Sightline Directory	Blind Cricket in England and Wales	Thomas Pocklington Trust	VICTA
RNIB	British Blind Sport	Turn 2 Us	
LOOK	LOOK	VICTA	
VICTA			
Action for Blind People			
Action on Hearing Loss			
Sibs			
Thomas Pocklington Trust			
Diabetes UK			

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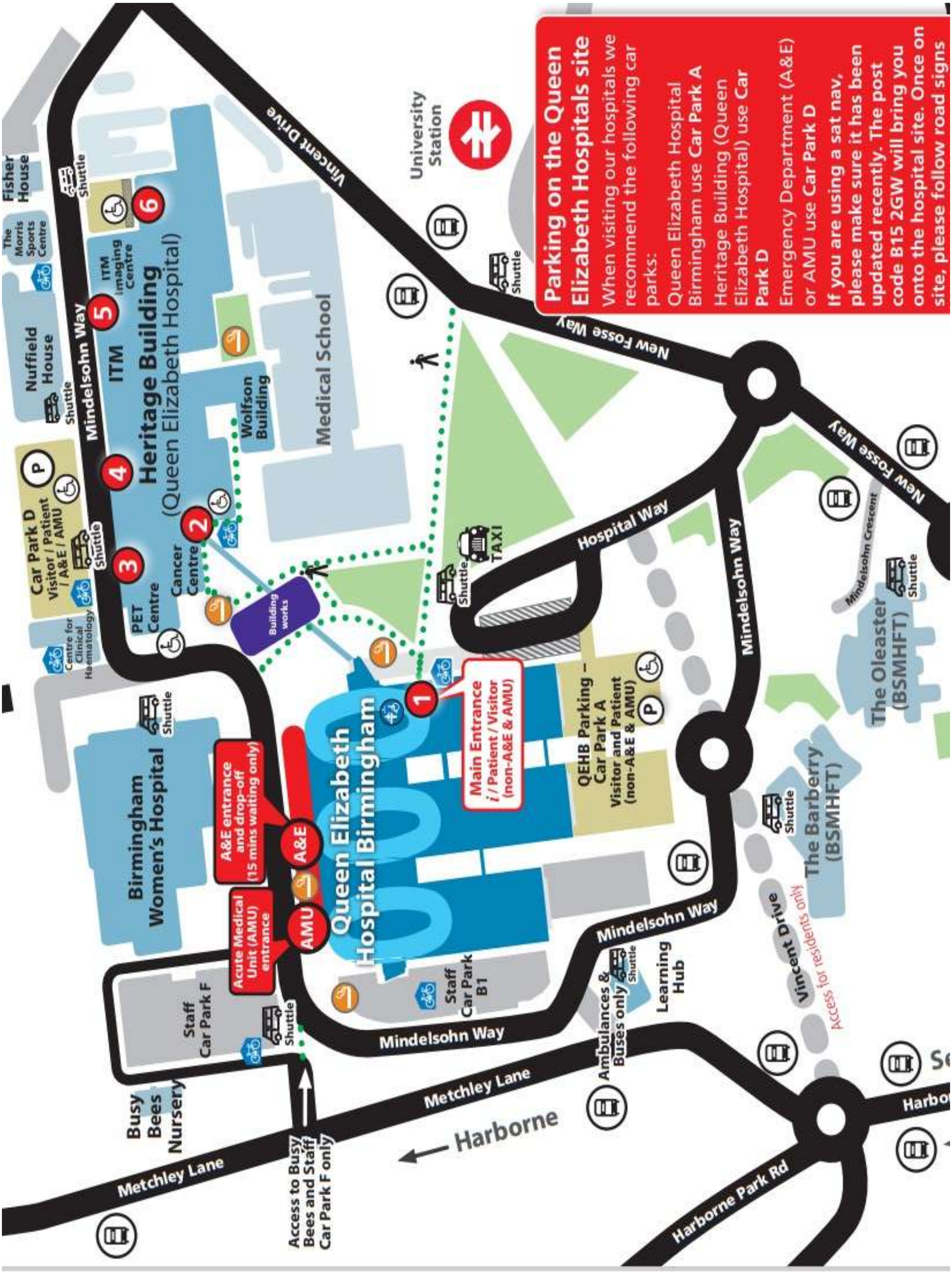
SECTION 6

Facilities at the Hospital and Floorplans

Map for Queen Elizabeth



Parking on the Queen Elizabeth Hospitals site

When visiting our hospitals we recommend the following car parks:

Queen Elizabeth Hospital Birmingham use **Car Park A**

Heritage Building (Queen Elizabeth Hospital) use **Car Park D**

Emergency Department (A&E) or AMU use **Car Park D**

If you are using a sat nav, please make sure it has been updated recently. The post code B15 2GW will bring you onto the hospital site. Once on site, please follow road signs

Facilities

Changing Places

Changing Places toilets are available at Queen Elizabeth Hospital Birmingham.

These toilets are equipped with a hoist, adult-sized height adjustable changing table, shower, sink and toilet. The facilities are designed to meet the needs of people with conditions such as muscular dystrophy or multiple sclerosis, and those with spinal or brain injuries.

Location – To the right of the information desk, past the WS Smith store. Key available from information desk staff.

Hearing loops

Hearing loops offer wireless signals that can be picked up by hearing aids to help overcome background noise. Portable hearing loop equipment is available in outpatient and ward areas.

Hearing loop equipment can be accessed through the ward or department sister.

Minicom

Minicom allows text communication via a telephone line for people who are deaf, hard of hearing or have speech impairments.

Minicom telephones have a keyboard and screen that transmit typed messages via a telephone line to the screen of a compatible device.

To access the Minicom service, please liaise with the ward sister.

COSTA

This is situated on the ground floor within the entrance of the main hospital building.

Restaurant

Situated on the first floor of the main hospital building.

In the main QEH building next to Costa there is a small café plus a take-away section. There is also a W H Smith which sells food and drink.

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SECTION 7

Frequently asked questions

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WOLFRAM SYNDROME ADULT'S CLINIC

FREQUENTLY ASKED QUESTIONS

1. When does the clinic take place?

You will be invited to a clinic approximately every 18-24 months, depending on the availability of appointments. If there is a diagnosis of Wolfram Related Syndrome (WRS) the time between clinics may be approx. every 2.5 years.

Clinic takes place on a Friday afternoon from 2:00pm. The Adult Support Co-ordinator or the clinic secretary, will contact you approx. 6-8 weeks before the clinic to invite you to attend and get a verbal confirmation of attendance from you. You will receive the invitation letter from QEH approximately 4-6 weeks before the clinic date.

2. Do I need to do anything before the clinic?

The ASC will contact you closer to the clinic date to confirm that you are still able to attend.

3. Why bother attending the clinic?

The advantage of attending the multi-disciplinary clinic is that you have several tests and consultations in one place, over the afternoon. The consultants are expert in WS, with a special interest in the condition. You also get to meet other adults and families living with WS. Please see the separate “Why should I attend the WS clinic?” page for more information.

4. Where is the clinic held?

The clinic is held at the Rare Disease Centre in The Heritage Building at Queen Elizabeth Hospital, Birmingham.

5. How long does the clinic last?

The clinic lasts approximately 3-4 hours.

6. Is there support available during the clinic?

There will be lots of people available to help you during the clinic. These include the diabetes nurse, and the clinic administrator. Your main point of contact during the clinic however, is Phillippa Farrant, the WSUK ASC. She will be there to support you during the afternoon, make sure you have everything you need and sort out any problems or issues you may have.

7. Who can I take with me?

You can take anyone else with you, a friend, parent or partner. We would recommend that someone else goes with you to clinic, as there is often a lot of information to take in.

8. We live a long way from the hospital, can we stay in a hotel?

Yes, but this is at your own cost. We can make a suggestion if necessary of the closest hotel to the hospital.

9. Can I get help with my travel costs?

You may be able to claim travel costs whilst at the hospital. For more information refer to the “Claiming Travel Costs” information sheet.

10. What happens at the clinic?

When you arrive at The Heritage Building, turn left inside the entrance and the clinic is through the double doors. To the right there is sometimes a receptionist you can inform, or if not turn left to the door and press the buzzer. A member of the team will come and introduce themselves and then take you to the waiting area and/or room to be seen. Don’t worry about getting to appointments on time, the team will organise all this for you and make sure you get to where you need to be.

11. Do I have to take all the tests?

We would advise that you have all the tests offered during the clinic.

However, if there is a test or appointment you feel particularly anxious about, please let us know **in advance of clinic** and we will advise the clinical team and the ASC, or arrange for someone to work with you prior to the test.

12. What happens at the end of the clinic?

Once you have finished your last appointment you are free to go home. A letter explaining the results of the appointments and tests, and summaries of each consultation, will be sent to you approximately six weeks after the clinic date. If you haven’t received the results letter by this time, please contact the WSUK ASC.

13. Who can I call if I need to contact the clinic?

If you have any questions about the clinic, please contact the clinic administrator, Amelia Hadjali on 07919 280674 or the WSUK ASC.

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SECTION 8

Claiming Travel Costs

WOLFRAM SYNDROME ADULT'S CLINICS

CLAIMING TRAVEL COSTS

You may be able to claim travel costs incurred while attending the Wolfram Syndrome clinic at the Queen Elizabeth Hospital. Whether you can claim and how you do it depends on different things. Please see below for more information:

Costs that can be claimed back (if eligible):

- Petrol (you will need to bring your invite letter with you to the clinic)

- Parking (you will need to keep a receipt)

- Train or bus fare (bring your letter and travel receipts)

- Under certain circumstances, taxi fares may be re-imbursed but this is at the discretion of the hospital and not guaranteed.

Who can claim:

You are entitled to claim for travel costs for NHS appointments or treatment if you receive any of the following benefits:

- Income Support
- Guaranteed Pension Credit
- Tax Credits **with** an exemption certificate
- Income-based Jobseeker's Allowance
- Income-related Employment and Support Allowance
- Low Income Scheme HC2 or HC3 certificates
- Universal Credit and meet the criteria

What Documents are required to claim travelling expenses

- Proof that you are in receipt of one of the above benefits (dated within 12 months, except item 7 above)
- Appointment letter or card
- Bus/Train ticket, Taxi receipt if applicable.

Payment can’t be made by the Cashiers without the relevant documentation. However, postal claims can be made by completion of an HC5 form.

How are the travel costs calculated?

Patients travelling on public transport will be reimbursed for the lowest cost form of public transport (including promotional or concessionary fares).

Patients travelling by private car may claim the lesser of, mileage allowance or equivalent public transport costs.

Claiming for taxi or escort costs

These costs may only be paid where deemed medically necessary in writing by your GP, Consultant or other healthcare professional involved in your care. Please note that escort costs will be paid on the basis of your eligibility not that of the escort. There are forms available from the Cashier’s Office for this purpose.

Exclusions

The following are **not** covered by this scheme:

- Visiting a patient in hospital
- Patients who discharge themselves from hospital at their own request
- Private patients

<u>If you are NOT in receipt of the items listed above:</u>

You may still be eligible for an NHS Low Income Scheme Certificate (HC2) for help with travel costs. The certificate is means tested, and you need to fill in and send off an HC1 Help with Health Costs form.

To get a copy of the HC1 form or for more information ring 0300 330 1343 (local call rate). Or you can ask for a form by emailing nhsforms@spsl.uk.com.
Once you have the certificate, which can take up to two weeks to process, bring it with you to the clinic along with your invite letter and any receipts to claim your travel costs.

The Cashier's Office is along the outpatients corridor on Level 0 and is open

Monday – Friday	09:30 – 13:00/13:30 – 16:00
Weekends and bank holidays	Closed

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SECTION 9

Meet the Experts

Meet the experts:

 **Endocrinologist**	A doctor who specialises in diagnosing and treating diseases and conditions caused by hormonal problems, such as diabetes and growth problems.
 **Neurologist**	This type of doctor specialises in diagnosing and treating brain and nervous system disorders.
 **Psychologist**	Psychologists at hospitals help prevent or treat the mental health, behavioural and emotional problems that patients and families may experience when coping with medical issues.
 **Urologist**	Specialises in diseases of the urinary tract. This can include diseases affecting the bladder, urethra, kidneys and adrenal glands.
 **Ophthalmologist**	A medical doctor who specialises in eye and vision care. They are trained to perform eye exams, diagnose and treat disease, prescribe medication and perform eye surgery.
 **Audiologist**	Uses tests to determine the extent of hearing damage and to identify the underlying cause.

 **Geneticist**	Contribute to the diagnosis and treatment of genetic disorders. They evaluate patient medical histories, perform genetic testing, analyse test results, and provide recommendations for managing or treating genetic conditions. Geneticists collaborate with other healthcare professionals, to ensure accurate diagnosis and develop appropriate treatment plans.

SECTION 10

Wolfram Syndrome Variants

Wolfram Syndrome Type 1

Wolfram syndrome (WS) is a rare autosomal recessive genetic disorder (the biological mother and the father must each pass one affected copy of the gene to the child) caused by mutations in the Wolfram syndrome 1 (WFS1) gene. WS is considered an ultra-rare disease and affects about 1 in 500,000 to 770,00 people in the UK. Medical experts estimate between 15,000 and 30,000 patients worldwide have this disease, including 114 - 150 in the UK.

There are currently no drug therapies or cures that exist for WS. Treatment focuses on symptom management.

The primary manifestations are insulin-dependent diabetes mellitus and optic nerve atrophy. Other common manifestations are neurodegenerative in nature and may include diabetes insipidus, sensorineural hearing loss, trigeminal neuralgia-like headaches, dysphagia (difficulty swallowing), bladder dysfunction, loss of sense of smell and taste, problems with balance and coordination, muscle spasms and seizures, gastrointestinal problems, and irregular breathing. As with other chronic disorders, patients may develop anxiety and depression. Diabetes mellitus is typically the first manifestation, usually diagnosed between the ages of 6-8, with optic nerve atrophy following between the ages of 10-12. Other manifestations tend to vary in onset.

Clinically, WS is best characterised as a spectrum of disorders, ranging in severity from mild to severe. WS patients carrying recessive and missense variants tend to have milder manifestations. The WFS1 p.R558C missense variant, for example, is associated with mild manifestations, but has a high carrier frequency (around 3%) in the Ashkenazi Jewish population. Syndrome variants include WS1, WS2, and WFS1 related disorder. The gene has also been linked to more common forms of Type 2 diabetes.

Wolfram Syndrome Type 2

Mutations in the CDGSH iron sulphur domain protein 2 (CISD2) gene have been found in a small fraction of patients with WS. Wolfram Syndrome patients carrying mutations in the CISD2 gene develop the primary features of WS, including diabetes mellitus and optic nerve atrophy, but they tend to develop other symptoms that are not typically seen in patients carrying pathogenic WFS1 variants, such as upper gastrointestinal ulceration and bleeding.

WFS1-Related Disorders (Wolfram Related Syndrome)

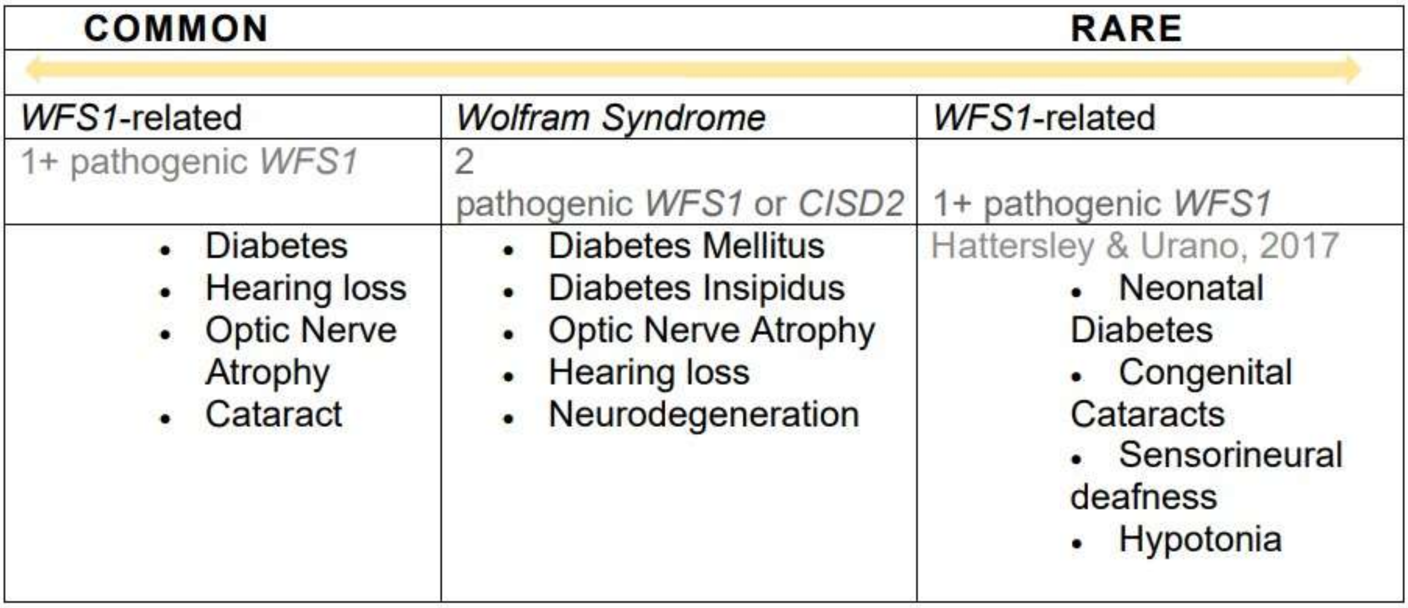
Some mutations in the WFS1 gene are associated with a distinct subset of patients who develop only one or a few symptoms seen in WS. Certain dominant pathogenic variants of the WFS1 gene cause deafness or diabetes alone. Other dominant WFS1 variants are associated with deafness together with mild optic nerve atrophy. It has been reported that autosomal dominant congenital cataracts are also associated with dominant variants of WFS1. Dr Urano at Washington University and Dr Hattersley at the University of Exeter have identified several dominant de novo WFS1 variants associated with a genetic syndrome of neonatal/ infancy-onset diabetes, congenital sensorineural deafness, and congenital cataracts.

These patients have WFS1-Related disorders, not Wolfram Syndrome (Figure 1).

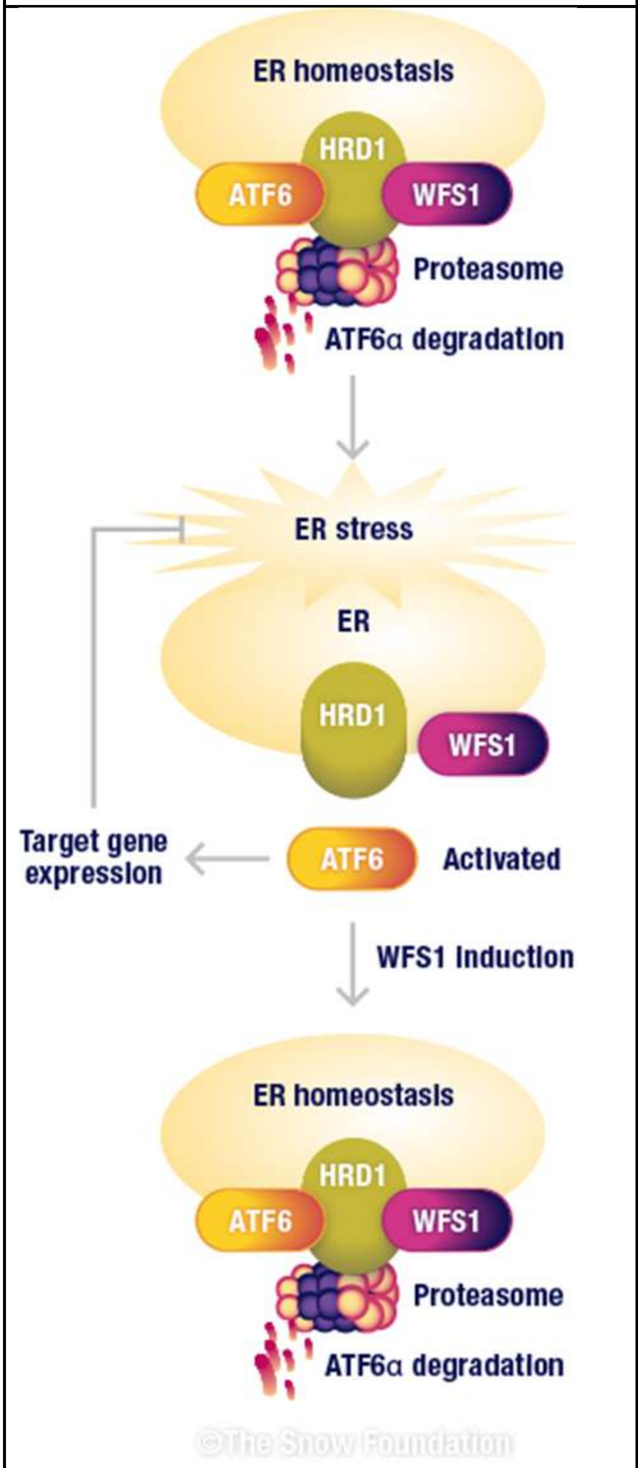
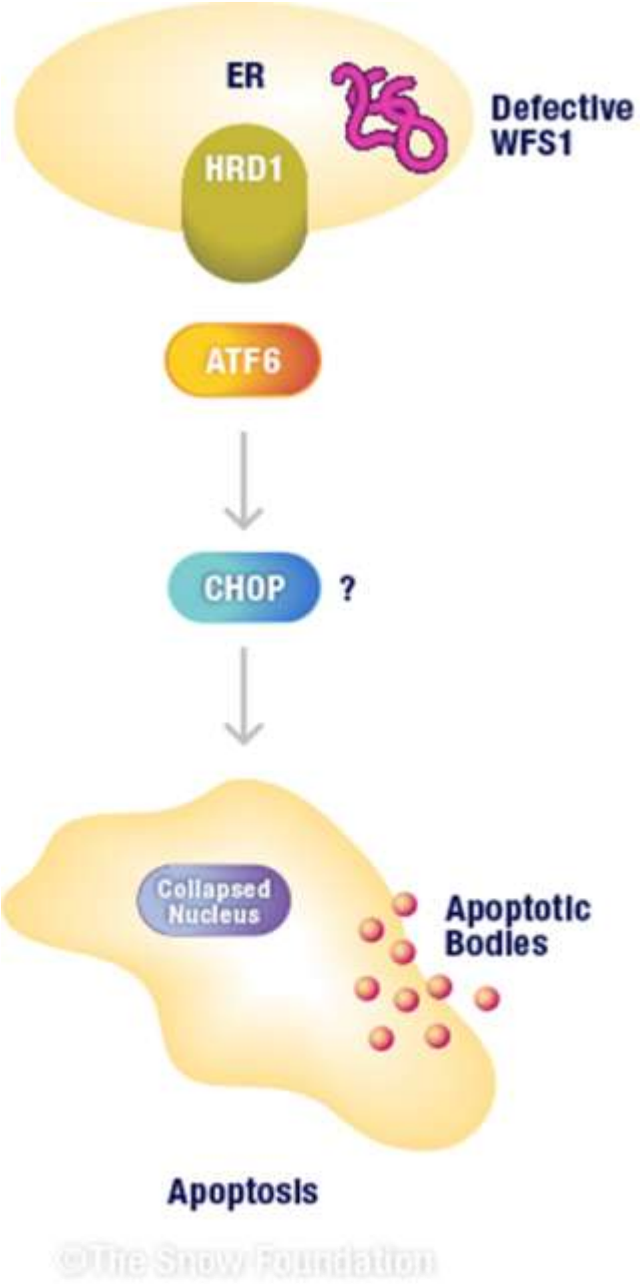
For more information on WFS1-Related Disorders, please contact Dr Urano at urano@wustl.edu or Wolfram Syndrome UK at admin@wolframsyndrome.co.uk.

There are currently no drug therapies or cures that exist for Wolfram Syndrome.

Wolfram syndrome and WFS1- related disorders



COMMON		RARE
WFS1-related	*Wolfram Syndrome*	*WFS1*-related
1+ pathogenic *WFS1*	2 pathogenic *WFS1* or *CISD2*	1+ pathogenic *WFS1*
• Diabetes • Hearing loss • Optic Nerve Atrophy • Cataract	• Diabetes Mellitus • Diabetes Insipidus • Optic Nerve Atrophy • Hearing loss • Neurodegeneration	Hattersley & Urano, 2017 • Neonatal Diabetes • Congenital Cataracts • Sensorineural deafness • Hypotonia

Normal	**Wolfram Syndrome**
	

WOLFRAM SYNDROME UK

Inform, Support, CURE

SECTION 11

Wolfram Syndrome – Adult at Work

WOLFRAM SYNDROME UK
Inform, Support, CURE

SUPPORTING ADULTS AND YOUNG PEOPLE WITH WOLFRAM SYNDROME AT WORK

General Information:

Wolfram Syndrome (WS) is a genetic condition which affects 1 in 770,000 of the total UK population or 1 in 500,000 children, so it is very rare. That's just under 150 people in the UK. The condition is caused by a gene mutation which affects the function of a protein called Wolframin, used in cells within the brain, pancreas, muscles, heart, liver and kidneys. The disruption in Wolframin is what causes the features associated with WS.

The condition leads to visual impairment (optic atrophy), diabetes mellitus, diabetes insipidus and deafness, along with other difficulties such as renal and neurological problems. Not all these symptoms are necessarily present in those diagnosed with WS, and each one can vary in severity and onset.

WS is not an easy condition to diagnose. Many patients have it for years before an accurate diagnosis of WS is confirmed. A consultant may only see one affected individual in a professional lifetime. There is a lack of local medical knowledge about the condition and how best to manage it. This often results in late diagnosis, a lack of standardised medical care, and can make work life and difficult for affected adults and young adults.

There is no cure for WS, however each symptom can be improved with treatment – Diabetes Mellitus can be controlled with insulin injections and Diabetes Insipidus can be controlled with medication. Clinical trials have started both in the UK and US on two different drugs which have shown promising signs during laboratory research. It is hoped that one, or both will slow down or halt the progression of WS.

A specialist WS Adult’s Clinic has been set up at Birmingham’s Queen Elizabeth Hospital which any adult or young person who has a confirmed diagnosis of Wolfram Syndrome in England can attend. By attending the clinics, individuals can get advice on the best treatments available to help maintain a good quality of life and delay progression of the condition.

Main characteristics of Wolfram Syndrome

CHARACTERISTIC	SYMPTOMS	AVERAGE AGE OF ONSET
Diabetes Mellitus The body cannot convert sugar or glucose to energy due to a lack of insulin hormone.	Excessive thirst, frequent passing of urine and weight loss.	Childhood before 16 years of age.
Diabetes Insipidus The body cannot concentrate urine due to lack of vasopressin hormone.	Excessive thirst, frequent passing of urine.	Teenage years in about 60% of people.
Deafness	Difficulty hearing in a crowded room, difficulty hearing high pitched sounds.	Teenage years, but usually does not affect hearing on a one to one basis.
Optic Atrophy Shrinkage of the optic nerve.	Difficulty seeing in the classroom at school, everything going grey.	Childhood before 16 years of age.
Renal Problems	Loss of control over bladder function may cause bed wetting.	Variable, can affect some children.
Neurological Problems	Loss of balance, sudden jerks of the muscles, depression and breathing problems.	Variable, can affect different ages, but not everybody.

Not all of the characteristics shown in the table above are necessarily present in those diagnosed with Wolfram Syndrome, and each one can vary in severity and onset. The challenge with some of these symptoms is that they can be initially overlooked.

How does Wolfram Syndrome affect the work life of an affected adult or young person?

Diabetes Mellitus:

Most people with WS have Diabetes Mellitus, which means they must inject insulin several times a day. A sample IHP can be downloaded from the Diabetes UK website: https://www.diabetes.org.uk/.

Diabetes Insipidus:

Some individuals with WS will have Diabetes Insipidus – which means they are often excessively thirsty and will need to pass urine very frequently. Allow them to access the water and allow them to visit the toilet as often as they need to prevent wetting accidents. Many individuals with diabetes insipidus will also suffer from disturbed sleep as they need to use the toilet frequently during the night. This can therefore affect them during the day as they struggle with tiredness.

Hearing loss:

Hearing loss can make it hard for a person to hear instructions in a noisy environment. Keeping an office door closed to limit external noises will help. Some individuals with WS may wear hearing aids or have a cochlear implant. Audio technologies which supplement and/or work in conjunction with the person's hearing aids such as hearing loop systems can be extremely beneficial too.

Visual impairment:

Optic Atrophy affects the individual's ability to see in a workplace. Some affected individuals find it takes time for their eyes to adjust when going from outdoors to indoors. Visual aids like magnifiers and access to the zoom function on an iPad can help. Reading materials in an enlarged font size can help.

Because of the vision loss, they can suffer with tiredness later in the day, so any meetings are better being planned earlier in the day.

Individuals with WS can feel very vulnerable when moving around a busy work environment because of their vision and /or hearing loss. Their visual impairment may also create difficulties when using stairs at work. Some may need assistance to get around the work building.

It is important that the local Visual Impairment Team are involved in supporting both the individual and the work place. They are able to help by:

1. Making an assessment of the individual’s work needs in relation to their visual impairment

2. Offer advice on how to make an individual’s work space accessible

3. Offer training and support to enable the individual to be fully included

4. Advice and support around the use of specialist equipment and skills such as Braille, Touch Typing and use of low vision aids

5. Help the individual move around safely in the work environment by providing mobility training.

Also, Access to Work which is a government funded grant, will pay either the full or a percentage of technical equipment or workplace adaptations as well as specialist training. It will be assessed first by a 3rd party, which is usually Capita.

Multi-sensory impairment:

WS can affect individuals at work in less obvious ways too. The multi-sensory impairment can make it very difficult for them to develop social skills, and they often fail to pick up social cues which can make them appear rude or overly shy. This can have a knock-on effect on their confidence and in their ability to make and maintain friendships.

Chronic fatigue:

Because the condition causes chronic fatigue, carers dropping affected individuals off at work may need access to the car park, to ensure the individual doesn’t have to walk too far.

Many individuals with WS can have “autistic” traits; in particular anxiousness when taken outside their normal environment or routine. These individuals like to know what they are going to be doing and where they will be doing it. Any sudden change in routine can be very upsetting for them.

The various physical difficulties add to the emotional burden carried by individuals with WS and it is perhaps not surprising that the majority of them have low self-esteem. This lack of self-confidence has a direct effect upon their relationships with others and if this has been carried into adulthood it can be very difficult to turn around.

It is important to remember that individuals with WS do not have developmental delay, and with the right support they have the potential to progress in their chosen career.

Please share the information below with your employer.

Diabetes UK have this guide for Employers and Colleagues in supporting someone with Diabetes at work:

The best way to get informed about diabetes and how it affects someone is to ask them. They live with the condition every day and will be able to let you know how you can best help them. If you know nothing about diabetes, it’s a good idea to start learning the basics.

Here are the top 10 things you need to know to support a diabetic.

1. **Is diabetes a disability?** People with diabetes usually don’t think of it as a disability. But the law often decides that it is. That’s because it’s a long-term condition that can seriously affect someone’s ability to do normal day-to-day things if it’s not treated.

   This means diabetes is nearly always covered by the Equality Act 2010, or the Disability Discrimination Act 1995 if you live in Northern Ireland. These acts say an employer needs to make reasonable adjustments so that someone with a disability like diabetes can do their job. The Equality and Human Rights Commission has guidance for employers on the Equality Act 2010.

2. **How do people manage diabetes?** Most people can manage their diabetes so it doesn’t affect their work. This takes careful planning and resourcefulness. It can mean taking medication at specific times and checking blood glucose (blood sugars) throughout the day. For some people with diabetes, this can mean injecting insulin and pricking their finger to check blood sugar levels.

   Some people can feel awkward about injecting in public and even feel embarrassed. Reassure your colleague that you understand what they’re doing and it’s not a problem. If you manage them, help them find somewhere appropriate to do it, so they don’t feel the need to hide in the toilet.

   Some people with diabetes are at risk of something called hypos, when their blood sugars go too low. Ask them what symptoms to look out for and what to do if they ever need help treating one. They should have a stash of hypo treatments usually things like jelly beans sugary drinks – which you may need to access in an emergency.

3. **Reasonable adjustments** If you manage someone with diabetes, ask them if you can do anything to support them at work. They may say no, but diabetes can affect people in different ways over time. So, make sure they know they can discuss their diabetes regularly in one-to-ones and appraisals if they want to.

   If someone tells their employer they have diabetes, the employer may have a legal obligation to make reasonable adjustments, so they can manage their diabetes and do their job.

   Reasonable adjustments might be making sure they have their breaks at set times, so they can keep on top of their blood sugar levels, or providing special equipment if they have eye problems. Reasonable adjustments don't have to cost money – they are more about taking a flexible approach to work

4. **Time off work for illness and check-ups** People with diabetes need to go to several healthcare appointments a year. They're an essential part of managing diabetes and help reduce the risk of serious complications. There's also an annual review with their healthcare team, which is vital in helping them manage their diabetes.

   If you manage someone with diabetes, it's vital you give them time off for these essential checks. Check your policies on managing people with long-term health conditions and approving time off for medical appointments.

   When people with diabetes get illnesses like a cold, flu or stomach bug, they may need to do extra checks, such as checking their blood sugar levels more often, checking they aren't dehydrated and managing what they eat carefully. They may need extra support from their healthcare team. So, allow them time to get better and provide flexible working options if appropriate as they return to work.

   Discuss this with your company's occupational health team if you have one. Stress can slow down their recovery even further and can affect their diabetes too, so think about emotional wellbeing too.

5. **Time off work for a diabetes education course** Education courses are available for people with diabetes to help them understand and manage their condition.

   If you manage someone with diabetes, encourage them to go on an education course, even if it means time off work. They may be entitled to time off for the course under the Equality Act 2010.

   Courses like DAFNE for Type 1 diabetes and DESMOND for Type 2 diabetes make a big difference to how well someone with diabetes can manage their condition. They can improve a person's health in the long term and reduce time off due to complications. And if people share what they've learned with colleagues, this awareness can spread across your whole organisation.

6. **Driving and diabetes** People with diabetes are usually allowed to drive. However, there are extra rules that depend on which medications they take and which driving licence they hold or want to hold.

   We have more information on driving with diabetes. And there's a lot more guidance available from the DVLA in England, Scotland and Wales, or the DVA in Northern Ireland.

7. **Pregnant women with diabetes** To increase their chances of having a healthy baby and keeping safe, pregnant women with diabetes need extra support. They must take extra care of their health at all stages of pregnancy. They'll have more appointments from pre-conception onwards. They'll probably need extra scans and will need their treatment reviewed at times.

   Some women who don't have diabetes before pregnancy develop gestational diabetes during pregnancy, which means they also need extra care and more appointments. Gestational diabetes usually goes away not long after the baby is born, but women are at increased risk of developing Type 2 diabetes in the future.

   So, if you manage a pregnant woman with diabetes, talk about whether you need to make some extra reasonable allowances. These might include flexibility around working hours and some time off for appointments. Take the lead from them and be available to discuss any issues they might have.

8. **Emotional wellbeing and diabetes** It's hard being diagnosed with diabetes. And it's often hard living with it. Be aware of any challenges your colleague is facing and be there for them if they need support.

   Stress and stressful situations at work, things like interviews, increased workload, threat of redundancy, can cause raised blood sugar levels and make it harder for someone to manage their diabetes. It can become a cycle of negative feelings that can leave someone feeling low and even lead to depression. We've got lots of information about stress and diabetes – take a look to make sure you're in the know and can support your colleague.

If you manage someone with diabetes who might be struggling like this, discuss if any reasonable adjustments at work could see them through this bad patch. If they need professional help, they should speak first to their doctor or a member of their healthcare team who could arrange for them to see a counsellor. If you have an employee assistance programme or in-house counsellor, you could point them there too. You can also recommend our helpline and forum.

9. **Can I help prevent my colleagues getting diabetes?** You can't prevent Type 1 diabetes, but staying healthy by eating well and exercising regularly can reduce people's chances of getting Type 2 diabetes.

   Think about introducing fruit and healthy snacks alongside, or instead of, cakes and biscuits. You could start up a lunchtime exercise class or walking group. If you manage people, give them regular breaks so they can step away from their work and stretch their legs.

   Use your intranet and other internal communications channels to raise awareness of the importance of a healthy lifestyle in preventing conditions like Type 2 diabetes.

10. **Can organisations refuse to employ someone with diabetes?** There are a few jobs or roles where safety-critical work may mean that you would need to carefully assess someone's ability to carry it out because of their diabetes or the way that it is treated. In most cases, diabetes won't stop someone doing their job.

    Employers are not allowed to have a blanket ban on employing people with diabetes. The one exception to this is the armed services which is exempt from the Equality Act 2010. In the emergency services, each local service has its own rules, but they must risk assess the role and look at each individual case. It is important that those conducting the assessment have both an understanding of the role and of diabetes and how it is currently managed.

For more details go to - https://www.diabetes.org.uk/resources-s3/2019-10/supporting-someone-at-work_v7.pdf

How Diabetes UK help

We're fighting for a world where diabetes can do no harm. And as the UK's leading diabetes charity, it's our job to tackle the diabetes crisis. We provide information, advice and support to people with all types of diabetes so they can learn to live well with their condition. And we bring people together so they can learn from each other and get to grips with diabetes.

Visit our website www.diabetes.org.uk/work.If you live in England, Wales or Northern Ireland, call 0345 123 2399

If you live in Scotland, call 0141 212 8710 Open Monday to Friday, 9am to 6pm.

Chat to others online in our support forum at www.diabetes.org.uk/forum

Summary

In summary, there are many different ways a workplace can support an individual with Wolfram Syndrome to get as much as possible from their experience at work:

✓ Provide them with visual aids and audio technology to enable them to access work resources

✓ Allow them extra time to get to meetings

✓ Allow them to access the toilet as often as they require

✓ Provide a safe and calm environment during break times

✓ Try to schedule meetings and work-related assessments for the morning, when their eyes are less tired

✓ Make sure they have a clear plan for each day, and give them plenty of notice if their usual routine needs to change.

✓ Provide an area close to the workplace for carers to drop them off and collect them.

✓ Make use of outside agencies such as local Visual Impairment Teams

WOLFRAM SYNDROME UK
Inform, Support, CURE

SECTION 12

Wolfram Syndrome—short guide in Urdu

WellChild

the national charity for sick children

Understanding Wolfram Syndrome – a short guide

Information in English and Urdu

ولفریم سنڈروم کو سمجھنا – ایک مختصر گائیڈ

معلومات انگریزی اور اردو میں

Understanding genetics together

WellChild the national charity for sick children

WOLFRAM SYNDROME UK *Inform, Support, CURE*

NHS Birmingham Women's and Children's NHS Foundation Trust

There are around **85 PEOPLE IN THE UK** with Wolfram Syndrome

ولفریم سنڈروم سے برطانیہ میں کم وبیش 85 لوگ متاثر ہیں

It is so rare that many doctors will be **UNAWARE OF IT**

یہ اتنی کم پائی جاتی ہے کہ بیشتر ڈاکٹر اس سے واقف بھی نہیں ہوتے

Just 1 in **770,000** people in the UK has Wolfram Syndrome

برطانیہ میں ہر 770,000 لوگوں میں سے 1 فرد ولفریم سنڈروم سے متاثر ہے

There is currently **NO CURE** but clinical trials have started

فی الحال ولفریم سنڈروم کا **علاج نہیں ہے** لیکن اس کے لیے طبی تحقیق شروع ہوچکی ہیں

SUPPORT is available for families

فیملیوں کے لیے **معاونت** دستیاب ہے

Wolfram Syndrome is a rare genetic condition

ولفریم سنڈروم ایک نایاب جینیاتی بیماری ہے

It is usually caused by a change in a gene called Wolframin (also called WSF1)

یہ عام طور پر ولفرامین (جسے WSF1 بھی کہا جاتا ہے) کہی جانے والی جین میں تبدیلی کے باعث ہوتی ہے

SYMPTOMS MAY INCLUDE

diabetes, loss of vision, loss of hearing, problems with the bladder and nervous system.

علامات میں درج ذیل چیزیں شامل ہوسکتی ہیں:

ذیابیطس، دکھائی نہ دینا، سنائی نہ دینا، مثانہ اور اعصابی نظام میں پریشانیاں۔

Not everyone will get these symptoms and some can be managed with medication

یہ علامات ہر شخص میں نہیں پائی جاتی ہیں اور کچھ علامات کا علاج دواؤں سے ممکن ہے

What is Wolfram Syndrome?

Wolfram Syndrome is a rare genetic condition that affects just under 100 people in the UK. This means that many doctors will be unaware of it.

What are the characteristics?

Characteristic	Symptoms	Average age of onset
Diabetes Mellitus – needs insulin. This affects almost all people by 16 years of age	Very thirsty Passing urine often Weight loss	Before age of 16.
Diabetes Insipidus	Very thirsty Passing urine often	Usually in teenage years. Does not affect everyone.
Loss of vision – called Optic Atrophy	Difficulty seeing in the classroom. Problems distinguishing colours; everything looks grey	Before age of 16. This affects almost all people.
Loss of hearing - deafness	Problems hearing in a crowded room	Usually in teenage years. This does not affect everybody.
Problems with the bladder	Loss of control with bladder. May wet the bed at night	Can affect some people but not all.
Problems with the nervous system – the brain, spinal cord and nerves.	Balance problems Jerking of muscles Depression Difficulties with swallowing or choking	Can affect different ages but not everybody.

Not all of the characteristics or symptoms are seen in people with Wolfram Syndrome. Each one can also vary and each individual with the condition can be affected differently.

Loss of vision (optic atrophy) and insulin dependent diabetes that developed in childhood always needs further investigation for Wolfram Syndrome.

What causes it?

Our bodies are made up of millions of cells and most cells contain sets of genes. Genes are similar to instructions and control how our bodies work. We inherit genes from both our mother and father. Parents of a child with Wolfram Syndrome usually have one normal copy of a gene called Wolframin (also called WSFI) and one changed copy of the gene. Both parents usually pass on one copy of the changed gene each for a child to be affected. It is no-one's fault; it is not because the mother ate the wrong things in pregnancy, or anything like that.

ولفریم سنڈروم کیا ہے؟

ولفریم سنڈروم ایک نایاب جینیاتی بیماری ہے جس سے برطانیہ میں 100 سے کم لوگ متاثر ہیں۔ جس کی وجہ سے بہت کم ڈاکٹر اس سے واقف ہوتے ہیں۔

اس کی خصوصیات کیا ہیں؟

خصوصیات	علامات	شروع ہونے کی اوسط عمر
ذیابیطس میلیٹس – اس میں انسولین کی ضرورت ہوتی ہے۔ سولہ سال کی عمر تک کے تقریباً سبھی لوگ اس سے متاثر ہوتے ہیں۔	بہت پیاس بار بار پیشاب آنا وزن میں کمی	سولہ سال کی عمر سے پہلے۔
ذیابیطس السیپڈس	بہت پیاس بار بار پیشاب آنا	عام طور پر نوعمری میں۔ ہر شخص متاثر نہیں ہوتا ہے۔
دکھائی نہ دینا – جیسے آپٹک اٹروفی کہا جاتا ہے	کلاس روم میں دیکھنے میں دقت۔ رنگوں کو پہچاننے میں پریشانیاں؛ ہر چیز خاکی نظر آنا	سولہ سال کی عمر سے پہلے۔ سب لوگوں پر اثر پڑتا ہے۔
سنائی نہ دینا – بہراپن	پربجوم کمرہ میں سننے میں پریشانیاں	عام طور پر نو عمری میں۔ ہر شخص اس سے متاثر نہیں ہوتا ہے۔
مثانہ میں تکلیف	مثانہ پر قابو نہ ہونا۔ رات میں بستر بھی تر ہوسکتا ہے	کچھ لوگ متاثر ہوسکتے ہیں لیکن سبھی لوگ نہیں۔
اعصابی نظام – دماغ، ریڑھ اور نسوں میں تکلیف۔	توازن کے مسائل پٹھوں میں جھٹکے ڈپریشن نگلنے میں دشواریاں اور دم گھٹنا	اس کا اثر مختلف عمر والوں پر ہوسکتا ہے لیکن ہر ایک پر نہیں۔

ولفریم سنڈروم سے متاثر لوگوں میں مذکورہ سبھی خصوصیات وعلامات نہیں پائی جاتی ہیں۔ ہر ایک کی کیفیت دوسرے سے جدا ہوتی ہے اور اس کیفیت سے متاثر ہر ایک شخص پر مرض کا اثر بھی الگ الگ ہوسکتا ہے۔

دکھائی نہ دینا (آپٹک اٹروفی) اور بچپن میں ہونے والی انسولین پر منحصر ذیابیطس کی ولفریم سنڈروم کے لیے مزید جانچ کی ہمیشہ ضرورت پڑے گی۔

اس کی کیا وجوہات ہیں؟

ہمارے جسم لاکھوں خلیات سے مرکب ہیں اور بیشتر خلیات میں کئی جین ہوتے ہیں۔ جین ہدایات کے مطابق ہوتے ہیں اور ہمارے جسم کے طریقۂ کار کو قابو میں رکھتے ہیں۔ ہم جین اپنے ماں اور باپ دونوں سے وراثت میں پاتے ہیں۔ ولفریم سنڈروم سے متاثر بچہ کے والدین کے پاس عام طور پر ولفرامین (جیسے WFS1 بھی کہا جاتا ہے) کہی جانے والی جین کی ایک عام نقل ہوتی ہے اور ساتھ ہی ساتھ جین کی ایک تبدیل شدہ نقل بھی ہوتی ہے۔ ماں۔ باپ میں سے ہر ایک تبدیل شدہ جین کی ایک کاپی متاثر ہونے والے بچہ کو دیتے ہیں۔ یہ کسی کی غلطی نہیں ہے؛ یہ اس وجہ سے نہیں ہے کہ ماں نے دوران حمل غلط چیزیں کھا لی تھیں یا اسی طرح سے کچھ اور ہوا تھا۔

Treatment

There is no cure for Wolfram Syndrome but treatments can help improve the symptoms. Diabetes Mellitus can be controlled with insulin injections and Diabetes Insipidus can be controlled with medication. Visual and hearing problems may be improved with glasses and hearing aids.

Clinical Trials have started which are hoped may slow or halt the progression of Wolfram Syndrome.

Wolfram Syndrome Clinics

If you suspect your child, or an adult that you know may have Wolfram Syndrome, ask your doctor to make a referral to either the Children's Clinic at Birmingham Children's Hospital or the Adult Clinic at Queen Elizabeth Hospital, Birmingham. By attending these clinics, families and individuals can get advice on the best treatments available as well as support and information.

The Children's Clinic is led by Professor Barrett. For further information call 0121 333 9269.

The Adult Clinic is led by Dr Wright. For further information call 0121 371 6879.

Wolfram Syndrome UK Support Group

Wolfram Syndrome UK is a national charity that was set up by parents Tracy and Paul Lynch after their daughter was diagnosed with Wolfram Syndrome. They provide support to individuals and their families affected by WS, try to raise awareness amongst doctors and fund research and the annual family conference.

For further information, call 01903 211358, email:
admin@wolframsyndrome.co.uk or visit:
www.wolframsyndrome.co.uk.

This leaflet was funded by a grant from Breaking Down Barriers which is funded by The Sylvia Adams' Charitable Trust.

علاج

ولفریم سنڈروم کا کوئی علاج نہیں ہے لیکن علاج علامات کی بہتری میں معاون ہوسکتے ہیں۔ ذیابیطس میلیٹس کو انسولین انجیکشن سے قابو میں رکھا جاسکتا ہے اور ذیابیطس انسیپڈس کو دواؤں سے قابو میں رکھا جاسکتا ہے۔ دیکھنے اور سننے سے متعلق مسائل میں چشموں اور سننے کے آلات کا استعمال کرکے بہتری لائی جا سکتی ہے۔

طبی آزمائشیں شروع ہو چکی ہے اور امید کی جاتی ہے یہ ولفریم سنڈروم کی پیش رفت کو دھیما کر دیں گی یا روک دیں گی۔

ولفریم سنڈروم کلینکس

اگر آپ کو شبہ ہو کہ آپ کا بچہ یا کوئی بالغ فرد جسے آپ جانتے ہیں، ولفریم سنڈروم کا مریض ہوسکتا ہے تو آپ اپنے ڈاکٹر سے یا تو برمنگھم چلڈرن اسپتال میں واقع چلڈرن کلینک برمنگھم یا کوئین الیزابیتھ اسپتال برمنگھم میں واقع اڈلٹ کلینک میں ریفرل کے لیے کہیں۔ ان کلینکوں میں حاضر ہوکر، فیملیاں یا افراد بہترین دستیاب علاج سے متعلق مشورہ نیز سپورٹ اور معلومات حاصل کرسکتے ہیں۔

چلڈرن کلینک کے سربراہ پروفیسر بارٹ ہیں۔ مزید معلومات کے لیے
0121 333 9269 پر کال کریں۔

اڈلٹ کلینک کے سربراہ ڈاکٹر رائٹ ہیں۔ مزید معلومات کے لیے 0121 371 6879 پر کال کریں۔

ولفریم سنڈروم یو.کے. سپورٹ گروپ

ولفریم سنڈروم یو.کے. ایک قومی خیراتی ادارہ ہے جسے ٹریسی اور پال لنچ نامی والدین نے اپنی بچی میں ولفریم سنڈروم کی تشخیص کے بعد قائم کیا تھا۔ وہ WS سے متاثرہ افراد اور ان کی فیملیوں کو تعاون فراہم کرتے ہیں، ڈاکٹروں کو معلومات دینے کی کوشش کرتے ہیں، نیز تحقیق اور سالانہ فیملی کانفرنس کے لیے امداد مہیا کرتے ہیں۔

مزید معلومات کے لیے 01903 211358 پرکال کریں،
admin@wolframsyndrome.co.uk پر ای میل بھیجیں یا
www.wolframsyndrome.co.uk ملاحظہ کریں۔

اس کتابچہ کے لیے بریکنگ ڈاؤن بیریئرس نے مالی تعاون فراہم کیا جسے سلویا ایڈمز چیریٹیبل ٹرسٹ سے فنڈ حاصل ہوتا ہے۔