WOLFRAM SYNDROME

A guide for individuals, families and carers

WOLFRAM SYNDROME UK

Inform, Support, CURE

www.wolframsyndrome.co.uk

Updated January 2026

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FOREWARD

Hello, my name is Tracy Lynch. I am the CEO and Co-founder, with my husband Paul, of Wolfram Syndrome UK. We started WSUK as a support group in 2010 following our daughter's diagnosis at the age of 8. Like many families, we had looked it up online and came across some very medical sites but there was nothing or no one to support us apart from a worldwide support group; so WSUK was born. We became a charity in June 2013 so that we could fundraise in our own right, instead of via other charities, which gives us more of a say in how the money we raise is spent.

Firstly, I would like to reassure you that receiving a diagnosis for Wolfram Syndrome (WFS) does not mean the end of life as you know it. We have been through it, as have the families that have shared their stories in this information book. The diagnosis has made many of us that much stronger as we try to find a treatment with the help of many fantastic researchers around the World. It has also brought us many new friends, who are now like family.

Wherever you are in the world you can be assured that any member of the WS family is there to support you, whether by phone, Teams, Zoom, WhatsApp, email or Facebook.

Together we will *Inform, Support, CURE.*

Keep strong!

Tracy

WOLFRAM SYNDROME UK
Inform, Support, CURE

Introduction to Wolfram Syndrome (WFS1)

Wolfram syndrome is a spectrum disorder that can cause a set of conditions which includes Diabetes Insipidus, Diabetes Mellitus, Optic Atrophy and Deafness as well as several other conditions. It is a complex progressive neurodegenerative condition which is very rare. Every person affected is different and may only have 2 or 3 of the main features. Some do have all 4.

Why is it called Wolfram Syndrome?

A syndrome is the name given to a condition where features occur in a consistent pattern and where the cause is not understood. Wolfram Syndrome is named after a Dr Don Wolfram who saw 4 siblings from the same family with Diabetes Mellitus and Optic Atrophy in 1938 at the hospital he worked at in North America. Since then, over 300 patients have been described in the world medical literature with WFS. It is also sometimes referred to as DIDMOAD, which is an acronym for the main features associated with the syndrome (**D**iabetes **I**nsipidus, **D**iabetes **M**ellitus, **O**ptic **A**trophy, **D**eafness).

How common is it?

Wolfram Syndrome is very rare. It affects about 1 in 770,000 of the total UK population, or 1 in 500,000 children. There are currently about 150 people, adults and children, diagnosed with WFS in the UK. A specialist doctor may only see one affected individual in their professional lifetime; many doctors will never come across it.

What causes Wolfram Syndrome?

It is an inherited genetic condition caused by a gene mutation. The gene that is usually affected is called WFS1 but other genes have also been identified. More information about the genetics of WS can be found further on in the booklet. (*The mutation in the genes affects the function of a protein called Wolframin. This protein is used in cells within the body including in the brain, pancreas, muscles, heart, liver and kidneys. The disruption in Wolframin is what causes the features associated with WS).*

The Wolfram gene was identified by the late Dr Alan Permutt from Washington University, St Louis, USA in 1998.

What are the chances of having another affected child?

The chances of parents having another child affected by Wolfram Syndrome are about 25%. WFS is inherited as an autosomal recessive condition; this means that both parents carry one abnormal copy of the Wolfram gene, and one normal copy. For a child to be affected, they have to inherit both abnormal copies, one from each parent. It is possible to test if an unborn child is affected during pregnancy. (More information can be found on the Genetics page in this book).

What are the features of Wolfram Syndrome?

Wolfram Syndrome is very varied and presents differently in different people. The following is a list of the most common features for Classic WFS1 – Wolfram Syndrome:

Diabetes Mellitus (DM)

Most people with WFS get Diabetes Mellitus, usually as a young child. This is when the body can't convert glucose (sugar) to energy, because the pancreas is not making enough of the hormone called Insulin. Glucose therefore stays in the blood or is passed out in urine which means that it isn't used up by the body. Symptoms of Diabetes Mellitus include thirst, frequent passing of urine and weight loss. This can normally be diagnosed from a blood test. This is usually treated with insulin injections although a few people only need tablets.

Diabetes Insipidus (DI)

Some people, but not everyone, with WFS is affected with Diabetes Insipidus. This is when the body cannot concentrate urine because the posterior pituitary gland in the brain is not making enough of a hormone called Vasopressin. Vasopressin usually regulates the amount of fluid in the body. Symptoms of Diabetes Insipidus often include being very thirsty and frequent passing of very dilute urine. This is easy to treat with medication generally tablets.

Optic Atrophy (OA)

Most people with WFS will get Optic Atrophy. This is when the optic fibre nerves weaken causing vision to become disrupted. Symptoms often present as difficulty seeing in the classroom at school, colour blindness or everything "going grey". In WS the vision problems

usually, but not always get worse and some people may be registered as Severely Vision Impaired (SVI) or Vision Impaired (VI) within about 8 years of the onset of eye problems.

In a few people useful vision is maintained for many years after a diagnosis is made.

Deafness (SND)

Some people, but not everyone, with WFS will develop some degree of hearing loss. This can include difficulty hearing in a crowded room or space and difficulty hearing high pitched sounds.

Most people can hear very well in one-to-one conversations even if they require hearing aids.

Renal Problems

Renal problems affect about two thirds of people with WFS at some point in their lives. There is a wide spectrum of issues, from mild incontinence when laughing or coughing, all the way to bladder failure. Most people can be helped with treatments including tablets.

Neurological Problems

Neurological problems may affect two thirds of people affected with WFS at some point in their lives, as the nervous system becomes damaged. These problems can include loss of balance, sudden jerks of the muscles, depression and breathing problems. Choking/swallowing problems may also occur in those affected, usually from the age of 20 onwards.

Diagnosing Wolfram Syndrome

As this condition is so rare not all doctors will be aware of it. Early diagnosis and the management of the conditions leads to better health outcomes for those affected and an improved quality of life. It is important that you share the information in this booklet with your doctor, so they know what information you have. The majority of the time you will be teaching the doctor. For further clinical information for you or your doctor, there is a useful information pack which includes the guideline on the WSUK website (http://wolframsyndrome.co.uk/wp-content/uploads/2021/11/New-Medical-Information-Pack.pdf).

Most of the features will exhibit during childhood. Diabetes Mellitus occurs in almost everyone with WFS1 during childhood. The latest onset is usually about 16 years old. Optic Atrophy also occurs on average at about 10 years of age and the latest onset is usually about 19 years old.

If both Diabetes Mellitus and Optic Atrophy are present by 15 years of age then an individual is likely to have Classic WFS1 - Wolfram Syndrome. Your doctor can take a blood sample that can be genetically tested to confirm the diagnosis.

However, the more we learn about this condition, the more we find that some people don't develop diabetes or eye problems until well into adulthood or may only develop one of these conditions.

Managing Wolfram Syndrome

The current treatment involves treating the various conditions present separately:

- Diabetes Mellitus can be controlled with insulin injections or the use of an insulin pump. These replace the insulin in the body and allows glucose to be converted in to energy for the cells to use. Very occasionally this can be managed with tablets.
- Diabetes Insipidus can be treated by replacing the hormone Vasopressin in the body by using a nasal spray or tablets. This means the body can regulate it's fluids better.
- There is unfortunately no treatment yet for Optic Atrophy but research is being done for this. There are a wide range of vision aids available that can help you with daily life. You should talk with your eye doctor about these.
- Deafness can be helped with the use of a hearing aid.
- Renal problems can be treated by tablets; or if severe, by passing a tube or catheter several times a day
- Different Neurological disorders respond to different medicines.

Once a child/person has been diagnosed with WFS, regular health appointments and assessments will be required. These assessments are to manage the presenting symptoms of the syndrome and also to test for the related symptoms that are known about so that they can be diagnosed and managed as early as possible.

For diabetes; diet and exercise advice will be given along with blood tests to look at the average blood glucose levels (HbA1c) over a few weeks and other treatments to manage any complications of diabetes.

Yearly tests for eyesight and “Audiometry” tests for hearing are recommended for those affected by WS to track the progress of Optic Atrophy and hearing loss as well as to assist with relevant vision or hearing aids when appropriate.

Regular testing for any issues with the neurological system, kidneys and digestive system are also recommended. These will all be checked when you are **invited** to attend a Wolfram Multidisciplinary Clinic at either Birmingham Children’s Hospital or The Queen Elizabeth Hospital (adult clinic), **but** should also be checked by your local doctor/hospital with your local routine appointments, to pick up any changes in between clinics.

Is there a cure for Wolfram Syndrome?

Unfortunately, at the moment there is no cure. The current research that is taking place is to understand why mistakes in the Wolfram gene cause the syndrome. There are research groups in America, France, UK, Estonia, Italy and Japan all investigating this problem. Trials are now under way on a few drugs that have been identified by researchers as potentially being able to slow down or halt the progression of the syndrome. Updates are posted on the WSUK website and in the newsletter

Clinicians and Teams within the Multi Disciplinary Clinics

Genetics-

My name is Denise Williams and I am a doctor specialising in genetic conditions. My role in the Wolfram syndrome clinics is to help individuals and their families by providing understandable information about the condition, explaining the way in which Wolfram syndrome is inherited and arranging genetic testing if this has not already been done. If appropriate I take the opportunity to discuss the risks to future children and / or other family members. The questions I am asked are very varied - I normally suggest you write them down before you attend the clinic as it is a long day and very busy, so important things are easily forgotten. I hope to provide the information necessary to allow families to make informed medical and personal choices. The first time I meet a family I expect to spend about three quarters of an hour with them, but some people need more and some less. Subsequent appointments are usually shorter and sometimes I am not needed. I always think that people will want to 'dip in and out' of genetics services at different points of their lives. What's really important is that I offer to see the young people affected by Wolfram syndrome in their own right. Genetics is taught really well in school, most commonly in year 10 and year 11, so I like to start discussions at this time. The teenagers pick it up really easily and often ask me challenging questions!

I work closely with the genetic counsellors, Shagufta Khan in the paediatric clinics at Birmingham Children's Hospital and Chris Platt in the adult clinics at the Queen Elizabeth Hospital in Birmingham. Both Shagufta and Chris have specialist training in genetics and counselling skills. Before your first appointment, either Shagufta or Chris will try to telephone you to obtain some basic information before you attend the clinic. They may ask about your family, so that a family tree can be drawn.

They may also ask your permission to obtain relevant medical information, including the results of any genetic investigations already carried out. Having this information ahead of the clinic allows us to make the best use of the time available in clinic.

Individuals and families attending the clinic have different knowledge, depending upon their previous experiences. I nearly always go ‘back to basics’ and discuss the way in which the condition is inherited assuming no previous knowledge. I feel more comfortable doing this as I know I haven’t missed anything out and the concepts involved are quite complicated – many people find going over the same thing a second or third time is quite helpful. I use visual aids to help me; I have photographs of chromosomes and I draw diagrams illustrating the way in which genes are passed from the parents to their children. I also have some embossed charts to help me communicate effectively with individuals who have a severe visual impairment.

If I have been able to obtain the results of any genetics tests, then I will be able to discuss these in detail in clinic. If not then testing can be initiated using a small sample of blood. Genetic tests are often complex and the results can take several weeks or months. We confirm the diagnosis of Wolfram syndrome when we are able to find 2 misprints, a bit like spelling mistakes, in the ‘Wolfram syndrome’ gene. This gene is known as WFS1. In the majority of families we have been able to confirm the diagnosis, but this is certainly not true for everyone. Like many rare conditions, Wolfram syndrome is not always straightforward so it is really important that everyone is assessed individually and regular evaluation and surveillance put in place according to that individual’s needs. For example, we are starting to see some individuals with a few of the clinical problems we expect in Wolfram syndrome, but the pattern of these features is a bit different to those we recognise in the classic form of the condition. Some of these individuals have a ‘misprint’ in only one copy of their WFS1 gene and we say they have Wolfram syndrome like disease. This seems to be very uncommon, but is important because it is inherited in a different way to the classic form of the condition. When this is important for a family I always discuss this carefully.

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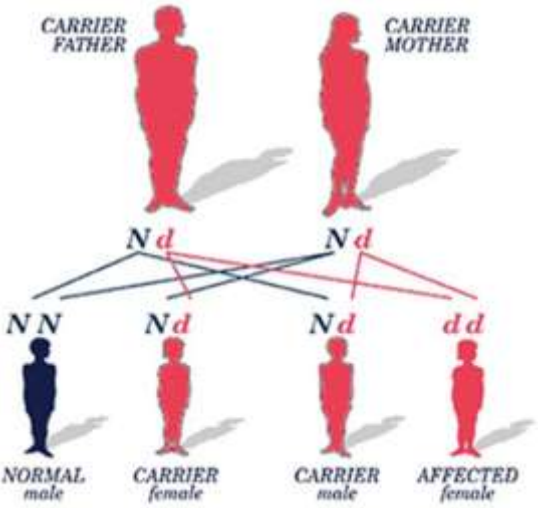

As mentioned already, part of my role in clinic is to discuss the 'risks' to other family members. From a practical point of view, finding the specific misprints responsible for causing the Wolfram syndrome in an individual means that we can use this information to test other family members who may be at risk of the condition or wish to know if they are carriers. I normally suggest this is arranged with the advice and support of the local clinical genetics service and I am in a position to liaise with my colleagues around the country and facilitate this.

Although there is currently no cure for Wolfram syndrome and this may still be a long way off, Professor Barrett who leads the multidisciplinary team in Birmingham is working closely with research doctors across Europe and America. There is no doubt that a greater understanding about the different misprints in the gene and the different ways in which people are affected by the condition, may lead to novel treatments for different aspects of it in the future. This is something we are all hoping to discuss with you in time.

Dr Denise Williams.
Consultant Clinical Geneticist,
Birmingham Children's Hospital.

. Neurological problems in Wolfram Syndrome

Wolfram Syndrome is a rare genetic condition which is characterised by insulin dependent diabetes mellitus, optic nerve atrophy and vision problems, diabetes insipidus and deafness. However neurological problems, apart from optic nerve atrophy and vision problems and deafness, can also occur.

On clinical neurological examination the most common other problems that are found are nystagmus (jittery eye movements which may be very subtle) and difficulties with balance and as a result walking. Some individuals may also have impaired sensation/feeling in their hands and feet and this may also contribute to the balance problems.

Other problems which are sometimes seen are stiffness in the legs and feet and a tremor of the arms and hands. This tremor often becomes more pronounced when the individual is trying to do something a little fiddly.

The majority of people with Wolfram Syndrome do not have problems with cognition/learning. There is however an increase in risk of behavioural and psychological problems, which may include anxiety and depression.

MRI brain scans are often normal in individuals with Wolfram Syndrome. However, in some people the brain size may be a little smaller and there may be some abnormalities seen in the brainstem (the lower part of the brain that becomes one with the spinal cord), the cerebellum (the balance centre of the brain) and/or the optic nerves and tracts (the nerves which carry information from our eyes to the part of the brain which analyses that information to make us “see”).

As already noted Wolfram Syndrome is a rare condition and neurological problems, apart from optic nerve atrophy and vision problems and deafness, are often subtle or not always present. As yet we have not been able to identify why some people with the syndrome develop such problems and others do not. One aim of the Wolfram Syndrome Clinic is to regularly review individuals with the syndrome in order to learn more about their signs and symptoms and how these may progress. Such knowledge will then help us to better

support individuals with Wolfram Syndrome and their families and hopefully help us to develop new treatments.

Professor Rajat Gupta
Consultant Paediatric Neurologist
Birmingham Children's Hospital

Visual Problems in Wolfram Syndrome

I am an eye doctor (ophthalmologist) with a particular interest in genetic eye diseases. I see patients with Wolfram syndrome in my specialist clinic at Addenbrooke's Hospital in Cambridge and at Moorfields Eye Hospital in London.

How is visual information sent from the eye to the brain?

The eye is a very sensitive camera that converts an image from the outside world into an electrical signal. At the back of the eye is the optic nerve, which is similar to a high-speed “broadband cable” that allows this electrical signal to be sent quickly to the vision centres at the back of the brain to be decoded. The figure above illustrates how visual information gets from the eye to the brain via the connecting optic nerve.

What is optic atrophy?

The majority of patients with Wolfram syndrome will develop optic atrophy. Optic atrophy means that the optic nerve has been damaged and it looks pale in colour when the eye doctor looks at the back of the eye with the appropriate equipment. Because the optic nerve is damaged, less visual information is sent from the eye to the brain, and this also happens more slowly with transmission errors. As a result, patients with Wolfram syndrome start to struggle with their central vision and they find it increasingly difficult to read small print and make out people’s faces (as in the example shown below). Visual difficulties usually start in childhood and they tend to get progressively worse with time.

What other eye problems can you get in Wolfram syndrome?

1. Diabetes is very common in Wolfram syndrome, but fortunately diabetic eye complications tend to be rare. Nevertheless, patients with Wolfram syndrome need to take particular care that their blood sugar levels are well controlled to avoid further diabetic eye complications in addition to optic atrophy.

2. A small group of patients with Wolfram syndrome can develop cataracts at a young age. If the eye doctor spots that a cataract is present and vision is getting worse because of it, the option of cataract surgery can be discussed.

What treatments can we offer at the moment?

1. Depending on how severely their vision has been affected, patients with Wolfram syndrome can be offered the option of being registered as sight impaired (partially sighted) or severely sight impaired ("blind"). The eye doctor will carry out the assessment and complete the Certificate of Visual Impairment (CVI) if the inclusion criteria are met (https://www.rnib.org.uk/your-eyes/navigating-sight-loss/registering-as-sight-impaired/).

2. Unfortunately, there is currently no proven treatment to stop the damage to the optic nerve and loss of vision. There is a lot of research being carried out at the moment to look for drugs that can protect the optic nerve. Gene therapy is also being considered, but this strategy is still at an early stage of development and so far, studies have only been carried out in mice .

3. As there are no effective treatments yet for the optic atrophy in Wolfram syndrome, visual and occupational rehabilitations are very important. An assessment in a Low Vision Assessment (LVA) clinic can be arranged and most eye departments will have an Eye Clinic Liaison Officer (ECLO) who can provide extremely useful practical advice to patients and their families.

Patients with Wolfram syndrome and their families must be very vigilant about various unproven "stem cells" treatments being offered on the internet.

How frequently should an eye check-up be carried out?

All patients with Wolfram syndrome should ideally have an annual check-up. Drops will usually be put in the eyes to dilate the pupils and make it easier to have a careful look at the back of the eye for any changes since the patient's last visit.

Mr Patrick Yu Wai Man
BMedSci, MBBS, PhD, FRCPath, FRCOphth
Clinical Senior Lecturer and Honorary Consultant Ophthalmologist

https://www.neuroscience.cam.ac.uk/directory/profile.php?py237

https://www.moorfields.nhs.uk/consultant/patrick-yu-wai-man

Wolfram Syndrome Spectrum Disorder Variants

Wolfram Syndrome – Classic WFS1

Wolfram syndrome (WFS1) is a rare autosomal recessive genetic disorder (the biological mother and father must each pass one affected copy of the gene to the child) caused by mutations in the Wolfram syndrome 1 (WFS1) gene. WFS 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 world-wide have this disease, including 130 - 160 in the UK.

There are currently no drug therapies or cures that exist for WFS. 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, WFS is best characterised as a spectrum of disorders, ranging in severity from mild to severe. WFS 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.

CISD2 - 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 WFS. Wolfram Syndrome patients carrying mutations in the CISD2 gene develop the primary features of WFS, 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-like/related)

As explained previously, Wolfram Syndrome is caused when an individual receives a mutated WFS1 gene from **BOTH** parents. In most cases, if only a single mutated WFS1 gene is received, patients do not experience Wolfram Syndrome complications.

However, in certain cases, despite having only one mutated WFS1 gene, individuals can have what is called WFS1-Related Disorder, exhibiting “Wolfram syndrome like” symptoms. This occurs if their specific mutation happens to fall within a certain group. WFS1-Related Disorder is associated with slightly different symptoms, including early-onset hearing loss and optic atrophy, but typically no diabetes.

In most cases, WFS1-Related Disorder is considered more mild than Wolfram Syndrome itself.

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

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

What is Diabetes mellitus?

Diabetes Mellitus occurs when the cells in the pancreas (an organ in your body) that normally produces insulin are damaged. The pancreas produces less insulin than normal, or no insulin at all.

When we eat food containing carbohydrate (starch and sugar) it produces glucose, which is transferred from the stomach into the blood stream and then into the cells to provide energy and maintain normal blood glucose levels.

Insulin is responsible for this process and acts like a key. It opens the door to the cells in your body and allows the glucose to enter. The body's cells then convert the glucose into energy. Without insulin, more and more glucose will build up in the blood stream and your body will try to remove the glucose. This can lead to a chain of events including the following:

The body will try to get rid of the excess glucose by pushing it out in the urine– resulting in the need to go to the toilet more often

- Because more urine is being passed, there is increased thirst.
- Because your cells are not getting the energy they need, you will feel tired.

- Because your body still needs energy, it will start to break down fat stores, so there will be weight loss.
- If this continues for any length of time, there will be a build-up of ketones, which are toxic to the body. This condition is called Diabetic Ketoacidosis or DKA.

Treating Diabetes mellitus

To maintain 'normal' blood glucose levels you need to do the job of your pancreas. This means injecting insulin several times a day/ or if on insulin pump therapy giving regular boluses, regularly monitoring your blood glucose levels, and making constant decisions about how much insulin to inject to keep your blood glucose as close to normal range as possible. One of the reasons to do this is to help you feel your best and give you more energy.

Blood glucose monitoring.

This is the best method of being in control of your diabetes, as it enables you to see how well your body is responding to your insulin, diet and activities, which in turn helps to keep you healthy and safe.

Susan Gleeson
Diabetes Nurse Specialist
Birmingham Children's Hospital

Diabetes Insipidus in Wolfram Syndrome

Wolfram Syndrome is a rare genetic condition which is characterised by insulin dependent diabetes mellitus, optic nerve atrophy and vision problems, diabetes insipidus and deafness. Diabetes insipidus means passing lots of urine that is not sweet, as it is not due to sugar problems.

In people without Wolfram syndrome, there is a gland in the brain called the Pituitary gland, which makes several hormones, one of which is Anti-diuretic hormone, or ADH. ADH travels round in the bloodstream to the kidneys, where it helps the kidneys to concentrate the urine.

About half of people with Wolfram syndrome will not make enough ADH, so that they are unable to concentrate the urine. Symptoms can be like sugar diabetes, with thirst, getting up at night to go to the toilet and passing lots of urine during the day. Sometimes this can make people feel extra tired.

There is a test that doctors do for diabetes insipidus – this is to ask for a urine sample first thing in the morning before having anything to eat or drink; and a blood sample also before any food or drink. These are used to check the concentrations of urine and blood. The urine should be concentrated first thing in the morning, and the blood a normal concentration. If the urine is very dilute and the blood is very concentrated, this suggests diabetes insipidus.

The treatment is to put back into the body, the hormone (ADH) that the body is not making enough of. This can be as a nasal spray, a tablet that dissolves under the tongue, or a tablet that you swallow. Most people manage very well with this medicine.

The medicine is sometimes called Desmopressin or DDAVP. There are not usually any side effects unless you take too much - in which case your body may retain too much water and you could get fluid overloaded. If you find you are not passing any urine, it is important to stop taking the tablets until you have had a good wee.

Your doctor will want to check your blood chemistry levels at least once every 6 months. It would be worth carrying a card with your medicine written down on it in case you have to see a doctor.

Professor Tim Barrett
Consultant Paediatric Endocrinologist
Birmingham Children's Hospital

Speech and Language Therapy

Some individuals with Wolfram syndrome can experience difficulties swallowing (dysphagia). It is important to recognise the symptoms of dysphagia as difficulties swallowing can be distressing. In certain cases, it can lead to weight loss, dehydration and cause chest infections or pneumonia.

Symptoms of dysphagia could include:

- Coughing
- Wheezing
- Throat clearing
- Gagging
- Choking
- Regurgitation of food/fluid
- Wet/'gurgly' or strained voice
- Laboured breathing after swallowing
- Eye watering or colour change in the face
- Throat irritation

In the Wolfram clinic at QEHB (Queen Elizabeth Hospital Birmingham), our role as Speech and Language Therapists (otherwise known as SLT) is to assess and highlight any swallowing difficulties to ensure individuals have the support they need to manage their dysphagia.

In clinic, you may expect an SLT to ask initial questions to find out more information about your swallowing and whether you have been experiencing any concerns. This is usually followed by an oral motor examination which is an examination to assess the physical condition and function of the mouth, and related structures. After this**,** usually a swallow assessment would take place where you may be asked to try various consistencies of food and drink. The SLT will then monitor for any overt symptoms of dysphagia and if there are concerns highlighted on assessment, the SLT will provide recommendations, advice and strategies to help. If required, the SLT may also refer you to your local SLT team for further support.

Whilst in the Wolfram clinic we mainly work with individuals who have swallowing difficulties, SLTs also work with individuals with communication difficulties. We would be happy to answer any questions you may have regarding this if this is something you are experiencing.

Sharnea Salmon - Specialist Speech and Language Therapist QEHB

Family Stories

The Lynch Family

Jennifer seemed to be a normal toddler just like her older brothers although rather shy, even around family members. She had suffered with coughing attacks which was put down to possible Asthma, as her dad Paul suffers with it & was having some toileting accidents which they said was childhood constipation. At the age of 5 we took her to the optician where she was diagnosed with Rotational Nystagmus and being longsighted. This explained her 'shyness'. They referred her to the local eye hospital to investigate the cause of the Nystagmus. Tests and an MRI were done with no obvious diagnosis, so she was referred up to Great Ormond Street (GOSH); so started our 3 years of visiting there. Another MRI was carried out as well as an ERG (electro-retinograph). This diagnosed her Optic Atrophy as well as an issue on the brain so we were then referred to see Neurology. Whilst waiting for this appointment she was discharged by our local Paediatrician for the coughing attacks even though they were still happening and was diagnosed with diabetes, at the age of 6, which we had caught early through some concerns I had.

We met the Neurology Consultant who was very nice and explained all of her problems to him. He then requested a Lumbar puncture be done along with about 20 blood tests, the Endocrine Consultant also requested a load of blood tests be done, one of which was for WSF1. I looked this up on the internet and wished I hadn't. In the end the endocrine tests weren't done as she was newly diagnosed with diabetes but under control. We could have found out she had WS then, but had to wait another 23 months before she was diagnosed.

Tests were also being carried out for the coughing attacks and bladder issues which hadn't settled down since everything started. The childhood constipation was sorted as soon as the diabetes was diagnosed, it was her system reacting to the sugar, which we are aware for now if she has a long period of hypos. More tests, visits to GOSH and a skin and muscle biopsy followed. In March 2010, at the age of 8, we were asked to attend GOSH to see 2 of her consultants and were given the news that Jennifer had Wolfram Syndrome. One of the consultants had tried to find out more about it but had only been able to find the worldwide WS support group and a page of

information about Professor Barrett.

Like everyone we went straight onto the internet to find out what help and support there was, which was pretty much zilch. This was when we decided that we would start up the UK support group. We contacted Prof Barrett to ask for his help and support with this, which he was very willing to do. Before the website went live we asked him to check over the information on the site to ensure that it was all correct. Through the website we have met and come into contact with many amazing people both affected by WS as well as those helping to treat and research the condition.

This then helped us, when in 2012 Jennifer had a 2nd severe choking attack which put her into intensive care (PICU) and on a ventilator up in London and away from home and family. All our WS family were sending messages of support during those difficult days.

The staff tried taking her off the ventilator 3 times during the first 2 weeks but each time failed, the longest time off was 36 hours. The only way to get her off the ventilator was with a ‘temporary’ tracheostomy, which Jennifer adapted to really well and very quickly. A further 2 weeks were spent on PICU, 1 week on a general ward and then we were transferred back to our local hospital where she spent a further 4 weeks before being allowed home permanently

Life carried on as normal, with Jennifer attending mainstream school, regular check-ups with her individual consultants, the WS Clinic and all our charity work for WSUK.

Life did change for the whole family when Jennifer was diagnosed with Type 1 Diabetes, we ‘grieved’ in a way for the life that we had lost. We could no longer decide to go somewhere spontaneously. We had to plan around her insulin injections, meals and snack times. With the diagnosis of WS this feeling of grief was slightly more intensified, but we feel that so long as we can keep her healthy and control her diabetes well there is no reason for her not to have a long and healthy life. The trachy does make life rather more restrictive now as we have so much more that we have to carry around with us when we go out and there are only a few of us that are trained for her care needs in an emergency, but we have her here with us and the chances of thetrachy coming out at some point in the future are now looking unlikely.

Since 2017 Jennifer has had to use a Bi-PAP ventilator at night to help with her sleep apnoea's and to help reduce the amount of CO2 she retains when she is asleep. Her short term memory has been affected which meant that when it came to exams she didn't do as well as had been predicted when she was in Year 9 .Her courage and strength have earned her 2 bravery awards over the years.

My motto to everyone is 'Even in the darkest times, stay positive. Keep strong and healthy. The only limitations to your life, are those imposed on you by others or by yourself'. The WS family will always be there to support you when you need them.'

The Ahmed Family

My name is Shiffa and I am now 19 years old. I was diagnosed with Diabetes Mellitus when I was 4 years old. This came as a shock to my family as I was quite young, it was a struggle to get my injections done and test my blood sugars. The diagnosis was made as I had become very weak and pale by going up and down the stairs to the toilet every 10 minutes which also led to dehydration. I was a very happy and energetic child, but I had become very tired and was sleeping for many hours during the day. Due to all this, my family took me to be seen by our local GP and he told us to go straight to the hospital from the surgery as my blood sugar levels were off the scale and dangerously high. This caused extreme distress to me and my family. I had to stay in hospital whilst, they carried out tests and stabilised my blood sugars. This was a difficult time for me and my family, but we received great support from doctors and nurses who helped us get through this time. At this time, we were not aware of Wolfram or that I could have this disease.

Approximately after 2 years, teachers started noticing that there had been a change in my vision as I was then struggling to see the board in class. They spoke to my parents and said that it would help if I was seen by the opticians. After this I had many eye tests done by the opticians who were unable to detect anything. They referred us to ophthalmologists in Bury but they also concluded that my eyes were fine. This was affecting my education as I had now moved school and the teachers here were not believing me when I told them I could not see the board. At this point I felt very helpless and did not know what to do as I was not receiving any help from teachers or medical professionals. The doctors at my local hospital then started doubting me and said to my parents that I was being bullied and that is why I was saying I cannot see. Me and my family were shocked when we heard this as we thought how can a medical professional say this? We informed my diabetes consultant of this, he thought it was important to be seen by the paediatrics eye specialist at Manchester Royal Eye Hospital to see if the diabetes and low vision were connected in any way.

At Manchester hospital it was apparent to the doctors straight away that my optic nerve was pale and after tests I was diagnosed with Wolfram Syndrome in 2010. The next few years were hard as my

vision deteriorated. However, I did receive support from teachers in order to complete my work in class, but I did feel as though my life had changed for the worse after this diagnosis. The disease then progressed and in 2014 I was diagnosed with Diabetes Insipidus. I had to be tested for this as I was going to the toilet constantly and was very thirsty despite my blood sugars being under control.

This affected my bladder and bowel movement, which caused me a lot of anxiety and affected my education. This affected me emotionally too, as I did not have the confidence to go anywhere in the fear that there would be another incident. I felt as though my freedom had been reduced after the diagnosis of diabetes insipidus as I have no control over it and am not able to go where I want, when I want. Whenever I leave the house, I am always in fear that something bad will happen due to previous experiences. However, I did not let any of the problems get in the way of me achieving my best in my academic career. I stayed focused and put in a lot of effort. It was definitely hard at times as I sometimes struggled to see things and it took me longer than others to complete work which sometimes made me wish I could work normally like everyone else and how much easier life would be then.

I stayed determined and managed to achieve good GCSE and A-level results. That just shows really that nothing can stop you from doing well if you believe in yourself and stay focused. Despite this, I receive lots of support from medical professionals, friends and family and whenever I am going through a bad phase in life, I know I will always have people there to support me. My family have been there with me through every stage of my journey through Wolfram and they never let me feel alone and always keep me motivated to do my best. I am now taking part in the trial for the medication to slow down the progression of this disease and am hopeful that we will see some positive results very soon. I am aware there is currently no treatment for this disease but am glad to have such a supporting network around me to keep me going and with the amount of research going on and all the researchers and doctors trying their best to find new medicines for this disease, I am sure there will be a cure soon.

My brother, Ayyan, was born in 2011. Up to the age 2 he was doing well but then one night we considered testing his blood sugar levels

as he was going to the toilet constantly and was very thirsty. When we checked his blood sugars they were extremely high so we thought we would wait until the morning and test them again. In the morning they were high again, so we took him straight to North Manchester hospital. He was diagnosed with Diabetes Mellitus and had to stay there for a few days whilst they stabilised his bloods. We knew that it could be linked to Wolfram as I had already been diagnosed with it. We were all very upset and hoped that it was not Wolfram's but there were high chances of this being the case. Later, within the same year, he was tested and diagnosed with Wolfram Syndrome. This was an extremely upsetting time and I was very distressed as I did not want him to go through the same experiences as me. My parents have been managing his blood sugars well with the help of doctors and nurses. He is now 9 and has not developed any other symptoms that are associated with Wolfram and hopefully does not develop any in the future.

We are very grateful to the WS charity that organizes all the conferences and other events. These conferences give us the opportunity to meet others suffering from the same disease as us and share our experiences. This makes us feel connected and makes us realise we are not on our own in this battle against defeating this disease. We also receive advice from other families and I especially benefitted from meeting one family as they informed us of a medicine that changed my life so much for the better. I was having sleepless nights running to the toilet constantly but since I have known of this medicine, I have felt much better. I would like to thank all the charity organisers and families that have been so helpful to me in my journey so far.

Darley Family

Our son Tom is 14 and was diagnosed with WS in 2022, after a complicated journey to diagnosis. We'd known from a young age something wasn't quite right with Tom but we kept being told by Drs that there was nothing wrong with him and that he was just a bit anxious. When he was 6 the optician told us he'd always failed to the colour-blindness test and sent us for a scan of his optic nerve. We went for a scan and were told all was fine, but when we were about to be discharged I asked why his pupils don't constrict properly and we were referred to Moorfields.

At this point we were told he had optic nerve atrophy and they were virtually certain he had dominant optic nerve atrophy which causes blindness and we were genetically tested. It took nearly a year to get the results back (yes, a year!), during which we really struggled, Tom was finding school difficult, we were coming to terms with the fact he was likely to lose his sight, but then the results came back negative! We struggled on, his primary school were not particularly supportive, and we were starting to notice that he needed the loo more than normal, he was struggling to regulate his temperature and he'd developed nervous tics. I googled his symptoms and came up with WS. It fitted - the eyesight, the anxiety, the temperature regulation, bladder issues, but my husband (very nicely) told me to stop googling and worrying myself as Tom was not diabetic so he couldn't have WS (we knew this from blood tests).

Fast forward to just before his 13th birthday, he'd been on various steroid drops for his eyes and our GP suggested a routine blood test, the result of which was that we were told he had type 2 diabetes. My slim, active little boy was told by the diabetic clinic to exercise more and I was told to manage his diabetes by diet and given literature about healthy eating and joining the gym for a boy with a BMI of 18.2!

This is where the lovely Tracy and the WS society came in. I was convinced now that Tom had WS, and Tracy agreed this is what it sounded like and became a lifeline as I began the journey of trying to convince someone to listen to me! It took 8 months, but in the end, my absolute insistence at the diabetic clinic that he didn't have type 2, and the decline in Tom's weight led them to agree to get him tested. They managed to get results for me in 2 weeks and kindly phoned me to give the me the news so we could grieve in private.

At first we were really worried about how we were going to tell him, but all the information on the WSUK website was incredibly helpful, and after reading an account where a young person said it worse when they knew their parents were hiding something from them, we decided to be as open and honest as we could be, but there was no big sit down, we just dropped things into conversation casually, telling him what he needed to know over time without making a big deal about it.

Every family, child and situation is different though, we make decisions and muddle through as best we can!

Whilst nobody ever wants a WS diagnosis or to have to decide how and when to break the news to their child, the actual diagnosis has made Tom and our lives so much easier. Our diabetic clinic have been fabulous, they got him from injecting to an Omnipod pump very quickly and Tom now has the freedom to eat pretty much what he wants when he wants. Whilst always a happy child, Tom has been anxious for as long as we can remember and nothing we'd tried had worked and I'd met a brick wall getting him any medication, despite the fact the only thing that really caused blood sugar spikes was his anxiety. However, after I was shut down by all avenues I tried, the diabetic clinic managed to get someone to see him and she agreed to prescribe medication and the change in him has been amazing. She also diagnosed him with mild autism which has really helped him to understand why he struggles with certain things (crowds, food texture etc) and made him much more confident in voicing his needs. Tom has always felt a bit different but now he knows why.

Whilst the idea of clinic can be a bit daunting, Georgina was there to support us at every step and made it so much easier. Tom made a friend at the second clinic and they message each other regularly. It's really helped for him to be able to share with someone who genuinely understands what he's going through.

As a family we are absolutely making the most of life since his diagnosis – getting travel insurance was cheaper and easier than we thought so we took him to Disney in Florida where they offer a disa- bility access pass which meant we walked straight past the 3 hour queues for rides and he also got virtually front row seats at Wimble- don and the rugby which he loved. School is amazingly supportive and he's thriving (the tics went as soon as he got the proper support he needed in secondary school). His friends are really caring and he was so excited to be voted year representative – acceptance from his peers despite all his differences has meant the world to him.

The picture below is Tom at the recent volcanic eruption in Iceland which we hiked to during our holiday .

Julie Fox

I was diagnosed with Wolfram like syndrome in 2014 and I am 57 years old.

I've had poor sight for most of my life. It gradually got worse until I can't see colours and only have one working eye which is blurred.

I've lived a great life had a beautiful son and a great job in finance.

In my 30s after having bladder problems, I started to self catheterise and still do. This was a real turning point and helped me immensely.

I've recently started wearing hearing aids and was so surprised how much I was missing out on, they are great.

Life has its ups and downs, but I try to stay as positive as possible, and it seems to help.

WSUK Family Support Co-Ordinators- Georgina King and Olivia Edwards.

We support children, young people and their families affected by Wolfram Syndrome to ensure they feel fully supported by the healthcare professionals working with them. We help families attend the specialist Wolfram clinics at Birmingham Children's Hospital (BCH) by making sure they have all the information they need before attending and will also help with logistical arrangements such as transport to the clinic and accommodation. We work to ensure the families have all they need to make their visit as stress free and pleasant as possible. We personally attend every clinic and are available to assist families throughout the time they are with us. We provide emotional and wellbeing support and advocate for children, young people and their families where needed.

When a new family is referred to the clinic one of us will visit them at home, if possible, to find out more about their situation, how we and WSUK can best support them, and to answer any questions the family may have.

Listening to families is at the heart of what WSUK does, and an important part of the Family Co-Ordinator's role is to gather feedback from families on their experience and opinions of the Wolfram clinics to help the BCH team provide the very best service that meets the needs of families.

Outside the clinic, we continue to act as an advocate for families, helping them access the support and benefits they're entitled to; whether that be the right support for their child at school, or that they're receiving all the benefits that they should be.

For more information about the Wolfram clinics or how we can help you, please contact us:

Georgina King

Tel: 07592 629813; Email: georginaking@wolframsyndrome.co.uk

I work 18.75hrs a week, Monday to Friday. If you contact me and I'm not available, please leave me a message and I will get back to you as soon as I can.

Olivia Edwards

Tel: 07756 778454; Email: oliviaedwards@wolframsyndrome.co.uk

I work 22.5hrs a week, Monday to Thursday. If you contact me and I'm not available, please leave me a message and I will get back to you as soon as I can.

Georgina King
Family Support

Olivia Edwards
Family Support

WSUK Adult Support Co-Ordinator -

The Adult Support Co-Ordinator's role is to support adults a f f e c t e d by Wolfram Syndrome and their families from the time of transition from children's services onwards. This will include supporting families through their life journey to help improve the quality of their lives and signposting them to information and relevant services. The ASC will also help WS affected adults feel part of their community.

Currently email the office admin@wolframsyndrome.co.uk or call:

07752 193635.

Further Information

Wolfram Syndrome UK (https://wolframsyndrome.co.uk)

This website/charity is run by families affected by this rare genetic disorder and the aim is to raise as much awareness as possible, funding for research and to support those affected.

Wolfram Syndrome Organisation (http://www.didmoad.org/)

This website provides more information on WS. Patients and their families can register and contact families all over the world.

Gene Reviews (www.ncbi.nlm.nih.gov/books/NBK4144/)

This article on Gene reviews provides a good review of Wolfram Syndrome Spectrum Disorder.

Orphanet (www.orpha.net)

Orphanet is an online database of rare diseases and related services provided throughout Europe. It contains information on over 5000 conditions and lists specialised clinics, diagnostic tests, patient organisations, research projects and clinical trials.

Euro-WABB (https://www.orpha.net/en/research-trials/registry_network/356652)

The Euro-WABB Project is a collaboration of doctors, scientists and patient support groups from all over Europe. This website provides information on Wolfram Syndrome and other rare genetic forms of diabetes.

Wolfram Syndrome Research Alliance (WSRA) (https://www.wsresearchalliance.org/)

Connecting and Supporting Wolfram Syndrome Researchers and

clinicians.

There are many others organisations listed on our website.

GENERAL— the following organisations might be helpful

ABELIZE (http://www.ableize.com/)

ABLEize is the biggest UK disability resource directory offering the largest collection of disability, mobility and health resources in the UK and Europe.

ACTION ON HEARING LOSS (www.actiononhearingloss.org.uk)

UK charity for people who are deaf or have a hearing loss.

AMINA - Muslim Women's Resource Centre (https://mwrc.org.uk)

Email: info@mwrc.org.uk FREE HELPLINE: 0808 801 0301

Amina is an award-winning organisation, recognised by Muslim communities and key partners within Scotland for its pioneering and responsive approach to addressing key issues and needs of Muslim women. Having invested in this specialist area where there was previously a gap in services in Scotland, Amina is recognised as the national hub for gaining access to, and consulting with Muslim women across Scotland.

Offices in Dundee, Edinburgh and Glasgow

ASIAN RESOURCE CENTRE (www.asianresource.org.uk**)**

The Old Toll House 110 Hamstead Road, Handsworth, **Birmingham** B20 2QS
tel. (0121) 523 0580; email: barc@asianresource.org.uk

Birmingham Asian Resource Centre is a front-line community based, not-for-profit organisation situated in the Handsworth district of Birmingham. The Centre serves the needs of the local communities, most of whom are BAME, through the use of their own mother-tongues, with a deep understanding of the religious, cultural and national aspirations of the people it serves. It provides resources and practical help, with a coherent policy of anti-racism, anti-sexism and non-discriminatory practices.

ADVOCACY PROJECT (www.advocacyproject.org.uk)

PO Box 58087, **London**, W10 9EB

Email: info@advocacyproject.org.uk Tel: 020 3960 7920.

We help marginalised and vulnerable people make effective choices about what happens in their lives. We support them to speak up and help improve important services we all need.

BLACK DISABLED PEOPLE'S ASSOCIATION

Email: bdpauk@aol.com, Tel: 07963117730

Exists to provide an effective support and advice network for Black disabled people living with physical, mental, or debilitating impairments across London.

CONTACT (http://www.contact.org.uk)

Contact a Family is the only national charity that exists to support the families of disabled children whatever their condition or disability.

CREATED BY PARENTS (www.createdbyparents.com)

Created by parents to make the difference. Our aim for this website is to share our experiences and to help families on the journey through transition and maybe beyond.

Tel: 0800 5870372 or 01749 676724
Email: admin@createdbyparents.com

DIABETES UK (www.diabetes.org.uk)

Diabetes UK is the leading charity that cares for; connects with and campaigns on behalf of every person affected by or at risk of diabetes. We help people manage their diabetes effectively by providing information, advice and support.

DISABILITY RIGHTS UK (https://www.disabilityrightsuk.org)

DR UK is itself led by people with diverse experiences of disability and health conditions, from different communities. We work with allies committed to equal participation for all. **Together we can be stronger.**

General Enquiries:0330 995 0400;
Email: enquiries@disabilityrightsuk.org

FAMILY FUND (http://www.familyfund.org.uk)

Are the UK's largest provider of grants to low-income families raising disabled and seriously ill children and young people. We help ease the additional pressures families face.

HOPEWELL (formerly NORTH MANCHESTER BLACK HEALTH FORUM (https://www.hopewellmcr.org.uk/)

A user led registered charity (No 1024631) registered in 1993 that works with vulnerable adults, women and families from marginalised communities living with long-term health conditions, poverty & economic pressures. Offers information & sign posting to local people with social care, housing & welfare benefits enquiries.

Email: info@hopewellmcr.org.uk
Tel: 0161 720 9974

INDEPENDENT DIABETES TRUST (IDDT) (https://www.iddt.org/)

We are an organisation for people living with diabetes run by peo-ple living with diabetes. We recognise that when one person in a fam-ily lives with diabetes, this affects other family members and we offer support to partners and parents. We raise awareness of important issues for people with diabetes and provide information in non-medical language.

Tel: 01604 622837 Email: enquiries@iddtinternational.org

SCOPE (http://www.scope.org.uk)

Are all about changing society for the better, so that disabled people and their families can have the same opportunities as everyone else.

Phone: 0808 800 3333; Email: helpline@scope.org.uk

Sibs (www.sibs.org.uk)

Sibs is the only UK charity representing the needs of siblings of disabled people.

SOUTH ASIAN HEALTH FOUNDATION (www.sahf.org.uk)

Promoting improvements in the quality of healthcare to South Asians across the UK.

South Asian Health Foundation (SAHF) is a registered charity founded in 1999 to promote good health in the UK's South Asian communities. We are one of the UK's leading British Asian health charities. Our mission is to assist people living in the UK, particularly those of South Asian origin, who are experiencing conditions of sickness, hardship or distress in particular by supporting organizations; implementing and establishing developmental projects which serve the needs of those persons and improve their conditions of need.

Telephone 07807 069719; Email: info@sahf.org.uk

THOMAS POCKLINGTON TRUST
(https://www.pocklington-trust.org.uk)

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

VISION IMPAIRMENT RELATED

ACTION FOR BLIND PEOPLE (https://www.rnib.org.uk/who-we-are/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.

BLIND PARENTS UK (formerly Blind Mums Connect) (https://www.facebook.com/groups/blindparentsuk)

BlindParents.UK supports all visually impaired parents, UK-wide. whether you are considering your first child or a grandparent, you are welcome to our peer-support groups and activities.

We are a growing organisation believing strongly in the power of peer support.

Our active forums provide a place to get to know others in the same situation.

We can also provide sling/buggy support, breastfeeding support, and one-to-one support from pregnancy through to starting school and beyond.

Tel: 01905 886252 Email: info@blindparents.uk

DEAFBLIND UK (https://deafblind.org.uk)

We are here because too many people are living with deafblindness and are not getting the help they need. We show people that there can be a life beyond deafblindness.

Whether you need some support to get back on your feet after a diagnosis, a helping hand to help you do the things you love, someone to turn to when you're feeling low or some information, advice and guidance, we're here to help.

Losing your sight and hearing can be frightening. Our team of experts is here every step of the way to show you life beyond sight and hearing loss.

Call us on: 0800 132320 Email us on: info@deafblind.org.uk

GUIDE DOGS FOR THE BLIND (www.guidedogs.org.uk)

Provide mobility and freedom to blind and partially sighted people. We also campaign for the rights of people with visual impairment, educate the public about eye care and fund eye disease research. Guide Dogs provides a wide range of services for children and young people, including mobility and life skills, large print books and grants for specialist technology. And we're here for the whole family, providing support and advice on a range of issues, including education.

Adult Services -Tel 0345 143 0229

Children's and Young People's services -

Email: cypservices@guidedogs.org.uk; Tel:0800 781 1444

General Enquiries -Tel 0118 983 5555

ROYAL SOCIETY FOR BLIND CHILDREN
(https://www.rsbc.org.uk/)

We provide a range of services in London and across England and Wales for blind and partially sighted children and young people, their families, and the professionals who work alongside them.

Tel: London office 020 3198 0225 or Bromley office 020 3198 0229.
email: enquiries@rsbc.org.uk

RNIB (www.rnib.org.uk)

Royal National Institute of Blind People (RNIB) is the leading charity offering information, support and advice to almost two million people with sight loss.

Sites for your country:

England- England - RNIB - See differently

Northern Ireland -Northern Ireland - RNIB - See differently

Scotland - Scotland - RNIB - See differently

Wales/Cymru -Wales / Cymru - RNIB - See differently

LOOK (www.look-uk.org)

Provides support, information and activities for families with visually impaired children and young people.

SENSE (http://www.sense.org.uk/)
Sense is a national charity that supports and campaigns for children and adults who are deafblind.

For information and advice call: **0300 330 9256**

SIGHT SCOTLAND (https://sightscotland.org.uk/**)**

Our tailored support is delivered by experienced experts. Find out how we can be there for you through our range of services.

We understand that sight loss can be scary, but it needn't be that way. With the right support things can be very different – which is where we come in.

For advice and information: call 0800 024 8973, or email hello@sightscotland.org.uk

SIGHTLINE VISION (NORTH WEST) (https://www.sightline.org.uk/)

We are a charity based in the north-west of England offering a **FREE** telephone-based befriending service designed to reduce loneliness and isolation for anyone living with a visual impairment.

Call 0800 587 2252 to speak to an advisor.

THE PARTIALLY SIGHTED SOCIETY
(https://www.partsight.org.uk/)

Are a national charity here to help anybody living with sight loss. Their specialist services focus on helping you to make the best use

of your remaining vision and their friendly team are at the end of a phone if you or someone you know is affected by sight loss.

Tel: 01302 965195 Email: reception@partsight.org.uk

VICTA (www.victa.org.uk)

Provides support, information, activities, breaks and holidays for families with blind or visually impaired children or young people.

Email: admin@victa.org.uk; Phone: 01908 240831

VICTA PARENT PORTAL (https://www.victaparents.org.uk/)

We know that navigating life with a visually impaired child can be difficult and confusing. Our aim for this Portal is to be a one stop information hub for all parents and carers raising a child who is blind or partially sighted.

Email: admin@victa.org.uk; Phone: 01908 240831

VI TALK (https://www.vitalk.co.uk/)

VI Talk is a CIO (charitable incorporated organisation) supporting blind and partially sighted people, their families and friends. It is also aimed at anyone who works in the field of visual impairment.

Email: info@vitalk.co.uk or leave us a voice message on 07512772770.

HEARING IMPAIRMENT RELATED

DEAFBLIND UK (https://deafblind.org.uk)

We are here because too many people are living with deafblindness and are not getting the help they need. We show people that there can be a life beyond deafblindness.

Whether you need some support to get back on your feet after a diagnosis, a helping hand to help you do the things you love, someone to turn to when you're feeling low or some information, advice and guidance, we're here to help.

Losing your sight and hearing can be frightening. Our team of experts is here every step of the way to show you life beyond sight and hearing loss.

Call us on: 0800 132320 Email us on: info@deafblind.org.uk

NATIONAL DEAF CHILDREN'S SOCIETY (www.ndcs.org.uk)

A national charity dedicated to creating a world without barriers for deaf children and young people.

SENSE (http://www.sense.org.uk/)

Sense is a national charity that supports and campaigns for children and adults who are deafblind.

For information and advice call: **0300 330 9256**

EDUCATION You can find more helpful links on our website

CALIBRE AUDIO LIBRARY (https://www.calibreaudio.org.uk/)

Since 1974, Calibre Audio has brought the joy of audiobooks to anyone struggling to access print, so they can immerse themselves in wonderful stories, memorable biographies or travel the world in their mind.

Phone: 01296 432339 Email: enquiries@calibre.org.uk

ClearVision: preschool onwards (https://clearvisionproject.org/)

ClearVision is a postal lending library of children's books designed to be shared by visually impaired and sighted children and adults. We lend books all across the UK and Ireland.

Tel: 020 8789 9575 Email: info@clearvisionproject.org

RNIB BOOKSHARE (https://www.rnibbookshare.org/cms/)

RNIB Bookshare UK education collection provides textbooks and materials to support the UK curriculum. We offer a range of accessible formats that can be read electronically or adapted to suit the personal reading needs of learners. We now have 698,912 titles with more being added all the time!

Email: Bookshare@rnib.org.uk Tel: 0300 303 8313

RNIB NATIONL LIBRARY SERVICE (https://www.rnib.org.uk/books)

RNIB Reading Services is absolutely free. So, whether you want Talking Books or braille, you can read to your heart's content.

Explore our reading options and get started today.

Tel: 01733 375351 Email: library@rnib.org.uk

SOS-SEN! (https://sossen.org.uk/)

SOS!SEN is a national charity aiming to empower parents and carers of children with SEN to tackle successfully themselves the difficulties they face when battling for their children's rights.

Email: admin@sossen.org.uk; National Helpline: 0300 302 3731

THOMAS POCKLINGTON TRUST (https://www.pocklington-trust.org.uk)

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

SCHOLARSHIPS:

OPEN LEARN (http://www.open.edu/openlearn/about-openlearn/try)

Our courses have been proven to increase confidence and develop the skills needed to enter Higher Education and succeed with learning.

You can choose an OpenLearn course from a wide range of subjects. Some are based on Open University course materials. Others are written specifically for OpenLearn.

What are the advantages?

- **OpenLearn free courses are available immediately.**

Our courses do not have a start and end date. You can start right away or at a time that suits you.

- **You can work through at your own pace**

You can spend as long as you like on an OpenLearn course, plus, if you sign up you can track your progress and work towards a **statement of participation**.

- **There are around 1000 courses to choose from**

The courses always focus on a specific area of learning. Some focus on important and fascinating academic subjects, whilst others help you develop skills needed for study or work.

- **You can try out what's on offer from The Open University**

If you're interested in taking an Open University course but are not sure what to study or if distance learning is right for you, then Open-Learn lets you get a feel for what's on offer.

- **You can work through at your own pace**

You can spend as long as you like on an OpenLearn course, plus, if you sign up you can track your progress and work towards a **statement of participation**.

- **There are around 1000 courses to choose from**

The courses always focus on a specific area of learning. Some focus on important and fascinating academic subjects, whilst others help you develop skills needed for study or work.

- **You can try out what's on offer from The Open University**

If you're interested in taking an Open University course but are not sure what to study or if distance learning is right for you, then Open-Learn lets you get a feel for what's on offer.

PRE-SCHOOL

Books on loan: picture, tactile, Braille books
ClearVision (www.clearvisionproject.org)

Tel: 020 8789 9575; Email:info@clearvisionproject.org

PRIMARY SCHOOL

BOOKS ON LOAN: for keystage1 and 2
www.rnib.org.uk/education

KEYSTAGE ONLINE
(http://www.ksol.co.uk/contents/Free11Downloads.aspx)

For primary school maths and English work and online preparation for 11 plus exam
Tel: 0121 733 6558; Email: enquiries@ksol.co.uk

SECONDARY SCHOOL

BOOKS ON LOAN: for keystage3
www.rnib.org.uk/education

DERWEN COLLEGE (https://www.derwen.ac.uk/)

A specialist college for young adults (aged 16–25) with special educational needs and disabilities (SEND).

Our positive and empowering culture gives students the confidence and experience to live life their own way.

There are no 'typical' students at Derwen College. For us, there is so much joy to be found in difference.

Tel: 01691 661234; Email: enquiries@derwen.ac.uk

INFOCUS (https://infocus-charity.org.uk/)

Children and young adults with special educational needs (SEN) and visual impairment often face barriers to learning, living and taking an active, independent place in society.
InFocus provides the specialist expertise, equipment and adapted facilities to inspire, challenge and empower these young people from across the UK to live their best lives**.**

Tel: 01392 454200; Email: enquiries@infocus-charity.org.uk

NEW COLLEGE WORCESTER, Worcester (www.ncw.co.uk)

Residential school and college for 11-19 year olds: supporting children and families prepare for exams, university and university applications.

Tel: 01905 763933; Email: info@newcollegeworcester.co.uk

USEFUL FURTHER EDUCATION LINKS
Starting college | RNIB

Starting university | RNIB

Resources for equality and employment | RNIB | RNIB

Young people | RNIB

QUEEN ALEXANDRA COLLEGE, Birmingham
(https://www.qac.ac.uk/college.htm)

For ages 16-25 years.

Tel; 0121 4285041; Email: info@qac.ac.uk

THE ROYAL NATIONAL COLLEGE FOR THE BLIND, Hereford
(https://www.rnc.ac.uk/)

Supporting education, employment and empowerment

Tel: 01432 376621; Email: info@rnc.ac.uk

ASSISTIVE TECHNOLOGY

BRITISH WIRELESS FOR THE BLIND (https://blind.org.uk)

Launched in 1928 we have been providing radios to visually impaired people for 90 years. We pride ourselves on providing a personal service to each individual who receives a new set.

For people with sight loss, life becomes a challenge; not just the difficulty of getting out and about, but also the everyday tasks that we take for granted - like turning on the radio in the morning to listen to the news.

By providing the equipment on a free loan to those who are unable to afford a specially adapted radio we help improve the daily lives of visually impaired people.

Tel: 01622 754757; Email: info@blind.org.uk

CONNEVANS (https://www.connevans.co.uk/viewPage.do?id=index)

We have a wide range of fantastic products and a wealth of experience, specialising in equipment for deaf and hard of hearing people and audio products. We pride ourselves on a high level of customer service so if you have any questions at all, please do contact us.

The name Connevans is derived from its founders Connie and Meurig Evans who started the company in 1961.

Today Connevans is run by their son David, daughter Mary and granddaughter Laura. With Connevans it's not just business, it's family! Enjoy your browsing and please get in touch if we can help

Email: askaquestion@connevans.com

Tel: 01737 247571

ENHANCED VISION (www.enhancedvision.co.uk)

Our extensive line of low vision aids have helped thousands of people regain their visual independence by providing the ability to read, write, see loved ones, or enjoy the outdoors. We are able to achieve these extraordinary results by offering the most diverse and reliable line of low vision aids available.

Phone: 0800 145 6115

LOW VISION SOLUTIONS (https://lowvisionshop.co.uk)
World Leaders in Low vision Magnification for People with Macular Degeneration and other Eye Conditions.

Phone: 0800 145 6115; Email: ordersuk@optelec.co.uk

RNIB (https://www.rnib.org.uk/your-eyes/navigating-sight-loss/**)**

If you have recently experienced sight loss, you may not be aware of the range of assistive technology available to help you access computers and read printed documents.

Tel: 0303 1239999

SYNAPPTIC (https://www.synapptic.com/)

Phones and tablets for people with sight loss.

Tel: 0191 9097 909; Email: sales@synapptic.com

TALKING NEWS FEDERATION (https://tnf.org.uk/)

The Talking News Federation exists to support and assist over 300 local Talking Newspapers to deliver local news and information in audio to blind, partially sighted and print disabled people.

Email:enquiries@tnf.org.uk Tel: 01793 497555

VISION AID (https://www.visionaid.co.uk)

VisionAid Technologies Ltd is a family owned & run business who have been providing solutions to assist VI and SVI people since 1996.

We have grown to become one of the largest specialist low vision and blindness product suppliers in the UK. Our range of over 1000 products are carefully tested & selected from over 100 manufacturers around the world.

We pride ourselves on listening to every individual's specific requirements & understand selecting the best product can seem a daunting task. That's where our friendly, expert advice and completely free, no obligation in home demonstrations do help (free demonstrations are available on most products).

Email: info@visionaid.co.uk ; Phone: 01775 711 977

ANDROID APPS FOR VI PEOPLE

1. **Google Talkback** - Google Talkback is an app that permits blind and vision-impaired people to easily interact with their Android smartphone.

2. **Magnify**- The app not only magnifies things but also contains a flashlight through which, you can easily read the text in low or no light. This is an innovative app for visually impaired people.

3. **Sullivan+** - The app has many interesting and very useful features such as AI mode to automatically finds the best results that fit the taken photos, Text Recognition to find a text, and tells you by sound.

4. **Supersense** - Supersense is a free Android app basically built visually impaired people. It helps the visually impaired be location aware, explore and navigate to nearby places of interest, read and find objects.

5. **Be My Eyes** - through this app you can lend your eyes to a VI in need through a live video connection or be assisted by the network of sighted users.

6. **Access Note** - is a sophisticated note-taking app designed to support visually impaired students and working professionals. AccessNote is compatible with VoiceOver

7. **Audible** - provides a wide selection of audible books, including recent popular titles, classics, and academic text.

GRANTS AND BENEFITS –more can be found on our website (https://wolframsyndrome.co.uk/benefits/)

CONTACT (http://www.contact.org.uk)

Contact a Family is the only national charity that exists to support the families of disabled children whatever their condition or disability.

DISABILITY GRANTS (https://www.disability-grants.org)

Your Guide to Grants for the Disabled

THOMAS POCKLINGTON TRUST
(https://www.pocklington-trust.org.uk)

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

Our strategic priorities are to increase awareness and understanding of the needs and aspirations of blind and partially sighted people. We are committed to working with partners and developing and implementing activities and services which meet these needs to increase independence and improve lives. These include:

- Acting as an advocate and positive change agent for blind and partially sighted people.
- Creating opportunities for blind and partially sighted people seeking employment.
- Enabling opportunities and supporting blind and partially sighted people in and entering education.
- Facilitating the voice and encouraging self-determination of

Being an effective partner and grant funder based on our knowledge of the sector.

TURN2US (http://www.turn2us.org.uk/default.aspx)

Turn2us is a charity that helps people in financial need to access welfare benefits, charitable grants and other financial help.

VICTA (https://www.victa.org.uk/grants/)

VICTA supports children and young adults who are blind or partially sighted by providing grants that support the purchase of equipment to aid their visual impairment.

Email: admin@victa.org.uk; Phone:01908 240831

WORK There are also others listed on our website.

ACCESS TO WORK (www.gov.uk/access-to-work)

Access to Work can help you get or stay in work if you have a physical or mental health condition or disability.

The support you get will depend on your needs. Through Access to Work, you can apply for:

- a grant to help pay for practical support with your work
- advice about managing your mental health at work
- money to pay for communication support at job interviews

EVENBREAK (https://www.evenbreak.co.uk/en)

Evenbreak exists to solve a couple of big problems
Employers told us they struggled to attract disabled candidates, disabled candidates told us they couldn't tell which employers were inclusive. So, we joined the dots and created the UK's most accessible job board to connect the two.

The employers who advertise on Evenbreak are actively aiming to attract disabled candidates and the registered candidates (somewhere in the region of 33,000 at the time of writing) want to work for inclusive companies.

Email: info@evenbreak.co.uk; Phone: 0845 658 5717

LOOKING FOR WORK IF YOU HAVE A DISABILITY
(https://www.gov.uk/looking-for-work-if-disabled)

Advice and guidance on how and where to look for work opportunities.

THOMAS POCKLINGTON TRUST
(https://www.pocklington-trust.org.uk)

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PROJECT NAI ZINDAGI
(https://www.aawaz.org.uk/projects/project-nai-zindagi/)

Project Nai Zindagi – meaning New Life is our brand new Hyndburn-wide project. This project is all about engaging with Muslim women to prepare them to access other mainstream provisions such as training, volunteering and employment. It is about offering individually tailored support to participants so that they can make progress to be more confident and knowledgeable and better skilled. This project will act as a bridge to introduce and to help the women access other services and opportunities.

Phone: 01254 398176 ; Email: info@aawaz.org.uk

SPORT AND LEISURE There are also others listed on our website.

ACTIVITY ALLIANCE (http://www.activityalliance.org.uk/)

In April 2018, we became Activity Alliance (previously known as the English Federation of Disability Sport). We join members, partners and disabled people to make active lives possible. Together, we

challenge perceptions and change the reality of **disability, inclusion and sport**.

Telephone: 01509 227750

ALL-ABOARD WATER SPORTS (https://www.allaboardwatersports.co.uk)

All-Aboard is a Watersports Charity. Our aim is to break down barriers and make it possible for everyone in our community to participate in a range of watersports such as sailing, kayaking, canoeing, rowing, paddleboarding, powerboating and other water related activities in the beautiful and historic Bristol City Docks. Our centre and activities are fully accessible and delivered by a highly trained team of instructors, staff and volunteers.

Tel: 0117 929 0801 Email: admin@allaboardwatersports.co.uk

BLIND CRICKET IN ENGLAND & WALES (www.bcew.co.uk)

The BCEW have been working in partnership with British Blind Sport 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.

Email: davidgavrilovic@yahoo.co.uk; Phone: 0208 2794642

BRITISH BLIND SPORT (http://www.britishblindsport.org.uk/)

British Blind Sport (BBS) is a national registered charity based in Leamington Spa. Since its beginnings as a registered charity in 1976, British Blind Sport has become the leading voice for visually impaired people (VI) in the world of sport and leisure, both at home and internationally.

Telephone:01926 424247; Email:info@britishblindsport.org.uk

BRITISH ROWING (https://www.britishrowing.org/go-rowing/learn-to-row/adaptive-rowing/)

Anyone can get involved in rowing regardless of physical, sensory or learning impairment. There are many benefits to being involved in

rowing; the sense of freedom, making life-long friends, and learning new skills whilst keeping fit and healthy. You can do all this on the water or indoors, just for fun or to compete in races. Adaptive Rowing is about removing barriers to participation in the sport for anyone who has an impairment or disability.

Email: info@britishrowing.org

DISABILITY FOOTBALL (https://www.englandfootball.com/play/disability-football)

We have an ambitious plan to develop disability football. Football Your Way is The FA's Game plan for Disability Football 2021-24. The plan is the first of its kind and covers seven key areas, demonstrating our commitment to ensuring disabled people can engage and participate in football their way, from grassroots all the way to the elite end of the game. The plan comes under the umbrella of the broader equality, diversity and inclusion strategy which is about creating a game for all.

DRIVING AMBITION (https://www.drivingambitionbrackley.info)

We have had many groups and individuals over the years especially from New College for the blind (Worcester) and referrals from the RNIB.

Based at Turweston Aerodrome, Brackley Northamptonshire NN13 5YD. Lessons on private land with a DVSA approved driving instructor (cars).

You can book a one to one off road driving experience for someone who is blind or partially sighted.

ENGLAND DEAF GOLF (https://www.england-deaf-golf.com/about-edg)

England Deaf Golf (EDG) (formerly English Deaf Golf Association (EDGA)), founded in 1983, is the governing body for deaf and hard of hearing (HoH) golfers in England as recognised by UK Deaf Sport, World Deaf Golf Federation and England Golf (formerly English

Golf Union and English Women's Golf Association which recently merged).

Email: Chairman@englanddeafgolf.co.uk

EXPLORE 4X4 (https://explore-4x4.co.uk)

Helping the visually impaired and SVI to experience something many of us take for granted is incredibly rewarding. We are as exhilarated by the experience as they are. We have many years of off road training behind us, from military personnel preparing for Afghanistan, to private motorists keen to learn more about their 4x4s, we have also instructed physically disabled people in off road driving, however, we have never considered the challenge of drivers without sight before.

Fill in the contact form on the website or call:

Suffolk 01787 320640 & Warwickshire 02477 717087

FA BLIND FOOTBALL
(https://www.englandfootball.com/play/Disability-Football/Blind-Football)

Blind football is five-a-side football - and, more specifically, it is an adapted version of futsal. Blind football is also sometimes known as B1 football or football five-a-side.

GARDENING WITH DISABILITIES TRUST (https://www.gardeningwithdisabilitiestrust.org.uk/)

Gardening with Disabilities Trust aims to help people back into gardening in spite of disability. We give out grants so that people can adapt their gardens and make gardening possible. Our clients tell us that it can change their lives, enhance their well-being and help them defy their disability.

The charity is entirely staffed by volunteers. Based in Kent, the Garden of England, we award grants to individuals and groups across the UK, and support people with all kinds of mental and

physical challenges. We believe we are the only charity which does this.

Email: info@gardeningwithdisabilitiestrust.org.uk

GOALBALL UK (http://goalballuk.com/)

Are you interested in playing Goalball? Then contact your nearest club and Get Involved!

Goalball UK are busy working to develop new clubs throughout the country and regularly hold taster sessions.

Tel: 0114 2235670; Email: enquiries@goalballuk.com
www.facebook.com/goalballUK

SENSE ADVENTURES (https://senseadventures.co.uk)

Sense Adventures offers guided day activities and short breaks in mixed groups to VI and sighted people in a friendly and relaxed atmosphere.

Sense Adventures gives you the chance to take time out to explore a new part of the English countryside in a safe and secure environment. Activities take place in the Malvern Hills, an area of outstanding natural beauty. We can accommodate individuals and couples alike.

Phone:01684 891796 / 07920 144614

SPORT ENGLAND (www.sportengland.org/our-work/disability/)

Sport England is committed to helping people and communities across the country create sporting habits for life. They know that disabled people are less likely to take part in sport with only one in six playing sport regularly compared to one in three non-disabled people. Their work will seek to challenge and change this to enable disabled people to view taking part in sport as a viable lifestyle choice.

UK DEAF GOLF (https://ukdeafsport.org.uk/sports_directory/golf/)

There are many opportunities to enjoy golf and the sport is loved by young and old. It is an activity that is very social whilst skill having an opportunity to compete against others of all standard. Below you will find specific information and links to the main golf organisation in the UK that support deaf golfers and provide opportunities for you to get involved

UK DEAF SPORT (https://ukdeafsport.org.uk/about-ukds/)

Leading Opportunities For More Deaf People To Participate In Sport Throughout Their Lives & More Deaf Athletes To Perform On The World Stage

PERFORMING ARTS

EXTANT(www.extant.org.uk)

Performing arts for visually impaired
Tel: 020 78203737; **Email:** info@extant.org.uk

MENTAL / EMOTIONAL HEALTH SUPPORT AND ADVICE

ANTENNA OUTREACH SERVICE

Antenna Outreach Service is a culturally sensitive mental health service. We work with Black African & African Caribbean people aged between 16 – 25 years old, suffering from mental health problems. We offer individual and parental support, advice and practical help.

Phone: 020 8365 9537;
Email: antenna@outreachservice.fsnet.co.uk

BLACK MINDS MATTER (https://www.blackmindsmatteruk.com/)

Black Minds Matter UK is a fully registered charity connecting Black individuals and families with free therapy by qualified and accredited Black therapists.

BLACK ORCHID

The aim of Black orchid is to provide culturally sensitive and appropriate mental health advocacy for people of African, Caribbean and other ethnic minority groups, between the ages of 16 and 65.

First Floor, 189c Newfoundland Road, Bristol BS2 9NY
tel. 0117 907 9982 /0117 904 8280;
email: black@orchid189c.fsnet.co.uk

GLOUCESTERSHIRE BLACK MENTAL HEALTH PROJECT

Home visits, welfare rights benefits, Support, advice and information for people with mental health problems who are from the African, Asian, Chinese and African Caribbean communities. Contact details: 27 Worcester Street Gloucester GL1 3AJ.
Tel: 01452 387744

GREENWICH MIND

Offers free counselling for clients from the Caribbean, African, Black British community living in Greenwich Borough. Clients must be

aged 18+ can be self-referred or referred through their GP or their supporting organisation. We offer long term and short term counselling, Short term 6-12 sessions. Long term 24 sessions.

Email: hazel.Williams@greenwichmind.co.uk; Tel:0208 853 1735

INSPIRE WELLBEING—The Northern Ireland Association for Mental Health(https://inspirewellbeing.org)

At Inspire we work together with people living with mental ill health, intellectual disability, autism and addictions to ensure they live with dignity and realise their full potential.

Email: NI/UK: hello@inspirewellbeing.org;
Ireland: dundalk@inspirewellbeing.ie

Phone: 028 9032 8474

MENTAL HEALTH SHOP

Advice, information, advocacy and support for people with mental health problems and their carers. Also offers a service to in-patients in psychiatric hospitals and units outside Leicester.

40 Chandos Street, Leicester, LE2 1BL
tel. 01162 471 525; email: bmhgrc.mhs@care4free.net

MIND (https://www.mind.org.uk/)

We provide advice and support to empower anyone experiencing a mental health problem. We campaign to improve services, raise awareness and promote understanding.

MIND CYMRU (https://www.mind.org.uk/about-us/mind-cymru/)

Mind in Wales. We are working to make sure everyone in Wales has access to the mental health information, support and services they need. The page is also available in Welsh.

LOCAL MINDS

Support people in communities across England and Wales. Their range of services include supported housing, crisis helplines, drop-in centres, employment and training schemes, counselling and befriending. Find out if there is one where you live.

For accessing all the above:
Mind Infoline: 0300 123 3393; Email info@mind.org.uk

MUSLIM COMMUNITY HELPLINE(muslimcommunityhelpline.org.uk)

The Muslim Community Helpline is a confidential, non-judgemental listening and emotional support service. The Muslim Community Helpline is a national organisation for women, men, youth and children which was launched in 2007. We are here to help and support, whatever your needs, and have trained volunteers with many years of experience on hand five days a week. We aim to provide a listening and emotional support service for members of the community in the United Kingdom.

Helpline numbers: 020 8908 6715 / 020 8904 8193;

Email:ess4m@btinternet.com

MUSLIM YOUTH HELPLINE (MYH) (www.myh.org.uk)

The core service is a free and confidential counselling service available nationally via the telephone, email, internet and a face to face befriending service in the Greater London area. Run by young Muslims trained in Islamic counselling skills.

Helpline: 0808 0808 2008; Email: help@myh.org.uk

MUSLIM WOMEN'S NETWORK (www.mwnhelpline.co.uk)

The overall goal of the helpline is to provide a national specialist faith and culturally sensitive service that is confidential and non-judgmental.

The helpline offers information, support, guidance and referrals to Asian and Muslim women and girls from diverse ethnic / faith backgrounds suffering from or at risk of abuse or facing problems on a range of issues.

0800 999 5786 (free from mobiles and landlines);
email: info@mwnhelpline.co.uk

NAFSIYAT – The Intercultural Therapy Centre (www.nafsiyat.org.uk)

Offers Intercultural psychotherapy and counselling.

Tel: 020 7263 6947; email: admin@nafsiyat.org.uk

RETHINK SEVERE MENTAL ILLNESS – Sahayak Asian Befriending Project (https://www.rethink.org)

Befriending service for Asian people aged 16 and over with mental health problems or who are experiencing emotional distress.

Assistance with accessing mental health services. Promotion of mental health awareness within the Asian communities.

Tel:0808 800 2073 (Helpline); Email: info@rethink.org

SAHAARA– women's wellbeing support group (https://www.southwestyorkshire.nhs.uk/creative-minds-projects/sahaara-womens-wellbeing-support-group/)

The support group provides creative activities and approaches as a pathway for promoting and maintaining mental and emotional wellbeing; building self-confidence and an opportunity to engage with other people. We aim to help people lead on to further education, training courses, volunteering and/or employment. Used by adult women who use our services and/or their carers.

Phone Yasmin Arshad at the Priestley Unit, DDH on 01924 512276 or email: yasmin.arshad@swyt.nhs.uk.

SCOTTISH MENTAL HEALTH (https://samh.org.uk)

Around since 1923, SAMH is Scotland's national mental health charity. Today, in over 60 communities we work with adults and young people providing mental health social care support, services in primary care, schools and further education, among others.

Information line 9-6 Monday to Friday: 0344 800 0550, or use the contact form on their website.

SHEFFIELD AFRICAN CARIBBEAN MENTAL HEALTH ASSOCIATION (www.sacmha.org.uk)

SACMHA has almost 30 years of experience of delivering specialist services to people in need of assistance with their health and social care needs. This could be because of their age, youth, disability, financial hardship or social disadvantage. SACMHA acknowledges and support the role of carers in its service provision.

tel. 0114 272 6393; email: admin@sacmha.org.uk

THE HARMONY PROJECT

Therapeutic intervention for individuals and families through 1 to 1 counselling, group work, family support and workshops in schools.

Tel: 020 7511 2800 Crisis line no: 0800 169 7261
email: info@harmony-project.co.uk

THE OREMI CENTRE (https://www.forher.org.uk/counselling/oremi-centre)

For Her is an online platform created to help young women between the ages of 16 and 29 get access to free emotional support resources in the London area. Oremi is a mental health day centre offering outreach, advice and information, and community development aimed at African, African Caribbean and Arabic speaking people.

Tel:020 8964 0033; **Email:** malcolm.phillips@hestia.org

WALTHAM FOREST BLACK PEOPLE'S MENTAL HEALTH ASSOCIATION (www.bpmha.org/menu.htm)

To support and empower Black People with mental health problems. To raise awareness about important mental health issues in the Black Community. To provide a forum for Black People to meet and discuss their personal mental health needs. Individual counselling is offered to users each week.

Tel: 020 8509 2646; email: reception@bpmha.org

INTERNATIONAL WS ORGANISATIONS

ALLIANCE OF FAMILIES AFFECTED BY WOLFRAM SYNDROME (https://afasw.com/)

Spanish WS Support Group

ASSOCIATION SYNDROME DE WOLFRAM (https://www.association-du-syndrome-de-wolfram.org/en/prise.html?start=5)

Website for French Wolfram Association providing information and support for families.

THE ASSOCIATION FOR RESEARCH AND ASSISTANCE TO WOLFRAM SYNDROME (https://aswolfram.org/)

The Spanish Association for Research and Support for Wolfram Syndrome was founded in 1999

BE A TIGER FOUNDATION (https://www.beatigerfoundation.org/)

USA Foundation

ELLIE WHITE FOUNDATION (https://www.elliewhitefoundation.com/)

USA Foundation

EYE HOPE FOUNDATION (https://eyehopefoundation.org/)

WS Group in Belgium

GENTIAN—WOLFRAM SYNDROME ITALY
(https://www.sindromewolframitalia.com/)

Italian WS Support Group

THE SNOW FOUNDATION (https://thesnowfoundation.org/)

The Snow Foundation is a collective voice for Wolfram syndrome patients, working towards a cure for Wolfram syndrome and developing novel therapies for diabetes, vision loss, hearing loss, and neurodegeneration.

UNRAVEL WOLFRAM (www.unravelwolframsyndrome.com)

WOLFRAM HEROES SAUDI ARABIA (https://wolframheroes.com/)

We decided to carry the flag for Wolfram Syndrome and Rare Diseases in Saudi Arabia and create a foundation to be an umbrella for rare diseases.

WOLFRAM SYNDROM (www.wolfram-syndrom.de)

German WS Support Group

WOLFRAM SYNDROME GLOBAL AWARENESS DAY (WSGAD)
(www.globalwsday.org)

1st October is the date everyone in the WS Community can come together to raise awareness of our condition around the world.

WS GLOBAL PATIENT REGISTRY
(https://thesnowfoundation.org/ws-global-patient-registry/)

We have partnered with the National Organisation of Rare Disorders, Inc. “NORD” to implement the first-ever WS global patient owned registry, a priority in the field of rare disease. Please help us improve patient care, strengthen our voice, and improve the chance for quicker drug development. Support The Snow Foundation’s vision of “a world without Wolfram syndrome. Sign up today at https://wsglobalregistry.iamrare.org/ to receive critical information about treatment, research, resources, and other initiatives.

More helpful organisations can also be found on our website

Your Wolfram Syndrome UK CEO and Trustee Board

Tracy Lynch
CEO & Co-Founder

John Isherwood
Chair of Trustees

Paul Lynch
Vice Chair & Co-Founder

Prof Tim Barrett
Trustee & Medical Advisor

Alan Nye
Trustee

Abby Gardner
Trustee

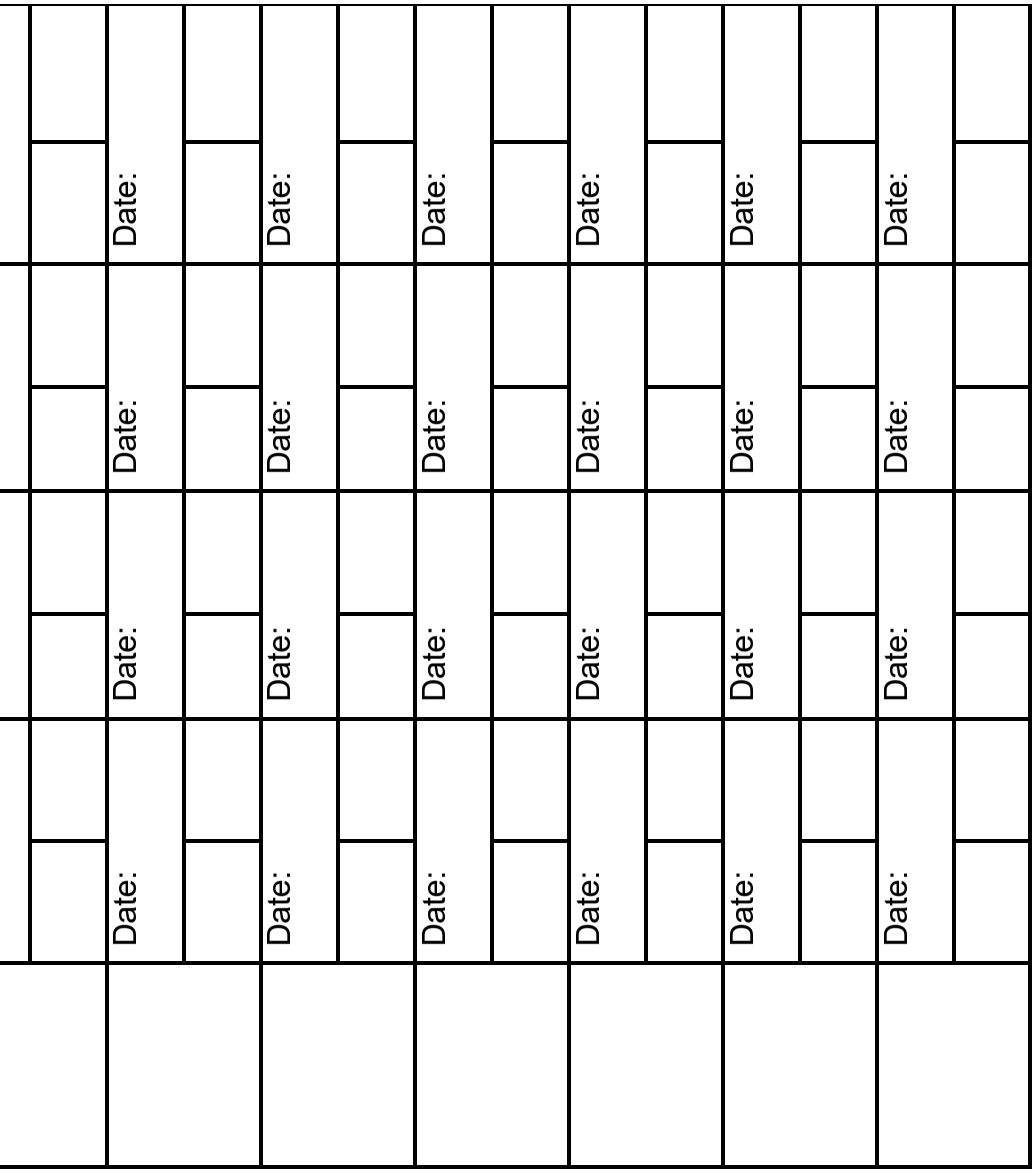
Medicines

You / your child may be taking a variety of different medicines; you may

Name of medicine	Date started		Date changed		Date changed		Date changed	
	Dose	How often	Dose	How often	Dose	How often	Dose	How often
EXAMPLE Thyroxine	Date: **3.2.12**		Date: **17.9.12**		Date: **21.3.13**		Date:	
	50 mcgs	**Once daily**	**75 mcgs**	**Once daily**	**100 mcgs**	**Once daily**		
	Date:		Date:		Date:		Date:	
	Date:		Date:		Date:		Date:	
	Date:		Date:		Date:		Date:	
	Date:		Date:		Date:		Date:	

OD – once daily. BD –twice daily. TDS- three times daily. QDS – Four

find it helpful to keep a record of the different medicines and the doses.



times daily. Nocte- at night

Thank you to the Medical Professionals for their help in producing this book & to the families that have shared their stories.

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

Wolfram Syndrome UK

9 Church Way, Worthing, West Sussex

BN13 1HD

Tel: 01903 211358

Email: admin@wolframsyndrome.co.uk

Website: www.wolframsyndrome.co.uk

Registered with FUNDRAISING REGULATOR