

## Main characteristics of Wolfram Syndrome

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

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



# Wolfram Syndrome

## The facts

### WOLFRAM SYNDROME SUPPORT & INFORMATION DAY

The annual family conference is a great way for families and individuals affected by Wolfram Syndrome and carers and support teams to meet up with each other, share experiences, hear talks on the latest research and to speak with clinicians on a more personal level.

For more information about the Support & Information Day:  
 Call Jody Blake on 01242 548762  
 or email [jodyblake@wellchild.org.uk](mailto:jodyblake@wellchild.org.uk)

#### FEEDBACK FROM THE DAY:

The balance of the day between research information and chatting to other people about their issues was really good.

Another one soon please, very interesting.

Very informative – wish I'd brought my son and daughter.



Call Jody Blake on:  
**01242 548762**

Or email:  
[jodyblake@wellchild.org.uk](mailto:jodyblake@wellchild.org.uk)

AN ALLIANCE BETWEEN

AN ALLIANCE BETWEEN

This information leaflet is for people who may have or care for someone with Wolfram Syndrome. As Wolfram Syndrome is very rare, few people actually have the syndrome. However, if you think you may be affected, or are worried about anything in this leaflet please contact [jodyblake@wellchild.org.uk](mailto:jodyblake@wellchild.org.uk) or [admin@wolframsyndrome.co.uk](mailto:admin@wolframsyndrome.co.uk)

## What is Wolfram Syndrome?

**Wolfram Syndrome is a rare genetic condition affecting around 1 in 770,000 people in the UK. Affected people commonly have diabetes mellitus and optic atrophy. It is not an easy condition to diagnose. Many patients have it for years before an accurate diagnosis of Wolfram Syndrome is confirmed.**

## Treatment

Unfortunately there is currently no cure for Wolfram Syndrome, however treatments can improve individual symptoms. Diabetes Mellitus can be controlled with insulin injections and Diabetes Insipidus can be controlled with medication. Visual and hearing problems may be improved through the use of glasses and hearing aids.

Clinical trials are about to start in both the UK and USA on two different drugs which have shown promising signs during laboratory research. It is hoped that one or both of them will slow down or halt the progression of Wolfram Syndrome. A cure for Wolfram Syndrome is still some way off.

For more information about current research, visit the "resources" page on the Wolfram Syndrome UK website: [www.wolframsyndrome.co.uk](http://www.wolframsyndrome.co.uk)

Optic atrophy + Insulin dependent childhood onset diabetes needs further investigation before Wolfram Syndrome can be excluded

## What support is available?



The Wolfram Syndrome Support Network is a partnership between the children's charity WellChild, Birmingham Children's Hospital and Wolfram Syndrome UK.

**Our overarching aim is to work together to raise awareness of Wolfram Syndrome and to provide the best possible support for families and adults living with the condition.**



### WELLCHILD WOLFRAM SYNDROME FAMILY COORDINATOR

In partnership with Birmingham Children's Hospital and Wolfram Syndrome UK, WellChild's Wolfram Syndrome Family Coordinator provides information, support, advocacy and advice to families across the UK caring for children and young people with this rare genetic condition. An important part of this role is to connect with families and feed back their experience to the team who deliver the children's Wolfram Syndrome clinics at Birmingham Children's Hospital (see Wolfram Syndrome Multidisciplinary Clinics). Through the Family Coordinator, families are able to influence how the clinic is delivered.

As part of supporting families a regular newsletter with lots of information and news for families and adults affected by Wolfram Syndrome is available. Email [jodyblake@wellchild.org.uk](mailto:jodyblake@wellchild.org.uk) if you would like to be added to the mailing list.

There is also up-to-date information and research about Wolfram Syndrome on the WellChild website. This information is medically endorsed, so it's the best place to start looking – visit [www.wellchild.org.uk](http://www.wellchild.org.uk)

For more information about the Family Coordinator role: Call Jody Blake on 01242 548762 or email [jodyblake@wellchild.org.uk](mailto:jodyblake@wellchild.org.uk)



### WOLFRAM SYNDROME MULTIDISCIPLINARY CLINICS

Specialist Children and Adult Clinics have been set up at Birmingham Children's Hospital and Queen Elizabeth Hospital, Birmingham. By attending these clinics, families and adults can get advice on the best treatments available to help maintain a good quality of life and delay progression of the condition as well as information about research. Both clinics have now been running for several years, they are well established and will soon be run from the new Rare Disease Centres at Birmingham Children's and the Queen Elizabeth Hospital. The clinics are available to anybody in England who has a confirmed or suspected diagnosis of Wolfram Syndrome.

For more information about the Children's Clinic:

Call Lindsay Wilson on 0121 333 9267  
or email [Lindsay.Wilson@bch.nhs.uk](mailto:Lindsay.Wilson@bch.nhs.uk)

For more information about the Adult Clinic:

Call Mandy Purslow on 0121 371 6890  
or email [mandy.purslow@uhb.nhs.uk](mailto:mandy.purslow@uhb.nhs.uk)



### WOLFRAM SYNDROME UK SUPPORT GROUP

Paul and Tracy Lynch, whose daughter Jennifer has Wolfram Syndrome, set up Wolfram Syndrome UK in 2010 following her diagnosis because they felt the UK needed a website and newsletter where families could find help & useful information, as there was nothing previously. The charity also focuses on increasing awareness of the condition, as well as raising money for research, the annual family conference and other ways to support people in the UK affected by Wolfram Syndrome. The most recent being the purchase of an 8 berth static caravan in on a 5 star Haven holiday village in Pagham, West Sussex which is rented out to WS families at heavily discounted price.

For more information:

Call 01903 211358, email [admin@wolframsyndrome.co.uk](mailto:admin@wolframsyndrome.co.uk) or visit [www.wolframsyndrome.co.uk](http://www.wolframsyndrome.co.uk)