WOLFRAM SYNDROME UK

Inform, Support, CURE

www.wolframsyndrome.co.uk

Parent's Pack

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

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

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

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SECTION 10

The Wolfram Syndrome Child at School

SUPPORTING CHILDREN AND YOUNG PEOPLE WITH WOLFRAM SYNDROME AT SCHOOL

General Information:

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

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

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

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

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

Main characteristics of Wolfram Syndrome

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

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

How does WS affect the school life of an affected child or young person?

Diabetes Mellitus:

Most people with WS have Diabetes Mellitus, which means they must inject insulin several times a day. The school should have an Individual Healthcare Plan (**IHP**) in place to ensure the pupil is adequately supported in the management of their diabetes, it should be as detailed as possible and drawn up with input from the child (if appropriate), their parent/carer, the school nurse and relevant school staff. A sample IHP can be downloaded from Diabetes UK website: https://www.diabetes.org.uk/.

Diabetes UK suggest that an IHP should include the following:

• Written permission from the parent/carer and the head teacher for insulin to be administered by a member of staff, or self-administered by the child during school hours.

• Exactly what help the child needs with diabetes management – what they can do themselves and what they need from somebody else.

• Who is going to give that help and when.

• Details of the insulin needed, the dose needed, when it's needed and the procedure for injecting or using a pump.

• Details of when the child needs to test their blood glucose levels, the procedure for testing them and the action to be taken depending on the result.

• Description of the symptoms of hypo and hyperglycaemia (and possible triggers) and what staff will do if either of these occurs. It should also include when the parent/carer should be contacted and when an ambulance should be called.

• Details of when the child needs to eat meals and snacks, what help they need around meal or snack time, e.g. whether they need to go to the front of the lunch queue, need help with carbohydrate counting or have any other special arrangement around meal/snack time.

• The things that need to be done before, during or after PE, e.g. blood glucose testing or having an extra snack.

• Details of where insulin and other supplies will be stored and who will have access to them. It should also include what supplies will be needed, how often the supplies should be checked and by whom.

• What to do in an emergency, including who to contact.

• Any specific support needed around the child's educational, emotional and social needs, e.g. how absences will be managed, support for catching up with lessons or any counselling arrangements.

• A description of the training that has been given to whom.

• What plans need to be put in place for exams (if appropriate)

• What plans need to be put in place for any school trips (including overnight) or other school activities outside of the normal timetable.

This is not an exhaustive list, and the IHP might also include other aspects of a child's care.

Diabetes Insipidus:

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

Hearing loss:

Hearing loss can make it hard for a pupil to hear instructions in a noisy classroom. Sitting the child close to the teacher can help with this. As well as keeping the classroom door closed to limit external noises. Some children with WS may wear hearing aids or have a cochlear implant. Audio technologies which supplement and/or work in conjunction with the children's hearing aids such as hearing loop systems can be extremely beneficial too.

Visual impairment:

Optic Atrophy affects the child's ability to see in classrooms. Sometimes moving the child to the front of the class can help. Some affected children find it takes time for their eyes to adjust when going from outdoors to indoors. Visual aids like magnifiers and access to the zoom function on an iPad can help. Many children will need to read material in an enlarged font size.

Because of the vision loss, they can suffer with tiredness later in the day, which is why it's a good idea to try to arrange assessments and test in the morning. Depending on the extent of their visual impairment, they may also need longer when undertaking exams and assessments.

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

It can also take them longer to get to each of their classes so they may need to leave classes five minutes before the other pupils. During break time it is difficult for a child with WS to avoid collisions with other children who are running about, and so they tend to isolate themselves and keep out of the way. Providing these children with safe and calm areas during break times can be helpful.

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

1. making an assessment of the child's education needs in relation to their visual impairment
2. offer advice on how to teach and make the curriculum accessible
3. offer training and support to enable the child to be fully included in school life and make the progress that is expected of them
4. advice and support around the use of specialist equipment and skills such as Braille, Touch Typing and use of low vision aids
5. help children move around safely in the school environment by providing mobility training.

Multi-sensory impairment:

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

Chronic fatigue:

Because the condition causes chronic fatigue, parents/carers dropping affected children off at school may need access to the car park, to ensure the child doesn't have to walk too far.

They find physical exercise difficult, mainly because of vision loss but also because the condition can cause chronic fatigue. Their lack of ability during physical education sometimes means they are excluded or ignored by the other children. Encouraging

children to participate in PE is especially important as research suggests that keeping a child as healthy as possible can actually slow the progression of the condition. Activity Alliance (https://www.activityalliance.org.uk/) can provide schools with inclusion training, giving them strategies to encourage participation.

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

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

It is important to remember that children with WS do not have developmental delay, and with the right support they have the potential to achieve good GCSE grades and move onto higher and further education along with their peers.

Summary

In summary, there are many different ways a school can support a child or young person with WS to get as much as possible from their experience at school:

✓ Sit them closer to the teacher/white board

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

✓ Allow them an extra time to get to each class

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

✓ Provide a safe and calm environment during break times

✓ Allow them extra time for exams

✓ Try to schedule exams and assessments for the morning, when their eyes are less tired

✓ Encourage them to participate in PE

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

✓ Provide an area close to the school for parents/carers to drop them off and collect them.

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

Educational Healthcare Plan/Statement of Special Needs

If your child has not got an Educational Healthcare Plan (England) or Statement of Special Needs (Wales and Scotland) please contact the WSUK Family Support Co-Ordinators or look at the local offer for your local authority. The local offer is exclusive to the local area to support SEN and disabled children. You can learn more about the local offer here https://fisd.westminster.gov.uk/kb5/westminster/fis/advice.page?id=pIWyNZV0rjU