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.

The medical information was produced with guidance by Prof Timothy Barrett Wolfram Syndrome Children's Professional at Birmingham and Dr Renuka Dias Wolfram Syndrome Children's Clinical Lead at Birmingham Children's Hospital.

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

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SECTION 9

Meet the Experts

Meet the experts:

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

 **Geneticist**	Contribute to the diagnosis and treatment of genetic disorders. They evaluate patient medical histories, perform genetic testing, analyse test results, and provide recommendations for managing or treating genetic conditions. Geneticists collaborate with other healthcare professionals, to ensure accurate diagnosis and develop appropriate treatment plans.
Transition	It is often used as a way to describe growing up and managing changes at key points in your life, while living with Wolfram Syndrome. This includes all sorts of things such as: changing schools, choosing a career, making new friends or managing your emotions. It also includes planning with you and preparing you for your eventual transfer to adult services. It is a gradual process that gives you, your family and anyone involved in your care, time to get you ready to move (transfer) to adult services and discuss what healthcare needs you will require.