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Warwickshire School Health & Wellbeing Service

June 2021 Newsletter

Rare diseases and genetic conditions

In this newsletter, we're raising awareness of rare conditions, diseases and genetic disorders. With 1 in 17 in the UK affected by a rare disease at some point in their life, and 1 in 25 children affected by a genetic disorder, chances are someone you know has a rare condition: this could be someone at school, a friend or family member. These conditions can be isolating and are often poorly understood by most people, which impacts the support provided. By increasing our understanding and empathy, we can reduce stigma and ensure we are there for the people in our lives should they ever need our support.

Offering support with rare conditions

Rare diseases and conditions can take many forms, with a vast array of possible symptoms. Because of this, there's no one-size-fits-all way of supporting someone with a rare condition. However, the following tips may help:

- Get to know the individual and allow them to tell you about their condition and ask for support on their own terms, if and when that's what they want. Try not to bring up any unusual symptoms they may have: let them lead the conversation, listen, and let them know you're there for them if they ever want your help.
- Research the condition using reliable sources. A good place to start is Rare Disease UK - **this page** outlines how you can verify information and provides links to relevant organisations. However, remember the individual will often be the one who knows their condition and how it affects their life the best.
- If their condition affects their daily living experience, help accommodate them by choosing activities that will be suitable for them when you spend time together.
- If someone has a child or close family member with a rare condition, often having someone they trust to talk to can be a help. Support them by making time to talk and showing you are listening. If you yourself have a family member with a rare condition, look for **support groups** where you can meet others in the same position.

Guides

Practical guides for families affected by a rare chomosone or genetic disorders

Guides to a vast range of rare & unique chromosone and genetic disorders

Support Services

Genetic Alliance UK - finding support for a rare or genetic condition (and what to do if no support group exists)

JIA - useful websites for families and young people

SWAN (Syndrome Without a Name) - the specialist network for UK families of children and young people affected by an unnamed or undiagnosed syndrome.

Want to receive parent/carer health & wellbeing updates directly to your inbox? Sign up here.

Juvenile Idiopathic Arthritis (JIA)

What is JIA?

JIA is a rare autoimmune disease. There are many types of autoimmune disease: in JIA, the immune system attacks the body's cells and tissues and causes swelling and pain in the joints which can be debilitating without effective treatment. A diagnosis of JIA not only affects the individual, but their families too. In the UK, JIA affects about 1:1,000 children, with 1:10,000 children being diagnosed each year – that's about 1,500 children.

What are the symptoms of JIA?

Symptoms of JIA can include intense joint pain and stiffness, swelling, fatigue, fever, rashes and unexplained weight loss. JIA can affect a child's mood and development: young children may not be able to verbalise their symptoms, but may show signs of being in pain, unhappiness and tiredness.

Continuous treatment is required to manage the condition and keep it under control. JIA can limit an individual's opportunities and experiences: however, with the right diagnosis, treatment and support from a team of experts, children and young people can enjoy a normal life.

#WearPurpleforJIA - Friday 18th June

The annual Wear Purple for JIA day is not just an opportunity to fundraise, but also to raise awareness about JIA among friends, colleagues and your community. Hundreds of people around the UK have taken part, organising purple-themed games, bake sales, newspaper articles, radio segments and school events, to name but a few ways of raising awareness and understanding of JIA. Get involved by asking your school to support the cause by allowing pupils and staff wear purple clothing on Friday 18th June 2021.

Genetic disorders

There are many rare genetic disorders: it is thought that there are currently more than 6,000 diagnosed disorders and new disorders are being identified every day. It's estimated that 1 in 25 children is affected by a genetic disorder. This means that in the UK, 30,000 babies and children are newly diagnosed each year and more than 2.4 million children and adults are living with a genetic disorder.

An example of a rare genetic disorder is **Angelman Syndrome.** Angelman Syndrome affects the nervous system and causes severe physical and learning disabilities. A person with Angelman Syndrome will have a near-normal life expectancy, but they will need support throughout their life. In most cases of Angelman Syndrome, the child's parents do not have the condition and the genetic difference responsible for the syndrome happens by chance around the time of conception. It is usually diagnosed between 9 months and 6 years of age, when signs of delayed development and other symptoms become apparent. You can learn more about Angelman Syndrome with this film from Angelman UK: **'Behaviour in Angelman Syndrome'.**

Angelman Syndrome is just one example of many uncommon genetic disorders that affect children, young people and adults across the UK.

Stories: living with a rare disease, condition or syndrome

Read real stories from people who have been affected by their own or a family member's disease, condition or syndrome.

JIA - Hallie's Story

Hallie Jane Jenkins is 8 years old. She was diagnosed with JIA in 2016 just after her 6th birthday. Her legs would ache an awful lot when she walked and one morning she woke up and her left knee was very very swollen and painful.

Angleman Syndrome - The 15-year-old helping to care for her step-sister

Teenager Katrina Shiell helps look after her step-sister Rhian, who has the genetic disorder Angelman syndrome.

Children with the world's rarest diseases

Imagine having a disease so rare it doesn't have a name - or even another person with the same diagnosis.

Did you know...

1 in 17 people will be affected by a rare disease at some point in their lives. This amounts to **3.5 million people in the UK**. The majority of rare diseases have no effective treatment. On average, it takes over four years to receive an accurate diagnoses of a rare disease. There are many people affected by genetic, rare and undiagnosed conditions and syndromes that are poorly recognised, understood and/or treated.

Source: raredisease.org.uk/what-is-a-rare-disease

Get your child's voice heard and make a difference

The Children's Commissioner for England, Dame Rachel de Souza, is launching a once-in-a-generation review of children's lives. It's called 'The Childhood Commission' and it will identify the barriers preventing children reaching their full potential and propose policy solutions to address them.

At its heart is 'The Big Ask' – the largest ever consultation held with children. In this survey, the Children's Commissioner is asking children and young people what they think is important for their future and what is holding young people back. The Children's Commissioner will use what children and young people tell her to show the Government what they think and what they need to live happier lives. **Find out more and take part.**

Coronavirus (COVID-19)

Get the latest government guidance here, including details of current restrictions and any local guidance. Remember, you can continue to help prevent the spread of COVID-19 by physically distancing from others, wearing a face mask when indoors in public, washing your hands regularly, and getting the vaccine when you are eligible to do so. Find out more about the COVID-19 vaccine.

Other useful links

NHS advice and symptom checker

WCC family guidance

Support accessing food in Warwickshire

Young Minds advice on talking to children about coronavirus

Coronavirus resources for autistic people

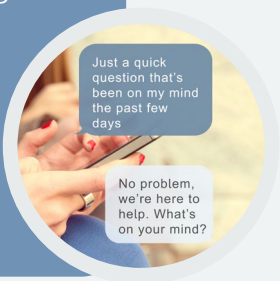
Get in touch for support

Your school nurse team is here to support children, young people and parents/carers in Warwickshire with a wide range of health and wellbeing topics. Please use the details below to contact us, or find out more on our website. Our office hours are Monday to Thursday 9am-5pm and Friday 9am-4.30pm. If you text outside these times, we will get back to you when the office is open again.

Parents/carers
Service mainline: **03300 245 204**
Text Parentline: **07520 619 376**

Young people 11–19 years
Text ChatHealth: **07507 331 525**

You can also refer your child to the service using our new referral form.



Follow us on twitter for health & wellbeing updates: @SchoolHealthC4H

Additional support from Family Lives

Family Lives is an organisation we work with who can provide additional support to Warwickshire families around any aspect of family life via a free supportline, online chat, email support and online forums. **Find out more.**