

JDRF: Here to support the type 1 diabetes community

JDRF is the world's leading type 1 diabetes charity and we won't stop until we create a world without the condition. Until that day, we will continue to fund about £60 million of world-class medical research each year to cure, treat and prevent type 1 diabetes. We make sure that research moves forward and that treatments are delivered to patients as fast as possible, and we give free support to help those who live with the condition and their families.

Healthcare professionals and parents alike will be no strangers to the difficulties faced by children and young people (CYP) living with type 1 diabetes, which could lead to serious psychosocial issues, including isolation, social pressure and depression (Frank, 2005). Our support to adults, CYP, families and teachers is therefore vital in ensuring that people living with the condition manage it effectively and stay happy and healthy.

Support for children and young people

Our support pack for children, the KIDSAC, remains popular for newly diagnosed CYP and their families. Along with information for parents, the KIDSAC includes Rufus, the bear with type 1 diabetes, which

helps young children learn and practise where to take blood tests and inject insulin on his patches.

We've recently added a book called *Type 1 Diabetes Made Simple: A kid's guide to type 1 diabetes*, written by Claire Pesterfield, a paediatric diabetes nurse at Addenbrooke's Hospital, Cambridge. Using simple language and cartoons, it introduces key issues relating to type 1 diabetes. It can also be downloaded online.

Cliona O'Connell, mum of Bebhinn, age 4, said:

"Rufus and the KIDSAC arrived on Monday. Thank you so much! Bebhinn and Rufus have been inseparable since he arrived and he has helped so much with her injections in such a short space of time. It's astounding! We really appreciate you sending the pack to us."

Harry Millward added:

"Rufus just arrived for my daughter who was diagnosed last month, aged 4. Thank you SO much. She is pretending to give him prick tests and jabs on his 'patches'. He is helping her come terms with her diabetes in a way just not possible otherwise. Thank you."



Dan Farrow
Community Engagement
Manager, JDRF



The KIDSAC pack for newly diagnosed children and their families.

“Our support to adults, children and young people, families and teachers is vital in ensuring that people living with type 1 diabetes manage it effectively and stay happy and healthy.”

Clinics across the country hand out a KIDSAC to newly diagnosed children, or the pack can be ordered for free at: <http://jdrf.org.uk/KIDSAC>.

Teaching the teachers

Type 1 diabetes is an often neglected and misunderstood issue among CYP and schools in the UK. It can lead to feelings of isolation from fellow pupils, and parents have even reported that their child has been bullied as a result of the condition. There are also many cases where parents have had to move schools because a good level of care was not being met.

Therefore, our brand-new school packs aim to take away the worry from parents by providing their children’s schools with the information and support they need. Created with the help of parents, CYP, healthcare professionals and teachers, the packs provide information on managing type 1 diabetes in school, as well as curriculum-linked lesson plans to help teachers to raise awareness among their classmates. It also includes plans for school assemblies, student cards to share information with teachers and other students about hypos, and information leaflets for parents of friends to help them understand the condition and to give them the confidence to include children with diabetes when they are making plans for parties or playdates.

As well as our packs for parents, we’ve also joined up with the National Children and

Young People’s Diabetes Network to create an e-learning module for teachers (available at: <http://type1diabetestraining.co.uk>). There are two courses in the module, both of which are certified for continuous professional development. The first aims to teach a basic level of understanding of type 1 diabetes, the signs and symptoms of hypoglycaemia and hyperglycaemia, and how to support CYP with diabetes. The second course focusses on best practice when monitoring glucose levels and how to administer insulin using a range of devices.

All of the school support packs are free and can be found at: <http://jdrf.org.uk/schools>.

Helping newly diagnosed adults

Our Type 1 Toolkit continues to be popular with teenagers and adults. Our most popular feature is *Straight to the Point: An in-depth guide to living well with type 1 diabetes*. This book, which can be ordered on its own, includes information about how to manage type 1 diabetes in many aspects of life, along with advice on how to avoid complications.

Chris, who has type 1 diabetes, was pleased to receive *Straight to the Point*. He said:

“It covers everything I can think of that I would want to know about at diagnosis and more for the future. It gives a huge amount of information in a very compact book, so it doesn’t look too daunting.”



The Type 1 Toolkit.

Many life stages create potential problems for people with type 1 diabetes. Our support aims to guide them through the unknown, providing advice on how to manage their condition effectively, whatever life throws at them. A Diabetes Specialist Nurse added:

“The packs are very inspirational and we are looking forward to giving them to patients.”

The free toolkit and book can be downloaded at: <http://jdrf.org.uk/toolkit>.

University life

For many teenagers, university is the first time away from home. To avoid the temptation to forget about their type 1 diabetes, we're creating an online site for students to obtain all the information they need about managing the condition effectively during uni life. We're working with university student services and accommodation providers to educate and provide relevant support. This covers everything, including meeting new people, medical care, insulin storage, alcohol, drugs and smoking, sex, exam stress, studying abroad and exercise. The university toolkit can be accessed at: <http://jdrf.org.uk/university>.

Starting a family

Starting a family is an exciting time in many people's lives, but it's often a worry for women with type 1 diabetes. That's why we've created a guide to provide all the information a couple needs to consider before, during and after pregnancy. The toolkit was written with the help of healthcare professionals and mums who have healthy, happy babies. Karen from London said:

“The toolkit was very useful. Pregnancy with type 1 diabetes is a daunting prospect, so it's

encouraging to know that, with some extra management, it is totally achievable to have a healthy baby.”

The pregnancy toolkit can be downloaded at: <http://jdrf.org.uk/pregnancy>.

Meeting others with the condition

Our Type 1 Discovery Days are well attended by people with type 1 diabetes across the country, making it the perfect event to meet locals with a connection to the condition. It covers talks on the latest type 1 diabetes research and inspirational stories from others.

We also hold Type 1 Discovery evenings, which are popular among adults with the condition. The informal evening, held in a pub, provides a series of short presentations about research, life with type 1 diabetes and all that comes with it, and it is a chance to meet others over some drinks and nibbles.

A family who came to a recent Discovery Day said:

“It was an emotional drive home as we relayed to Leo and Faith all the information and the realisation that Leo's life could change so positively in a matter of years. We thank you for continuing that hope for so many like Leo.”

A list of all our upcoming Type 1 Discovery events can be found at: <http://jdrf.org.uk/discover>. ■

Frank MR (2005) Psychological issues in the care of children and adolescents with type 1 diabetes. *Paediatr Child Health* 10: 18–20

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Talk to us

We're continuing to grow our national team to deliver all this support to people affected by type 1 diabetes across the country. For more information about the support we provide, call us on: **020 7713 2030**, or email: outreach@jdrf.org.uk.

All of our free support packs can be ordered online at: <http://jdrf.org.uk>.

