

Adjusting to a new diagnosis of type 1 diabetes (support for children, young people & families)

Department of Paediatric Psychology

Information for Patients and Families

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Being diagnosed....

A diagnosis of type 1 diabetes can be a huge shock for the whole family. Young people, their parents and siblings are suddenly tasked with taking on board lots of new information and making practical changes to day to day routines. Some young people will have been unwell for some time, creating added pressure and concern for the family. These experiences can be incredibly stressful, and it is normal for families to experience a range of emotions.

As a family you may feel a sense of loss, sadness, anger, confusion, guilt or denial. In some cases young people and families blame themselves, even though a diagnosis of type 1 diabetes is no one's fault; it can happen to anyone at any time. These feelings are common and they are a normal response to adjusting to a big change. The process that follows diagnosis is a journey of adjustment as young people and their families get used to living with diabetes in their lives.

Your young person's journey

A young person's experience of their diagnosis and the challenges they face, will depend upon their age and stage of development. Very young children will not understand that they will have diabetes for life, nor why they cannot eat sugary snacks whenever they feel like it. Adolescents, on the other hand, will be managing different challenges, like loss of freedom and independence, as they find themselves relying more on family members, school support staff, and healthcare professionals to help manage their care.

For all young people, a diagnosis requires learning new skills and having to make significant lifestyle adjustments. This takes time and energy and can feel like a big challenge. Your diabetes healthcare team are here to help you overcome any challenges you may face and to offer support at different stages of your journey. We know that there is a lot of information to take on board during the first few months after diagnosis, and that this can feel very overwhelming and often leave families worried about "getting it right". We encourage you to share with us how you are coping so we can help. Seeking support is an important and normal step in a family's journey to adjusting to diabetes.

Our vision: *"To empower children and their families to manage diabetes so that they can continue to live a healthy and happy life".*

How we monitor your journey

We know that young people and families will face different challenges along their way. Our diabetes team will carry out regular check-ins with you and your family to explore any difficulties you may be facing. As a team we will monitor your young person's emotional health and provide additional support when needed. We will also give your young person a short questionnaire about their emotional wellbeing at their annual review appointment. This helps us screen for any difficulties and offer support early on.

Often we see difficulties occur when young people or families experience changes. Common examples might include - moving from primary to secondary school, transitioning through puberty, exam time, family challenges or losses. These changes may contribute to difficulties in emotional wellbeing. If you find that your young person is struggling to adapt to any of these changes, please talk to a member of the team.

Common signs of difficulties may include:

- changes in mood, such as feeling sad, worried or angry a lot of the time.
- changes in behaviours, such as withdrawing from friends, not wanting to go out to places or to partake in activities or hobbies.
- sleep or appetite difficulties.
- family arguments e.g. when diabetes becomes a battle ground.
- school difficulties, such as falling behind with studies, getting into trouble frequently, friendship problems or bullying and not wanting to attend school.

As a team we aim to



Support and empower your young person to manage their diabetes throughout childhood and into adult life.



Understand the highs and lows of having diabetes and the difficulties young people can experience as they adjust to the diagnosis.



Work with families and young people to build coping skills and resilience in dealing with the common challenges of living with diabetes.

Meeting others with type 1 diabetes

It can be really helpful for young people and their parents to meet other families living with diabetes. Below are the details of some local groups you could become part of....



This is a grant funded group which offers a variety of sports to children and young adults with type 1 diabetes. Friends and siblings are welcome, and support for parents and carers is also offered. Find us on Facebook 'T1 Access to Sports', or email: T1accesstosports@gmail.com



The Highs and Lows Choir

This is a choir for 6 to 17 year olds who either have, or live with someone who has type 1 diabetes. If you don't want to come alone you're welcome to bring a friend. The choir practices from 7 to 8pm at Attenborough Arts Centre in Leicester. Find them on Facebook, 'Highs and Lows Leicester Children's Diabetes Choir', or contact Sarah on 07984 278 909 for more details.



Hinckley Coffee Mornings

Coffee Mornings - contact Rachel on 07929 012 206 for more details, or join the Facebook group 'Type 1 Diabetes parent support group, Hinckley'.



Leicester Parents Group

Leicester Parents Group are linked to Diabetes UK as a community group. The Facebook page 'Leicestershire Parents Group' can be used to put you in contact with other families and you will find information about local events. You can also email them on info.lpgdiabetesuk@gmail.com

Useful resources...

Social Media:

We now have our own Paediatric Diabetes Team twitter page @CYPD_UHL which offers up to date information and guidance. There are other social media platforms with online support groups for people with diabetes. They are a great way to connect with others who have similar experiences, and to offer support for children and parents.



Facebook

Type 1 Diabetes Support & Information
The Insulin Gang
Diabetes UK
T1 Access to Sports
Type One Teens
Parents of Type 1 Teens in the UK
Parents of Type 1 Uni Students and Young Adults



Twitter

@CYPD_UHL
@LYDIASARA19
@inputdiabetes
@JUSTDUK1T
@Faulkner_alysa
@ninjabetic1
@DiabetesSocMed
@JDRFUK



Youtube

<https://www.youtube.com/user/journalistjen>



You can also download the Leicester Children's Hospital app. The app gives you lots of information about coming to the hospital and about your diabetes team. There are lots of resources to help you manage your diabetes.

Blogs: <https://typeonewriters.wordpress.com/>

Books:

- What to do When You Worry too Much - by Dawn Huebner.
- The Anxiety Survival Guide for Teens - by Jennifer Shannon.
- Get Out of your Head and into your Life for Teens - by Ciarrochi, Hayes & Bailey.

Websites:

- **Type 1 Resources** <https://www.t1resources.uk/home/>

A collection of resources for people with type 1 diabetes. The resources are reviewed by healthcare professionals and updated regularly.

- **Diabetes UK**

School - <https://www.diabetes.org.uk/guide-to-diabetes/your-child-and-diabetes/schools/parents>

Going to University - <https://www.diabetes.org.uk/guide-to-diabetes/young-adults/university>

Living Life - <https://www.diabetes.org.uk/guide-to-diabetes/young-adults>

- **DigiBete** www.digibete.org this is a video platform and social enterprise created in partnership with the Diabetes Team at Leeds Children's Hospital.

- **Health for Kids/Teens** <https://www.healthforkids.co.uk/>

<https://www.healthforteens.co.uk/> offers health advice and support through online webchat and school nurse texting service. They give information on feelings, growing up, health, lifestyles, relationships, sexual health and local services.

- **Young Minds** <https://youngminds.org.uk/> a charity aiming to support children and adolescents' mental health. Offers free texting service for young people in crisis, and a parent helpline. It also provides information and support around several psychological conditions commonly experienced by young people.

- **Centre for Fun and Families** <http://www.cffcharity.org.uk/> uses group work to support parents, carers and teenagers who are experiencing behavioural and communication difficulties.

- **Connections** <http://www.leicester.gov.uk/connexions> Tel: 0116 454 1770 provides a careers service for young people who live in Leicester City, aged 16 to 19. Offers specialist personal advisers trained to work with young people with special educational needs or disabilities (SEND), up to the age of 25, to help them make decisions about their future.

- **Online counselling** www.kooth.com

This is an online counselling service for young people.

Encouraging words from celebrities living with type 1...

"It's frustrating having diabetes, but it doesn't stop you doing anything."

Henry Slade (rugby player)

"I've always had the opinion that everyone has something to deal with and there are worse things than being diabetic."

Jeremy Irvine (actor)

"Everyone with diabetes is in my eyes a bit of a legend."

Jonny Labey (actor and dancer)

"Children in the UK with diabetes are special people. Having diabetes makes us stronger."

Amelia Lily
(X Factor singer)

"Bread I can bolus for, cheese I can bolus for, but for some reason when they're all together (pizza) it's this magical thing that I can never get right. It's insane, what is that?"

Este Haim (singer)

"I have a much better quality of life because I'm more focused on my diabetes. Yes it's more work, but I feel a lot better about it."

Ed Gamble (comedian)

"I think my diabetes has definitely made me stronger. It's a big contributor to my character as a person."

Nick Jonas (singer and founder of Beyond Type 1)

Psychology and diabetes in Leicestershire

We have 2 part-time psychologists who provide specialist support to the Children's Diabetes Team. Our psychologists offer group and individual work sessions to help young people adjust to their diagnosis, manage diabetes related distress, and improve confidence in skills needed for diabetes care. They can also support young people with low mood and anxiety, as well as family, relationship or school difficulties connected to diabetes.

If you think your child would benefit from psychological support then please discuss this with any member of the team.

Feedback from our young people & families

"They took my worries seriously and acted quickly."

"I felt comfortable talking to someone new and I found it easy saying how I feel."

"Without the help we wouldn't be where we are today."

"The group was a really good atmosphere. I would recommend it to others. The adults were really nice and caring and I enjoyed meeting other YP with diabetes."

"My daughter has seen things from a different perspective."

"My son worries less about unnecessary stuff and learned that he needs to take care of his diabetes."

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔
على هذه المعلومات بلغةٍ أخرى، الرجاء الاتصال على رقم الهاتف الذي يظهر في الأسفل
જો તમને અન્ય ભાષામાં આ માહિતી જોઈતી હોય, તો નીચે આપેલ નંબર પર કૃપા કરી ટેલિફોન કરો

ਜੇ ਤੁਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਭਾਸ਼ਾ ਵਿਚ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਹੇਠਾਂ ਦਿੱਤੇ ਗਏ ਨੰਬਰ 'ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ।

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