HEALTH FOR TEENS

NHS
Leicestershire Partnership
NHS Trust

Adjusting to a new diagnosis of type 1 diabetes

Information for young people and their families or carers.



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….

Highs & Lows Peer Support Group

Our peer support group is a way of meeting other young people and families who understand the daily challenges of living with Diabetes.

We aim to offer a range of activities to suit all ages, interests and backgrounds.

Instagram:

Highsnlows_support_group

Email address: Highs and lows group@gmail.com

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

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

Useful Resources:

Websites:

Diabetes specific resources include:

- Type 1 resources https://www.t1resources.uk

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

- Diabetes UK Main charity in UK focused on curing and preventing diabetes, as well as helping people to live well and longer with the condition. Their website also lists local support and peer groups and events.
School - https://www.diabetes.org.uk/guide-to-diabetes/your-child-and-diabetes/schools/parents

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.

Digibete How to hold a hedgehog is a video to help young children understand the emotional impact of diabetes and how it can be managed. **www.digibete.org/content/page/how-to-hold-a-hedgehog**

BreakthroughT1D Research – please visit for further diabetes knowledge and treatments and resources on navigating life with a diagnosis**. https://breakthrought1d.org.uk/**

Health and Wellbeing resources:

Health for Kids/Teens

- https://www.healthforkids.co.uk/
  https://www.healthforteens.co.uk/

Both websites offer 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.

Tellmi

Online mental health and wellbeing community where young people can access free, safe and anonymous support.
www.telmi.help

Young Minds

Young Minds is 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.

https://youngminds.org.uk/

Heads Up Leicester

Heads Up Leicester uses group work to support parents, carers and teenagers who are experiencing behavioural and communication difficulties.

https://www.headsupleicester.org.uk/

Harmless

They help you to address and overcome difficulties related to self-harm and suicide. You can visit their website at harmless.org.uk.

The Mix

This is a support service for young people and you can talk to them via their online community, on social, through their free, confidential helpline or their web counselling service. You can visit their website at www.themix.org.uk.

SHOUT

SHOUT is a free, confidential 24/7 text support service. Text 85258.

https://giveusashout.org/

Alumnia

Is a free online support for 10-17 year olds offering online 7 week course for young people struggling with self-harm. Each course has up to 14 young people, all accessing the sessions from their own phones, tablets or laptops across the UK. **–** **www.selfharm.co.uk**

What's Up? A mental health app

Offers information and help on anxiety, depression, self-esteem and stress. It teaches mindfulness, thought challenging, grounding, breathing control and includes an online forum and helpful websites and links for young people in crisis.

www.thewhatsupapp.co.uk

Calm Harm

Provides tasks that help you resist or manage the urge to self-harm. The app helps you to learn self-control, care rather than harm, express your feelings in a different way and provides safe alternatives to self-injury. It is completely private and password protected.

https://calmharm.stem4.org.uk/

Self-Help for Anxiety Management (SAM)

Uses a range of self-help methods for people who are learning to manage their anxiety, including information about anxiety, self-monitoring tools, relaxation and tips on putting self-help into practice.

Other useful resources...

Social Media:

Why not follow our social media account?
Search for '**healthforteens_leicester'** on Instagram to stay up to date with our latest content.

Blogs:

- https://typeonewriters.wordpress.com/

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

YouTube

- https://www.youtube.com/user/journalistjen

Books for Children and Young People

- *Daisy Donald by Jade Byrne* is a story book about a 6-year-old girl with type 1 diabetes who uses her superpowers to empower her by taking control of diabetes. **Available on Amazon.**
- *How to Manage a Mammoth by Dr Rose Stewart* is a picture book for young children and families living with diabetes containing ideas and tips around ways to manage living with diabetes. **Available at Blackwells.** See also link to animated version of the book—www.digibete.org/how-to-manage-a-mammoth
- *Type 1 Origins Comic by Revolve Comics* is a free to download comic book series of the journey of being diagnosed with type 1 diabetes. **Available at www.revolvecomics.com**
- Get Out of your Head and into your Life for Teens - by Ciarrochi, Hayes & Bailey
- *The Boy, the Mole, the Fox and the Horse by Charlie Mackesy* is a book of quotes promoting positive wellbeing and life lessons for all ages. **Available at Amazon**
- Books on anxiety - *The huge bag of worries by Virginia Ironside / What to do when you worry too much by Dawn Huebner / The anxiety survival guide for teens by Jennifer Shannon.* **All available on Amazon**

Resources for Parents and Carers

Services

- Early Intervention Service (EIS) – Offers a range of support interventions for children and young aged 5-18 years and parents/carers. The service aims to promote positive mental health, increase healthy coping strategies,

and encourage communication and support. Telephone: 0116 2543011. Email: reception@rllr.org.uk.

- **The Relationships Centre (Formerly Relate)** - For young people who are unhappy, unsettled or struggling because of conflict within the family or other family issues. This service is available to all young people, aged 8-18 years. Telephone: 0116 2543011. Email: reception@rllr.org.uk.
- Citizens Advice LeicesterShire - They can provide general advice on housing, cost of living, debt and help with budgeting. Website: www.citizensadvice.org.uk. Telephone: 0808 2787970. The telephone lines are open 9am – 4.30pm Monday to Friday.
- Saffron Lane Neighbourhood council - Offer free, independent advice, information and advocacy on debt and money advice, welfare benefit and welfare rights, and housing issues. Website: srcentre.org.uk.

Support Groups

The Highs & Lows Support group is a local group, supported by Diabetes UK, and is for children, young people and parents in Leicester, Leicestershire and Rutland. Friends and siblings are also welcome.

Facebook: T1 Access to Sports
Email: highsandlowsgroup@gmail.com

Books for parents/carers

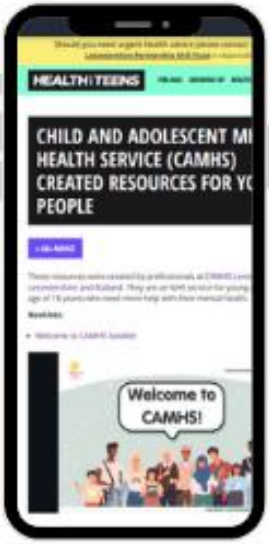
· *The Incredible Teenage Brain by Bettina Hohnen, Jane Gilmour & Tara Murphy* - Everything you need to know to unlock your teen's potential. **Available on Amazon.**

· *Grounded by Claire Wilson* – Discovering the missing piece in the puzzle of children's behaviour. **Available on Amazon.**

· *The Stress Solution by Dr Chatterjee* -The 4 Step to calmer, happier, healthier you. **Available on Amazon.**

Want to learn more about CAMHS and the support we offer? Check out the **CAMHS collection on the Health for Teens website**! It's a space made just for you with all the information and resources you might need, anytime you need them.

https://bit.ly/CAMHSLeicester



Psychology and diabetes in Leicestershire

We have clinical 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. You may receive a telephone call, see the psychologist in your usual clinic appointment or have a separate F2F appointment.

Feedback from our young people & families

"They took my worries seriously and acted quickly."

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

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

"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."

If you need support with your diabetes, support is available from:

Non-urgent support:

9am – 5pm Mon – Fri
(excluding Bank Holidays)
Children's Diabetes office: 0116 258 6796

Leave a message for the Diabetes Nurses with your name, telephone number and a brief message.

Out of hours service:

Available weekdays **after** 5pm and Bank Holidays

Call Hospital switchboard on: 0300 3030 1573.
Say your child has diabetes and ask switchboard to put you through to the 'Children's on-call Registrar'.
Explain to the doctor what your concerns/problems are. The doctor will then give you advice on what to do.

For Urgent Mental Health Support and advice

- If you need urgent mental health support, you can call NHS 111 and press option 2 or visit https://111.nhs.uk/ and follow the on screen instructions. This service is totally free and confidential. Families can call NHS 111 and choose Option 2, 24 hours a day, seven days a week and speak to a qualified call handler if they require advice around urgent mental health concerns for children and young people. Please note however that the NHS 111 line is not an emergency service. Where there is an immediate, serious and life-threatening emergency, call 999 or attend A and E.

- In office hours you contact your GP to make an urgent appointment – GP can refer to Crisis Team.

- SHOUT - Free, 24/7 text messaging support wherever you are in the UK. If you need someone to talk to about how you're feeling, text YM to **85258.**

- To talk with someone confidentially about how you feel you can ring HOPELINEUK on **0800 068 4141** or the Samaritans on **116 123.**

We warmly welcome any comments and suggestions you may have. To share your feedback, feel free to speak with a member of our team, fill out our Friends & Family Test or reach out to our Patient Advice and Liaison Service (PALS). For more information, please visit www.leicspart.nhs.uk/contact/patient-advice-and-liaison-service-pals/.

Our Patient Advice and Liaison Service (PALS) and Complaints Team is here to help you with any compliments, questions, comments, or concerns you may have relating to our services. They can also:

- Provide confidential advice and support to patients and service users, their families and carers
- Listen and respond to any compliments, comments or suggestions Provide information about services and local support groups
- Help to resolve concerns on your behalf
- Give you information on how you can get involved in helping us to develop our service

If you would like to speak to them, you can contact them on:

- 0116 295 0830 (Monday to Friday 9.00am – 4:30pm) You can leave a voicemail message at any time, and they will call you back.
- lpt.pals@nhs.net

You can use the ReachDeck, our accessibility toolbar if you are accessing this leaflet electronically. ReachDeck is especially useful to people who have a hidden disability, such as dyslexia (or other reading difficulties), have a visual impairment or have English as a second language. You can visit www.healthforteens.co.uk/about-reachdeck/ to learn more about ReachDeck. If you would like to access this leaflet digitally, please speak to a member of our staff.

If you need help to understand this leaflet or would like it in a different language or format such as large print, braille, or audio, please speak to a member of our staff.

Why not follow our social media account?
Search for '**healthforteens_leicester'** on Instagram to stay up to date with our latest content.

Here are some useful resources for young people and their families or carers:

SCAN ME	Information discussed during appointments will be kept confidential (this means we will keep your information within certain limits). Please scan the QR code or visit www.leicspart.nhs.uk/privacy-policy/ to learn more about our Trust's privacy policy.		
	lptnhs.com/ MHSupport		lptnhs.com/ WhileYouWaitCAMHS
	lptnhs.com/CAMHS Leicester		www.healthforteens.co.uk

Date Implemented:
Last Review:
Review Date:
Leaflet No:
Website: www.leicspart.nhs.uk
Email: feedback@lecispart.nhs.uk