

Living with diabetes

Living with diabetes can be a challenge at times. It can feel a bit like having a full time job without a break. Having to spend a lot of time thinking about what is going on in your body can feel frustrating.

Why do I feel like this?

Do I need to eat something?

Most of the time you will feel able to cope with these thoughts and feelings with the support of your family, friends and healthcare professionals. However, always having to check your blood sugar levels can leave lots of people with diabetes feeling fed up and tired. This can lead to '**diabetes burnout**'.

Can I play sports?

What are my blood sugars doing?

What is diabetes burnout?

Diabetes burnout can happen at any time, especially when you have lots of other things going on in your life, like exams, school pressures or relationship problems. When life is stressful, caring for your diabetes can feel less of a priority. You may find yourself:

- ignoring high blood sugars.
- forgetting to check your blood sugars.
- eating and drinking things without giving yourself the right amount of insulin.
- avoiding talking with family members or healthcare professionals about your diabetes, or getting into arguments.

On burnout...

"For me it was the constant monitoring of BGs and wishing to gain a break from it so I could push forward with other things I was striving for in life."

"You almost have to come to terms with the fact that you are going to feel 'burnt out' once in a while."

What are the effects of diabetes burnout?

Diabetes burnout can leave you feeling rubbish, both emotionally and physically. It can have a serious impact on your health, cause high blood sugar levels and may lead to diabetic ketoacidosis (DKA) and a stay in hospital. Your family and school life might also be affected.

Things you need to know...

Diabetes burnout is normal and **not** your fault. The other things going on in your life may affect how motivated you are to care for your diabetes.

Feelings like stress, anxiety, guilt, low mood, anger, frustration, resentment, shame and helplessness are common and often experienced amongst people living with diabetes at some stage.

Your diabetes team are here to help. Talk to us and let us know how you are feeling. We want to know about your worries and fears when you come to clinic.

*Asking for help
is not giving up.
It is refusing
to give up.*

Here are some thoughts from some of our young people living with diabetes:

"I have realised, it's not my fault, there isn't any shame attached to not getting it right. It is hard work, and it takes up a lot of time and energy."

"If you can overcome burnout you can do anything... it makes you stronger mentally."

"It takes resilience and determination to overcome burnout. It is constant and rubbish, but when you overcome it, it is great."

10 Top tips!

Here are some tips to help you stay motivated and on top of your self-care:

1

Let people know how you're feeling

Talk to your family and your diabetes team. Be honest about your experiences, so you can get the support you need.

2

Build a support network

Find people who will help and encourage you. That might include friends as well as family and your diabetes team. You can also use social media to access support for young people with diabetes. There are some links and hashtags for you to follow at the end of this booklet.

3

Try breathing exercises and relaxation

Notice how your breathing becomes quicker when you're feeling stressed or frustrated? Try to slow it down by imagining you have a balloon in your stomach. As you breathe in, the balloon inflates and your stomach expands. As you breathe out, the balloon deflates and your stomach relaxes. Use the following apps: **Stop Breathe & Think Kids; MyLife Meditation; Calm; What's Up?**

Let it out!

There are lots of positive things you can use to express your feelings of frustration. Keep a journal, create some art, play or listen to music, practice sports, punch a pillow - whatever works for you! Use the **Catch it** app to log your feelings and change your thoughts.

4

Do more of the things you enjoy

When we feel low or worried, we often stop doing things that make us happy. Make sure you set aside time to do things that make you smile, even if you don't feel like doing them. Download the **#Reason2** app, and post your reason to be happy. Or try the Positive Steps session on the **What's up?** app.

5

Self-care

6

Do something nice for yourself everyday, whether that's simply enjoying a hot bath, listening to your favourite music, reading a book or doing a mindfulness meditation. When diabetes is not going well it's easy to be hard on yourself. **Remember, nobody is perfect!** To keep things in perspective. Make a list of 3 to 5 positive things in your life each day, however small, and celebrate them! The 'My Diary' section on the 'What's Up?' app is great for this.

Set yourself a goal

Think about the changes you want to make and set yourself a small goal, then break it down into achievable 'stepping stones'. For example:

Goal: To check my blood sugars before school.

Steps:

1. Set alarm 10 minutes earlier.
2. Leave blood testing kit by side of bed.
3. Ask Mum/Dad to bring me a cup of tea to celebrate achieving my goal!

9

Use a problem solving approach

Think: What is the problem?

Example: Going to school without having my insulin because there isn't enough time.

Take action: Write down 3 solutions to the problem. Weigh up the pros and cons of each problem before picking one to try. Remember, problems often get bigger if left, so take positive steps!

8

Remember why it is important

When you're juggling so many other things in your life, it's easy to forget why looking after your diabetes is important for you. Make a list of your own reasons, for example: 1) It means I have more energy for things I enjoy; 2) It means my parents worry less; 3) I can apply for my driving test; 4) I could help other people with diabetes.

Talk to a psychologist

You can request to talk to one of the psychologists in the diabetes team. They will be able to offer you further support and guidance.

10

Useful apps... There are lots of things you can do to help manage your feelings and emotions about your diabetes. Apps can be a great way to record your thoughts, learn relaxation and mindfulness techniques and help you achieve your diabetes related goals.



Leicester Children's Hospital

This app gives you lots of information about visiting the hospital and about your diabetes team. There are also lots of resources to help you manage your diabetes.



Calm

Uses guided meditation, sleep aids, relaxing sounds, music and stories to enable better self care. There is a section for young people and for parents.



Stop, Breathe & Think Kids

Uses missions to develop superpowers of quiet and focus to help younger children have more peaceful sleep.



My Life Meditation by Stop, Breathe & Think

Uses meditation, mindfulness, relaxing music and sleep aids for all ages. It enables you to check in with your emotions and makes recommendations based on how you feel.



Catch it

Uses a diary to help you record your mood and teach you how to look at problems in a different way.



Deapp

Offers a structured educational course where patients and families can learn about type 1 diabetes and use that knowledge to help manage their condition themselves.



Headspace

Allows you to complete a few minutes of meditation every day, with targeted sessions on physical health, personal growth, stress management and anxiety relief.



#Reasons2

Helps you to create a personal profile and record your own reasons to be happy by posting images, photos and recording your achievements.



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.



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.



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:

We now have our own Paediatric Diabetes Team twitter page @CYPD_UHL which offers up to date information and guidance. There are many 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 offer support for children and parents.

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



Twitter

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



Youtube

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

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>

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.

Psychology and diabetes in Leicestershire

We have 2 part-time psychologists who provide specialist support to the Children's Diabetes Team, Dr Emily Robinson & Dr Louise Brittenden.

They offer 1:1 support and group sessions for young people who require support with their diabetes care. They work closely with the rest of the diabetes team, and they can attend your clinic appointment. They can help with a range of issues including:

- diabetes burnout.
- low mood and anxiety related to diabetes care.
- difficulties following your treatment plan.
- family, relationships or school difficulties.

If you would like to speak to one of the psychologists, please ask a member of the team, who will put you in touch.

Feedback from our young people & families....

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

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

"They took my worries seriously and acted quickly."

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

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

"Lovely staff, easy to get along with and more than helpful."

"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."

Meeting others with 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 us 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

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)

If you need urgent psychological support...

- **General Practitioners**

Call your GP surgery. Currently, many GP surgeries are offering telephone consultations in the first instance.

- **NHS helpline 111**

If you need help urgently, NHS 111 can offer you advice over the phone. They can also offer appointments with out of hours doctors.

- **Emergency Department**

In a life threatening situation, if you are struggling to keep yourself safe, you can go to the Emergency Department or call 999.

- **Helplines**

Samaritans (freephone 116 123) or Childline (0800 1111) – they also have an online chat.

You can text a public health (school) nurse for confidential health advice (Leicester City - 07520 615 386) (Leicestershire and Rutland - 07520 615 387).

Leicester Partnership Trust have a Central Access Point (CAP), offering urgent mental health support for people of all ages in Leicestershire. Contact them on 0116 295 3060.

- **Online counselling and resources**

Visit www.kooth.com to chat with an online counsellor.

Visit these websites for advice and resources relating to emotional wellbeing:

www.youngminds.org.uk www.healthforteens.co.uk

www.healthforkids.co.uk

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔
على هذه المعلومات بلغة 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।

Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu

If you would like this information in another language or format such as EasyRead or Braille, please telephone 0116 250 2959 or email equality@uhl-tr.nhs.uk