

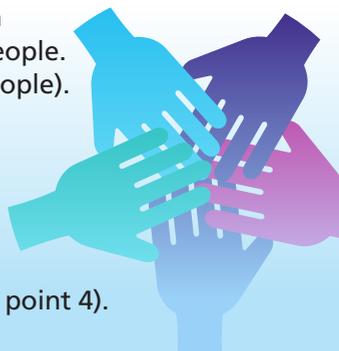
# Your life, your way with type 1 diabetes

Created by people with type 1 diabetes to support you through the emotional, mental and physical aspects of living with the condition.



## 1 You're not alone

- There are almost 400,000 people in the UK with type 1 diabetes (T1D), that's one in every 167 people. Globally, it's 41 million people (or one in 190 people).
- It is a natural response to feel alone when you are living with T1D, especially if you don't have people in your life who know about it and are interested in supporting you.
- If you feel alone, please note there is support out there for you (both online and offline – see point 4).



## 2 Your diabetes is not your fault

- T1D is an auto-immune condition. This means your immune system mistakenly attacks insulin producing cells in your body.
- Please remember that you did NOTHING to cause your T1D. Don't blame yourself or let others blame you.
- It is normal to feel a range of emotions (including confusion, anger, shock, guilt and denial) when you find out that you have T1D. These feelings are common and may come and go throughout your life. Allow yourself time and space to come to terms with your diabetes.



## 3 Be kind to yourself

- T1D can affect you more emotionally than you may first realise. It's equally important to give yourself the time to focus on your emotional wellbeing, as well as your physical health.
- Learning about diabetes is like learning a new language, you won't be fluent straight away. You will make mistakes and learn something new every day.
- Diabetes can be tough, there is no shame in seeking help, as soon as you need it.
- Be proud of what you do everyday, remember you are doing the job of a pancreas!



## 4 It's important to find support

- You may find it helpful to connect with other people who know what it is like to live with T1D.
- In addition to the advice you get from your diabetes team, do your own research. The more you know, the better you'll be able to live well with T1D. Ask your team about courses – e.g DAFNE and BERTIE etc that are available to you (see point 10).
- Don't feel ashamed to ask for help from someone you trust, managing diabetes is best in partnership, the earlier you seek help the better.
- **Diabetes distress** and **diabetes burnout** are real and shouldn't be dismissed (see point 10). If you ever feel burnt out, speak to your diabetes team and see if they can offer you psychological support.
- Diabulimia, eating disorders and self-harm with insulin may develop. If they do, please ask your diabetes team for psychological support (more info [here](#)).



### Support and Social Media

- There is a huge T1D online community where you can find information and support. There is no need to share anything personal.
- Do question what you read on social media. Avoid following people with extreme views, especially those promoting products to cure T1D (ie cinnamon), or those who post perfect sugar levels (see point 5).
- Speak to a trusted healthcare professional before you act on any information you find online.



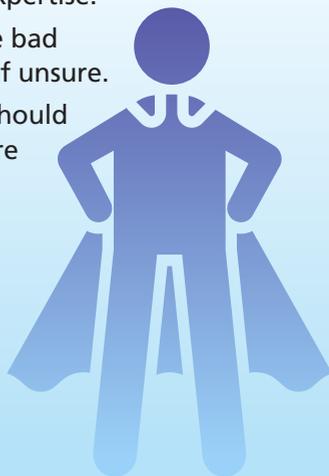
## 5 You are more than your highs and lows

- There are over 42 factors affecting blood glucose (see point 10), many of which you can't control, so know that you have not failed when glucose levels are high or low. Don't feel guilty or let anyone judge you (including your healthcare team).
- T1D will never define you as a person. You are so much more than a number.
- Everyone's diabetes is different, so try not to compare with others.
- Every day will be different, celebrate the good days and accept the bad days will happen.
- Don't chase perfection, it is a myth and doesn't exist in T1D or life.



## 6 You will become an expert and an advocate for your diabetes

- As you learn more about the condition yourself, you find out what works for you and it might be different to what is in a textbook.
- You'll receive a lot of well-meaning but unsolicited advice about the choices you make. Be confident to manage the way that works best for you, this will grow as you gain experience and expertise.
- Learn who to trust and be prepared to challenge bad information. Do speak with your diabetes team if unsure.
- Know your rights (point 10) and what care you should receive. You may need to assert yourself to ensure your care needs are met and to get jargon-free information that makes sense to you.
- **There are lots of new technologies available to support your diabetes (e.g pumps or sensors). Ask your team what is available on the NHS.**
- Employers and places of education are required by law to make reasonable adjustments to help you live with diabetes (see point 10).



## 7 Your life, your way

- T1D shouldn't be a barrier to stop you from doing anything you wish in life, it just changes your approach to doing it.
- It will take more planning, but people with type 1 can have children.
- Keep up your activities and hobbies and know that you can still go travelling. You may need to do some extra planning beforehand though, or get a travel letter from your healthcare team.
- Follow the diet you want: the best diet is one you enjoy, sustain and afford and keeps you well in the lifestyle you want to lead.
- You are unique and how your body responds daily to living with T1D will be individual to you, so work closely with your diabetes team to discover what works best for you.



## 8 My blood glucose is low, what next? (blood glucose below 4mmol/L)

- Get specific individual information from your team about how to treat your hypos. (see **this resource** from Trend UK for more information about hypos).
- Symptoms vary but can include feeling shaky, sweating, pale, hungry, irritable, blurred vision.
- It helps to understand that if you are recently diagnosed you may still be producing some insulin (**honeymoon phase**).
- If you don't know why you are having frequent hypos or unsure what action to take, contact your team for support. You may need to have a glucagon injection prescribed if you are having severe hypos (family members and carers should be shown how to use it) see this resource [www.glucagenhypokit.com](http://www.glucagenhypokit.com)).
- Make sure you let your family, friends and colleagues know what to do if you are having a hypo and the signs they should look out for too.
- If you have a severe hypo and become unconscious, you will need immediate emergency treatment. Someone should dial 999 for an ambulance. You should be put on your side with your head tilted back. Glucose treatments should **NOT** be put in your mouth.



## 9 My blood glucose is high, what next?

- Symptoms vary but can include feeling: thirsty, tired, blurred vision, infections, peeing more, losing weight.
- Steroid treatment, being ill, stress and infection may increase blood glucose. Its really Important to test more often and adjust your insulin dose.
- Know your sick day rules and when to check for ketones. More information [here](#).
- Be aware of diabetic keto-acidosis (DKA). If you start vomiting, are unable to keep fluids down, or are unable to control your blood glucose or ketone levels, you must seek urgent medical advice. **DON'T STOP TAKING YOUR INSULIN EVEN IF YOU ARE UNABLE TO EAT.**
- If you have continually high sugar levels, it is important to stay hydrated with lots of water.
- If worried about consistently high sugar levels then speak to your diabetes team.



## Key resources – Please click the links to find out more

- Know more about type 1 diabetes
- Courses to learn about type 1 diabetes
- Online and offline support
- [www.nhs.uk/conditions/type-1-diabetes/get-support](http://www.nhs.uk/conditions/type-1-diabetes/get-support)
- JDRF the type 1 diabetes charity
- Diabetes UK (charity)
- Diabetes burnout and diabetes distress
- Your legal rights
- Employment and diabetes
- Visual nutrition guide – carbs and cals app and book (including world foods)
- Diabetes and exercise – running or other exercise
- 42 Factors that affect your blood sugar level
- Good diabetes apps
- Other type 1 diabetes guides (1. For going into hospital and 2. For parents and carers of children with type 1)





© Developed with over 250 people living with diabetes, carers and healthcare professionals working with people with type 1 diabetes.

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email: [ruth.miller2@nhs.net](mailto:ruth.miller2@nhs.net)

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