How to banish diabetes burnout

Tips for young people with diabetes and their families

Deborah Christie, Professor of Paediatric and Adolescent Psychology at University College London Hospitals, on how to avoid “burnout” from diabetes for young people with the condition and their families.

Burnout can do everything it can to stop teenagers and young people looking after the self-management of their diabetes, and it can push parents of families affected into a spiral of feeling nothing is good enough. It can make people dread going to the clinic as it encourages you to feel guilty if glucose (blood sugar) levels are not “good enough”. Don’t despair! There are ways to turn down the burn and get life back on track.

Living with diabetes requires a lot of effort on the part of the young person who has the condition (whether type 1 or type 2). They need to think about what they eat, take the “right” amount of insulin and manage exercise. This can be very tiring as it takes a lot of effort. Young people who take on most of the responsibility for managing diabetes may notice they miss clinic appointments, forget to take their insulin, or stop bothering to pay attention to what they are eating, or what their blood sugar levels are. This can lead to tension and arguments at home if parents get worried and start reminding their child what needs to be done, which, in turn, can often have the effect of increasing any feelings of frustration. Young people with diabetes often tell me: “On the one hand I want to, and on the other hand I don’t want to,” or “I know I should, but I just can’t be bothered,” when describing the self-management of their diabetes. They can get more and more fed up and unhappy with the situation, with a common complaint being: “The harder I try the worse it gets.” Burnout can have the effect of making young people suffering from it appear to be difficult, non-compliant or “bad”.

Coping with diabetes as a family
Parents, siblings and families often get forgotten when a family member has diabetes. They have to live with diabetes too. Parents of younger children usually need to take on most of the management – even when their child is at school. Parents of teenagers have to balance encouraging independence with worry about safety and “letting go”. Burnout makes parents and young people with diabetes feel that the condition has taken over. It can feel like there is no way to deal with the endless attention the condition demands.

Burnout in parents has the opposite effect to young people. Rather than forgetting to do the things that need doing, parents cannot stop thinking about them. Constant worrying about getting blood sugar readings “right,” constant testing 24 hours a day (especially in younger children) and constantly reminding and checking levels. For most parents this is a “normal” state of affairs. But when they become completely exhausted and frustrated and distressed about “never getting it right” then the flames of burnout have been ignited.

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The following tips are designed to help ease the management of diabetes for the whole family:

1. Noticing burnout is giving you a hard time is the best place to start
You might feel more stressed than usual, you might feel anxious or your mood might be a bit lower than usual. You might notice that you are feeling angry about things or getting into arguments. You might have lost interest in things that you used to enjoy doing. Is this OK? If the answer to this question is no, then you’ve taken the first step towards getting your life back on track.

2. Be kind to yourself and focus on the solutions, rather than the problems
No one can be perfect all the time so if you have a day when you don’t get everything exactly right and remind yourself that you can start again tomorrow. Write down what has gone well - even if it is nothing to do with diabetes - even if it was only for a couple of minutes. Diabetes is just one small part of your life and you are not your diabetes. What have you managed to do? How come? What made this one small positive step possible? Was it something you did, or said, or something someone else did or said? Keep track of these sparkling moments and forgive yourself for the things that do not go so well. You are only human!

3. Ask for help
Don’t suffer in silence. Get some support. Family, friends (and co-workers) can only help if you let them know what you need them to do. Find someone you trust to let you take a few hours off. Get someone to share the jobs like checking blood sugar readings at night-time. Get your diabetes team to put you in touch with another parent so you can swap a night of babysitting with each other. Burnout loves making people feel like they are isolated - so don’t let it win!

4. Negotiate a “diabetes holiday”
Teenagers that are exhausted trying to remember to take insulin and count carbohydrates every day can take a short holiday and let an adult take care of things in the evenings for a few days or weeks. Work out what is helpful, such as counting carbohydrates together at a meal, or calculating the amount of insulin to take. Work out what isn’t helpful, such as being asked constantly if a particular food is the “right” food to be eating, or whether or not you have done your blood glucose readings. Swap your pump for injections done by someone else for a short period of time (you must talk to your diabetes team if you are going to do this one). Be creative, but give yourself permission to “take a break” from the constant need to pay attention, which is the nature of diabetes self-management.

Parents can take a holiday too. Ask your partner or family member to take over from you for a few days. I know lots of parents often feel they are the only one managing things at home and have very little support. So ask another parent from your nearest diabetes clinic for help - or perhaps organise a sleep over so you can have a night off, go out for dinner, go to the pictures, go out for a coffee, have a massage or a manicure. It doesn’t have to be much. Give yourself permission not to be “on the job” for as little as an hour. You can always repay the favour when they are feeling “singed” by burnout themselves.

5. Keep things in balance
Who are you keeping diabetes under control for? Is it your clinical team or is it for you? Work out the pros and cons for you of not letting burnout win. You may want to have good blood glucose control to reduce the risks of diabetes complications, or to stop your parents or partner or doctors nagging you. But try and remind yourself what matters to you and how to make the benefits of not letting burnout win relevant to your own hopes and dreams, hobbies and interests.

6. Use your diabetes team
Don’t suffer in silence. You are not the only person living with diabetes who is feeling like this. Your diabetes team will help you think of practical ways to manage the effects of burnout. And if they don’t, then think about changing teams! Ask to speak to a psychologist if the team has one. Look at what support groups are available in your area. Ask your diabetes team to help you start up a group if there isn’t one available where you live.

7. Use the power of your mind
Mindfulness can help understand, address and overcome the mental and emotional impact of having diabetes, including the emotional and psychological conditions that give rise to diabetes burnout. If your healthcare team cannot offer a course then have a look on the internet for what might be available in your area.

8. Connect with others
Social media can be a force for good and bad - so ask others what websites they find helpful. Check out blogs and websites for suggestions and advice. Do the stuff that works for you and ignore the stuff that doesn’t.

More information
Try the free app Stop, Breathe, Think at: http://www.stopbreathethink.org/

Teenagers may also enjoy reading The Mindful Teen by Dzung Vo

Beyond Type 1 - “highlighting the brilliance” of people with type 1 diabetes: www.facebook.com/beyondtype1

Parents might find the Children with diabetes website helpful at: https://www.facebook.com/groups/UKCWD/

Talking online and meeting other young people who are also battling burnout as well as those who have successfully overcome it can help motivate you. Ask your diabetes team to organise a Tree of Life workshop (http://bit.ly/2j98Sc5), or a “social” where you can meet other people so you don’t feel like you are the only one struggling.

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About the author
Deborah Christie is a Professor of Paediatric and Adolescent Psychology. She has worked with children and adolescents for over 25 years at Great Ormond Street Hospital for Sick Children and University College London Hospitals. Deborah is passionate about working with children, adolescents and their families to help people find new preferred positive stories about their future lives. She is an inspirational motivational speaker and loves working with medical teams to help them engage positively with young people about diabetes.