

Looking after yourself while looking after them

Shirley Garland's nine-year-old son was diagnosed with Type 1 diabetes when he was just two. She helps to manage the Facebook page for the parents of children and teenagers with Type 1 diabetes, which currently has over 3,000 members. She feels very strongly about the importance of parents looking after themselves, as well as their child. Here, in her own words, she explains why

The day you are told your child has Type 1 diabetes comes as a huge shock. Your child will suddenly be admitted to hospital for up to a week and when they are discharged, it feels like you have been cast back to the role of new parents leaving the security of the maternity hospital with your first baby. Except this time you are armed with needles and insulin rather than nappies.

At the time of diagnosis, the hospital deals very much with the here and now, depending on how ill the child was at the time they presented. Those few days are spent educating parents about Type 1 diabetes, focusing on how to manage it daily at home.

After the initial shock, many of us will do our best to be positive, for our child's sake if not for our own. We throw ourselves into learning about insulin dosing, carb counting, finger pricking and ketones. We may call our bosses at work and say we need a week off, or perhaps 10 days, while we stay in hospital with our child and 'get it all under control'.

Once home, there are some time consuming things that have to be done, like paperwork. You will be introduced to a world that involves the Long-Time Illness

card and perhaps the Domiciliary Care allowance.

If your child attends school, you will need to contact it and advise them of the diagnosis and apply for SNA hours.

If you work, you may need to call your boss again and tell them that you won't be back for another week or so, especially since you are so tired as you hadn't realised that you would need to get up every night, perhaps more than once, to check if your child's blood glucose levels are stable.

Multitasking and not accepting help

As a mother, I am used to multitasking, but many of us do not accept help and believe we can do it all ourselves. However, nobody really explains the relentless nature of caring for a child with Type 1 diabetes. The younger the child at diagnosis the more years of caring is required, and the higher number of hours of sleep lost and time spent worrying and doing diabetes-related 'stuff', which can at times be all consuming. We become very caught up in learning it all.

Before we know it, six or 12 months can go by and nothing much seems to have changed. We may have made it back to work, but might find ourselves

applying for reduced hours or taking carer's leave.

We may resign ourselves to accept that we won't be getting that promotion we had been working so hard towards or that this may not be the right time to plan for another baby. We may not be getting the support we need from our child's school and may even be required to go into the school every day to administer insulin. We may also have a problem finding a childminder who is confident to care for a child with Type 1.

The first-year slump

At some point in this first year, no matter how positive we felt at diagnosis, nearly all of us will feel despair and exhaustion. It will dawn on us that this is not going away no matter how much we do or how hard we try. We all have to accept that Type 1 diabetes has become an invisible member of our household, the eternal uninvited guest who always demands our attention and time.

Many of us very understandably end up falling into a trap of mental and physical exhaustion at some point by the end of that first year.

We may have gained a lot of weight through comfort eating or a lack of time



to plan and cook healthy meals, or we may have lost a lot of weight through stress and lack of time to eat properly.

We may find ourselves crying for no reason, or for a very good reason, and we may be snappy and irritable. Our other relationships may suffer and our other children may be suffering from a lack of attention or from worry about their sibling. They may be acting out and causing us even more stress and friends, family and work colleagues often have little comprehension of the enormity of it all.

We may give up going out with friends as we are just too tired to stay awake at night, or we may feel suddenly that our lives have nothing in common any more.

Addressing burnout

Speaking from a mother’s point of view, I know that many of us experience burnout. We need to take time out to build ourselves back up again. Very little advice is given at the time of diagnosis about the importance of looking after ourselves and yet this is key. If we cannot look after ourselves, how will we look after our child?

In my case, it was about 15 months in before I ended up flattened in bed for

a fortnight with the flu. I was a walking target for it. I was doing everything myself day and night for my son who was diagnosed just after his second birthday, while still looking after my other five children, a long-term live-in foreign student, and working as a childminder.

I was burnt out and it took me all of that winter to climb slowly back out of the deep hole, which I had unwittingly helped to dig for myself.

True to form, I insisted on learning the hard way, but thankfully, I have a husband more than willing to share our son’s care once I allowed him to help. He was more than able to step into the breach and take a lot of the pressure off me when I needed it, and yet up to then, I felt somehow that it was my responsibility and mine alone, and that I was letting my son down if I didn’t do it all.

While the guilt is unfounded, many mothers will blame themselves for something they did or did not do when pregnant, or afterwards, to cause their child to develop this condition.

When I speak to parents now whose child is newly diagnosed, I always mention the importance of looking after themselves from the day of diagnosis.

Get somebody else to sit with your child in hospital while you go home and have a shower and a hot dinner. Get out of the hospital daily for a short walk in the fresh air.

Speak honestly and openly to your family for support. Show anyone who is willing, how to look after your child. Meet with your friends for a coffee or a walk and talk about how you are feeling. Go on a night out, but on those nights, try to forget about it all and get involved even if you don’t feel like it.

Accept invitations out even if you don’t feel like it. It’s so important to try to keep your own life ticking over while you come to terms with all the other changes.

Have date nights with your partner if you have a babysitter you can trust to mind your child. You don’t have to go far from home if you still feel anxious. Even just go for a walk around the block to have a chat and keep in touch. See how long you can go without talking about diabetes!

One of the biggest strains in caring for a child with Type 1 diabetes is that it’s a 24/7 job, 365 days of the year. You learn to sleep with one eye and ear open.

Share the care

Diabetes never takes any time off, which is why it's very important to have other family members trained in how to manage your child's care needs especially if you are a single parent. We are not machines and we cannot sustain full-time care on an open-ended basis.

It's crucial that there is at least one responsible trained adult that you can trust to look after your child in case of an emergency. This will also give you some peace of mind if you have this backup in place.

Over time, school can become a respite for parents, providing those few hours in the day where somebody else is responsible for monitoring blood glucose levels and giving you a few hours to get other things done. Although it is likely that you will feel the need to bring your phone with you just in case the school needs to contact you.

This is a prime example of where parents of children with Type 1 diabetes can never fully switch off unless their child is in the care of another adult that they trust implicitly.

We are constantly on alert and this is why it is essential that we take opportunities to unwind and relax, even when we don't feel like it. It is important because we are important and we need to remember to put ourselves first when we can.

Try to keep up any hobbies or interests you have, such as playing a sport or being a member of a club. Consider taking up something new, but make it something that you personally enjoy. While yoga may help some to de-stress, it may not be for you.

Think about whatever it was that you used to enjoy and see if you can build it back into your life. Do what makes you happy without feeling guilty for taking that time out.

Give yourself treats

On the days when you are feeling down and disheartened, give yourself little treats. Leave the housework and go out and buy yourself something nice or go window shopping. Treat yourself to a coffee in peace.

Acknowledge to yourself the amazing job you are doing. Look back at all you have learned and how far you have come since that day of diagnosis. Look at your child and recognise how well they are doing and feel proud for all you do for them.

Tell yourself every day how great you are. Refuse to entertain the negative thoughts. If you have made a mistake, well who hasn't? All you can do is your best and if you have tried your hardest and done everything you know to do and asked for help when you need it, then you can rest assured that you can do no more.

Diabetes at times has a mind of its own. We have no crystal ball. We can't see inside our children's bodies to know what is going on when blood glucose decides to act up. All we can do is our best.

Seek help and support

Finally, if you do feel that everything is getting on top of you and you are

struggling to cope, remember your supports and seek help. Speak to your child's diabetes team. Go to your GP. Attend a counsellor. Meet with other parents who have children with Type 1 diabetes or engage with them online in a support group.

I have been a member of an online support group for seven years now and find it invaluable. I have also had to speak to my GP about my stress levels and I have seen a counsellor to help me to find my way, as at times, I am overwhelmed by the feeling that this is not where I expected or wanted to find myself.

There is no shame in seeking help. Never suffer in silence as it will not benefit you or your child. The sooner you seek help, the sooner your life will improve. There is no rule book and we all need to adjust and find our own way, but help is out there. All you have to do is ask.

I cannot take away my son's diabetes no matter how hard I try but I am always so proud of him – he is brave and strong and he makes me feel humble at times for all he copes with.

I do everything I can to make sure his life is as 'normal' and healthy as it can be, but I also need to look after myself, so that each morning he has a mum with a smile on her face to greet the day.

