



“Every day you’re left thinking, ‘Did I damage him today?’”

Type 1 diabetes is a lifelong and potentially lethal affliction that has reached epidemic proportions. It is incredibly difficult to manage — young sufferers and their families tell their moving stories.
Report by *Caroline Scott*

WELCOME RESPITE
James Gilson, 3, plays calmly at home — but when his blood sugar level soars, he becomes angry and

As your children scoff their body-weight in chocolate coins at 5am next Friday morning, followed by half a selection box and that massive tube of festive pink Smarties (it’s Christmas! Who’s counting?), spare a thought for the parents of children with type 1 diabetes. For them the Christmas weekend will pass in a feverish blur of carbohydrate-to-insulin calculations.

You need to be an Olympian mathematician to keep up with Christmas grazing. The traditional lunch is carb-heavy, especially when you factor in pudding. But what if you’ve injected your three-year-old with the correct amount of insulin, then find he’s much too excited to sit down and eat? Suddenly you’re chasing him round the table trying to force-feed him juice or honey to correct the dose. And then you need to test again — another injection — to see if his blood sugars are back into normal range.

James Gilson was diagnosed with type 1 diabetes 18 months ago. At 20 months old his pancreas stopped producing insulin — and the grief is still raw. James proffers a minute finger so his mum can test his blood for sugars with a small digital device. And then we test mine: it’s a small puncture, but it hurts — and it goes on hurting for a while. James isn’t fussed. He does this 15 times a day and often more — a simple virus or the excitement of opening his stocking will send his blood glucose rocketing. A fine needle pierces the skin just above his nappy and this

is connected via a loop of plastic tubing to his insulin pump.

When he starts charging round the table, Kate can’t tell if he’s showing off or if the sudden burst of manic activity means he’s “high”, so she tests again, then corrects his insulin by reprogramming the pump, and she does this throughout the day and night. In a child this small, the difference between a high or a “hypo” (when his blood sugar runs dangerously low) might be 0.1 of a unit of insulin.

All the children I’ve met with type 1 deal with its incessant demands with heart-rending bravery; the older ones — outwardly anyway — with practiced indifference. But their sleep-shredded parents are less cool. Many use the word “rollercoaster” when they try to describe living with type 1 diabetes. Actually, it’s like clinging to a rollercoaster by your fingertips while wrapping your head around A-level biology. You need nerves of steel and a brain capable of grasping complex algorithms because it requires constant — at this age hourly — calculations and decisions about how much insulin to deliver with what carbohydrate ratio to keep blood glucose as close to its normal range as possible.

If that’s not complex enough, external temperature, stress, illness, exercise and general excitement all affect blood glucose and need to be factored in. Whether children have a pump like James (the needle needs changing every 48 hours) or inject »»»



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TAKING IT STEADY
Thanks to a new app, mumoActive, which monitors his blood-sugar levels, Angus Steed, 10, was back on his skateboard the day after he was first diagnosed

themselves with a pen (up to five times a day), it's a frustratingly inexact science and, in a growing child, insantly difficult to get right.

Parents with type 1 children get used to wearily trotting out stock responses — then after a while, not bothering: “No, he isn't having a tantrum, his blood sugar is through the roof. And yes, he does look well doesn't he? But really, he's not...” When the body is regularly bathed in blood glucose at two or three times the normal rate, it damages the tissues, particularly the small blood vessels in the eyes, the kidneys and those that supply the nerves in the hands and feet. And all this damage goes on silently. You end the day surrounded by notebooks filled with tightly packed figures, trying out to work out why the insulin dose that worked yesterday, sent blood glucose soaring to dangerous levels today.

The number of children diagnosed with type 1 diabetes — that's the genetic variety of the disease, not the one caused by an unhealthy diet — has been increasing year-on-year across the world for the past 50 years, to the point where it has now reached epidemic proportions. Britain has the fifth-highest incidence — after Finland, Sardinia, Canada and Sweden. There are now around 29,000 children with type 1 diabetes in Britain, more than double those in France: 1,000 new cases were reported last year with the highest prevalence in Wales and the South West. Karen Addington, chief executive of the Juvenile Diabetes Research Fund, a charity which tirelessly fundraises to find a cure, describes type 1 diabetes as “a condition that is still one of Britain's best-kept secrets’.

For the past three years the biggest increase has been in toddlers; this year that increase has flattened out and an increasing number of teenagers have been diagnosed with type 1. No one knows the reason for the explosion in numbers or the patterning. It's too fast to be genetic, although about 10% of cases of type 1 diabetes have a family history of autoimmune disorders. The closest scientists have come to unraveling the cause is to link it to environmental factors, possibly better hygiene, which may interfere with the body's immune response.

And while the rise has gone hand in hand with a mega increase in incidence of type 2 diabetes (the one linked to obesity) there is no connection between the two. Our confusion and ignorance over this drives parents of type 1 children to distraction. Type 2 diabetes is closely related to diet and lifestyle and mirrors the rise in childhood obesity. Type 1 is an autoimmune disorder — the body's defence system mistakenly attacks the insulin-producing beta cells in the pancreas: without insulin, glucose can't enter the body's cells to be converted into energy. There have been a flurry of breakthroughs — particularly in stem-cell

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research — but for those dealing with the disease every day it remains a chronic, life-threatening, lifelong disability with no known cure.

The Gilsons knew next to nothing about type 1 before James was diagnosed. When he started to drink copiously — downing one bottle of water after another — their GP suggested a urine test the following day to check for sugars, but in the end, things moved too fast.

James became floppy and unresponsive and at bed time they rushed him to A&E in just his pyjamas and a nappy. “As soon as we arrived they did a blood test — his blood-glucose level was 44 (the normal level is between 4 and 6). The room immediately filled with people,” says Kate. “I remember

asking the registrar: “Is he going to die? She said: “He's in a very bad way. I can't promise we can save him, but we're doing everything we can. It's just a very slow process.”

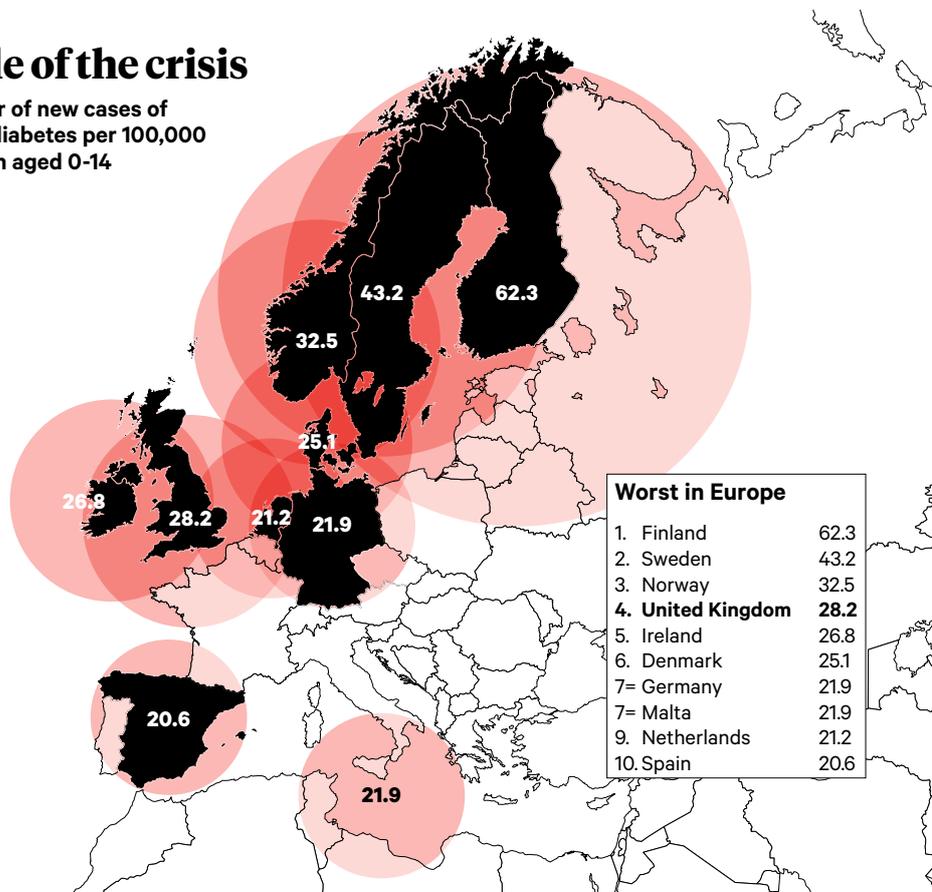
The family was in hospital for three days. “From 9am to 5pm we saw doctors, nurses, a nutritionist and a psychologist. It was too much to take in — and I'm an accountant — if you're not numerical, you'd struggle.” At home, everything was the same, but changed forever. “I heard the shop opening across the road, the dog barking, people going to work as usual and I thought: how can all this be going on when our life has fallen apart?” And on top of the sadness was a nagging guilt. “He could have died — but he hadn't. We'd been lucky, so why couldn't I cope?”

The sofa is covered in scratch marks made by James when food has hit his system faster than the insulin and his blood sugar has soared sky high, making him angry and upset. During highs like this, he's punched his mum and smashed a window upstairs with a toy hammer. Conversely, if he's eaten something that is slowly absorbed, the insulin might work too fast, leaving him sleepy and disorientated. His baby sister, Clara, is oblivious for now to the impact of all this on her life. “When your plans to go out go horribly wrong all the time,” says Kate. “After a while, you stop trying...”

When James goes down for his nap, Kate allows her guard to drop and tears stream down her face. Looking after him is so time consuming, she can't go back to work, so they struggle on Matthew's income from supply teaching. The financial as well as emotional strain is immense. ➤➤➤

Scale of the crisis

Number of new cases of type 1 diabetes per 100,000 children aged 0-14



Worst in Europe	
1. Finland	62.3
2. Sweden	43.2
3. Norway	32.5
4. United Kingdom	28.2
5. Ireland	26.8
6. Denmark	25.1
7= Germany	21.9
7= Malta	21.9
9. Netherlands	21.2
10. Spain	20.6

“We did everything we could to be good parents. We analysed the research about what age to wean, we obsessed about when he should have gluten... You work so hard so your child can have the best life and suddenly none of that matters. People think the hardest thing about diabetes is jabbing him with needles, but it isn't. The worst thing is putting him through all this and still not managing to keep good blood-glucose levels. You do the very best you can, but at the end of almost every day you're left thinking: did I damage him today?”

This year, for the first time, the National Paediatric Diabetes Audit (NPDA) reported on the health of diabetic children in Britain and the findings are shocking. Dr Justin Warner, clinical lead for the NPDA, warns that there is a “worryingly high” number of British children and young people aged 12 and over showing early signs of serious complications. Twenty-seven per cent of young people over 12 with type 1 diabetes have high blood pressure associated with heart attack and stroke, over 14% have early signs of retinopathy, putting them at risk of blindness and over 7% excess protein in their urine, indicating future kidney disease. And while the percentage of children with excellent blood-glucose control has risen slightly from 15.8% to 18.4%, that really isn't saying much — in Germany and Austria 34% have excellent control — that still leaves the vast majority — more than 80% of children in the UK — struggling with poor control, with the greatest concentration among teenagers.

Parents who have quickly become experts must learn just as fast to drop the reins when their children hit their teens. “I work with children of 4 or 5 who are furious about their diabetes and already beginning to resent the way it influences their relationships with their parents and their friends, and stops them doing things

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they want to do,” says Deborah Christie, consultant clinical psychologist at University College Hospital, London. “Diabetes interferes with every aspect of adolescent development: they talk about the burden of constantly having to think about it, of having to remember to do painful blood tests and give themselves injections, constantly being nagged, always being different.”

Emily Good, 17, was diagnosed four years ago at 13. “We were on holiday at the time and mum noticed the weight loss, the thirst, the incontinence. I lost a couple of stone within two weeks. She already knew what the diagnosis would be.”

“At first, I couldn't accept it,” Emily says. “I was petrified of needles. I spent days crying. Because I was 13, the doctors handed control to me, and that scared me a lot because I didn't know what I was doing. For the first year, I kept breaking down. I thought: why me? There's no family history. And I still do that because whatever you do, you never know if you're going to get the level right. I hate having to eat loads of food

when I go low, even when I'm not hungry. I feel so fat, it's horrible.”

Hormones play havoc with diabetes control. And Emily's body still creates small, but unpredictable, amounts of insulin which sends her low — earlier this week, she had a seizure on her way to college — her blood glucose had dropped to 1.1. But she also has periods when it stays high — above 20 — for weeks at a time, no matter how much she corrects. At the moment — it's 1.30pm — her blood glucose is 13. “Some days I don't eat lunch till 3 or 4pm because I don't need it. Also, I tend to forget to give myself insulin,” she says. “I just get on with life.”

Emily went through a phase of running her blood-glucose levels high so she didn't gain weight. “Then I realised the impact on my health, so I do try to keep them within normal range, it's just very hard.

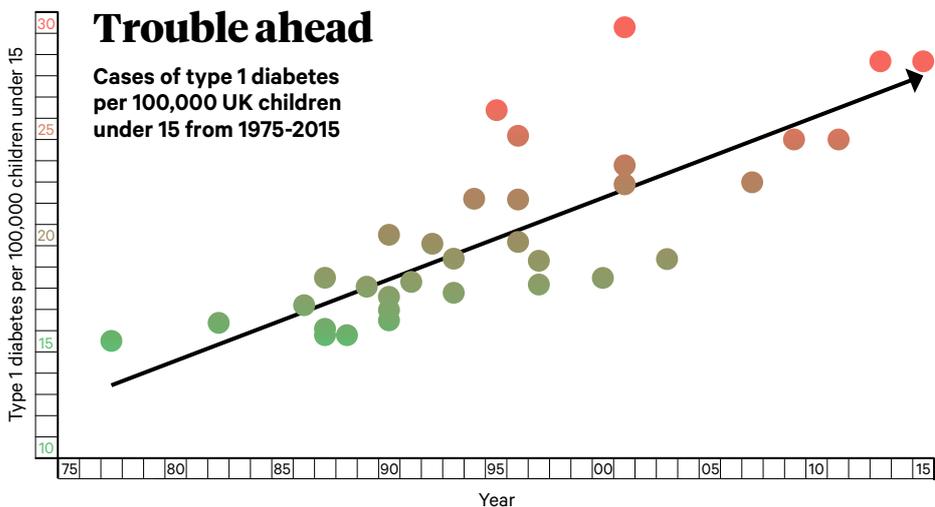
“Mum is not coping,” she says. “She hasn't for a while. And since the seizure, she's been really bad. She fusses about me going out, whether I've eaten, when I'm going to eat again. We have screaming rows when we just yell at each other — I understand why she worries, but I don't want her to run my life.”

The first year of Emily's A-levels didn't go well. “One teacher told me, ‘You can't take your insulin in class, you're distracting everyone else.’ It's not fair!” That teachers are not sensitive to the problem is a frequent complaint. Another child told me she had to keep her insulin kit, including her finger-pricker, in the school office, so she just stopped testing. Emily has dropped back a year and is studying for a City & Guilds diploma in animal management, which she really enjoys.

“I saw a young girl the other day who said, ‘I can't even put words to how much I hate diabetes..’” says Deborah Christie. “The effect of all this is that is that they'll ignore it, not do their blood tests, not do their injections and they get sick. The diabetes damages them and then they hate it even more. It's a vicious circle. And the longer you have poor control, the greater the risk of long-term damage.”

Yet bizarrely, there is no national mandate for standardised treatment; despite its prevalence, childhood diabetes appears to have completely fallen off NHS radar. “Fewer than one in five young people in the UK have adequate blood-glucose control — it is an absolute outrage,” says Christie. “We don't have proper education for doctors, we don't have standardised guidelines for healthcare professionals... Diabetes isn't just biological, it's a bio-psycho social condition. it requires good state-of-the-art medical care and good education, which is provided in many European countries at a much better level than here.”

Both blood-glucose machines and insulin injections are getting better and faster, and there are apps to help people with



TOUGH TIMES

Emily Good, 17, was diagnosed aged 13. "I kept breaking down. I thought: why me? There's no family history"



carb ratios. Pumps take away the bother of injecting — but a lot of teenagers can't hack them — only 19% use one. You can't have spontaneous sex with a pump attached to your stomach and anyway, you still have adjust your doses manually.

"We're trying to replace a very delicate, beautiful and complex body mechanism and the tools we have are just not good enough," says Professor Greene. "Diabetes remains an enormous challenge for most people."

Deborah Christie talks about "perfect poor control": a young person who regularly runs their blood-glucose levels so high — 12, 13, 14 — it makes doctors shudder. "They can't be bothered to give themselves as much insulin as they should so they inject just enough to keep themselves out of hospital. There are huge numbers of kids who fit into that group and they're very difficult to engage — as far as they're concerned they

don't have a problem, they feel well enough. They think they're bulletproof, but their parents are terrified they're going to end up with retinopathy and amputated limbs."

Harvard professor Doug Melton has been working on turning stem cells into insulin-producing beta cells since his own son and daughter were diagnosed with type 1 as small children. When, after 23 years of research, he announced in October last year that "We are just one pre-clinical step from the finish line," it was the diabetic world's equivalent of putting a man on the moon. But science moves at a glacial pace and no one is expecting a "cure" any time soon. In the mean time, scientists at Imperial College London have been given an NHS grant to trial a micro probe patch for continuous glucose monitoring (CGM) which painlessly measures the glucose value of interstitial fluid — the wet stuff between the cells.

"We regularly see people in their twenties and thirties who have lost their sight," says the researcher Dr Nick Oliver. "They express this heartbreaking regret that they didn't keep their diabetes under control, but it's tough for teenagers. The hassle, the pain and the stigma can be overwhelming."

Although the National Institute for Health and Care Excellence (Nice) has recommended CGM devices for some children, they're currently painful and often inaccurate, and few actually have them. I meet dozens of teenagers online who are testing their blood glucose once a day — some aren't testing at all.

Some use a long-acting "background" insulin just to keep themselves ticking over. I've met others who say they go for days using none at all. When their lips tingle and their legs go wobbly, they know they have to have a snack. "I know about the complications and they're scary," one 15-year-old told me. "But I still don't do it."

It doesn't have to be that way. Sheldon Steed and his wife, Alexandra, have a son Johnny, 6, who was diagnosed with diabetes in 2010 aged 17 months. When his brother, Angus, 10, started to run high blood sugars in January this year, they didn't go to hospital, they had a 45-minute appointment with a doctor and had him skateboarding again the next day. The reason the Steeds felt this confident is down to a new, free app: mumoActive, a communications-and-tracking platform designed by Sheldon when Johnny was first diagnosed and which the family now uses to continually monitor the blood sugars of both boys.

"When Johnny was diagnosed we were devastated," he says. "With diabetes, you don't know where your sugars are. No idea where they're going. He says now they have access to the information they need throughout any part of the day, so they manage "with power, not fear". He shows me a screen shot of Angus skateboarding the day after diagnosis, alongside a blue chart showing his sugars throughout the morning.

The platform lets you record notes, track and message people in a closed network. Some big London trusts are getting behind MumoActive and there are talks with NHS Scotland about integrating the service there. "If kids are giving themselves just enough insulin to stay out of hospital, then maybe with the right information in front of them they can know how much more to give so they aren't buzzing all the time from high sugars, but they can avoid hypos," he says. "But we have to make it easy and fast. The idea is not to show you how bad things are, but to get diabetes out of the way so you can get on with your life" ■