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'I just get on with it': Diabetes and daily life
A report sponsored by Novo Nordisk

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Section 1: Introduction

1.0 Introduction

This report, which has been compiled by Involve North East (INE) for Novo Nordisk, analyses the findings of research into the experiences of patients with Type 1 and Type 2 diabetes.

1.1 Involve North East

Involve North East is an independent charity working across the North East. We are experts in innovative and practical involvement, working with patients, communities and harder to reach groups to gain the insight needed to design the best, most responsive and most cost-effective health and social care services.

1.2 The project and its aims

The aims of this research are to explore the physical, social, emotional and economic impact of hypoglycaemia (hypos) and other complications on people with Type 1 and 2 diabetes.

The research will examine experiences of living with diabetes, including:

- The impact of hypos on daily routines, employment and exercise/food regimes
- Key challenges in medicine management
- The effectiveness of health professionals' contact with diabetes patients

1.3 The context

Diabetes is a very common life-long health condition. Recent estimates suggest that around three million people in the UK have been diagnosed with diabetes; and that an estimated 850,000 people also have the condition but are as yet unaware of it. A report published in 2010 by Diabetes UK¹ predicted that by 2025 there will be more than four million people with diabetes in the UK. The same report estimated rates of diagnosis at around 400 people every day – which equates to three new diagnoses every ten minutes.

While good diabetes management has been shown to reduce the risk of complications, poorly managed diabetes is associated with serious complications including heart disease, stroke, blindness, kidney disease, nerve damage and amputations leading to disability and premature mortality.

In order to meet the overall aims of the research, we asked participants to tell us about their experience of living with diabetes, focusing in particular on the management of hypoglycaemic episodes and other symptoms; their experience of taking medication and the impact of associated conditions; and the impact of diabetes on their daily life, including working life.

¹ Diabetes in the UK: Key statistics on diabetes, Diabetes UK 2010
http://www.diabetes.org.uk/Documents/Reports/Diabetes_in_the_UK_2010.pdf

Section 2 - Methodology

2.0 Methodology

In order to gain in-depth information about the views and experiences of a range of diabetes patients, we chose to take a primarily qualitative approach, giving participants the opportunity to describe their experiences and identify priorities that could inform future commissioning and treatment decisions.

2.1 Participants

We interviewed 26 people. Twelve of these had Type 1 diabetes and 14 had Type 2 diabetes.

Full profiles for the participant group are set out in Appendix 1.

2.2 Questionnaire

We developed a set of largely qualitative questions which we put to every participant in order to ensure that all participants were asked exactly the same questions. We chose not to ask for written answers, preferring to conduct individual telephone and face-to-face interviews and encourage participants to answer questions as fully and informally as possible. Conversations were recorded with participants' consent, and transcribed to provide verbatim responses in every case.

We spoke to 23 people by telephone, and carried out three face to face interviews. Although we had hoped to convene at least one focus group where participants could compare experiences, most interviewees were either in paid work or caring for young children, and it proved impossible to identify a time, date and location that a significant number could attend.

The questionnaire is included in this report as Appendix 2.

Questionnaire responses are set out in Appendix 3.

Section 3 - Findings

3.0 Findings

This section provides a summary of the findings of the research undertaken for this project.

3.1 Age at diagnosis

We asked participants to tell us how long ago they were diagnosed with diabetes.

Not surprisingly, most of our 12 Type 1 participants were diagnosed much earlier than people with Type 2. Ten were diagnosed with Type 1 diabetes before they were 20 (the earliest diagnosis came at 21 months, and seven people were aged 10 or younger), and all but one person was diagnosed before the mid-twenties. At the other end of the scale, one participant who believed she had a Type 1 diagnosis was not diagnosed until she was 48.

The earliest Type 2 diagnosis was at 23 years old, and in line with common patterns in the condition 64% of Type 2 patients had been diagnosed in their 40s and 50s.

Four Type 2 patients had been diagnosed within the last five years (one was diagnosed early in 2013).

3.1.1 Gestational diabetes

Two Type 2 participants had had gestational diabetes. In one case this had continued to affect her, and while the other participant's condition had appeared to correct itself after the birth of her child, it recurred when she was 52.

3.2 Hypoglycaemia (hypos)

Every Type 1 participant had suffered from hypoglycaemic attacks at some point, while 64% of Type 2 participants had had them.

3.2.1 Frequency

Two Type 1 participants reported that they were currently experiencing daily hypos. However, at the other end of the scale three of the Type 1 cohort had managed to reduce the number of their attacks down to four or fewer per year.

Two other Type 1 participants had begun to have more frequent attacks. For one person this had been caused by a change in work patterns:

“I’ve actually just changed departments at work and I’ve had quite a lot [of hypos] recently because I’m a lot more energetic at work so I’m trying to change my insulin regime to try and control that, but I’m not quite there yet. I’d say a couple a week at the moment”

The other participant whose attacks had become more frequent was less clear about the reasons:

“Up until I was 35, I didn’t have many, for several reasons, but probably partly because I didn’t take quite enough care of myself. And also because at the age of 35 my body seemed to change. I went from being able to go to the gym for two hours at a time, climbing mountains, things like that, to a 10-minute warm-up sending me having a blood sugar reading that went from 14 to 2”

Hypos were generally less frequent among people with Type 2 diabetes: eight of our 14 Type 2 participants had either never had a hypo or no longer have them, while nobody with Type 2 was currently suffering from daily or weekly hypos. One person, however, recalled having frequent hypos when she was first diagnosed:

“I don’t get them now. I used to have at least one a week, when I first went on the tablets. I was on three Metformin a day, but because I was so well controlled and completely cut out all the sugar, three tablets was too many and I cut them down”

3.2.2 Recognition of hypos

There appeared to be some variation in recognition or acknowledgement of hypos among Type 2 participants. Several people initially said they did not have them, but after hearing a description of common symptoms one person said:

“Well I do, then. I’ve just never put it down to that!”

Other people recognised the early warning signs of hypos and knew how to divert a severe attack, so did not consider that they suffered from hypos in spite of exhibiting common symptoms:

“I kind of have them. I control my diabetes purely by food. My battery quickly runs out . . . by the middle of the morning I start to go, it feels like being drunk for free. My head goes fuzzy and I can’t think straight so generally speaking I have a mid-morning snack or something”

“I don’t really get them, just slightly weak feelings only after I haven’t eaten for most of the day or something like that”

“I have not had any attacks since I was diagnosed, but I do get a bit shaky in the night”

3.2.3 ‘Allowing’ hypos to happen

For one Type 2 participant, her caring responsibilities meant that she did not feel she could allow herself to have hypos, and had had to abandon an attempt to lose weight in order to keep her blood sugar high:

“I used to get hypos quite frequently because I was trying to lose weight and reduce the insulin I was taking. I was doing it with the nurse at the hospital, and I was getting frequent hypos . . . Then my husband had a stroke in January and unfortunately he is no longer able to drive, it means I am now the only driver. So, in order that I can drive safely I do what a lot of people with diabetes do, I tend to eat something before I get in the car – which is putting the kibosh on my trying to lose weight. It means I am not getting any hypos, which is wonderful in a way but it’s a fact that I would still be losing weight if I wasn’t doing what I’m doing”

Another participant, a young woman who has been Type 1 for 10 years, had her own reasons for keeping her blood sugar high and avoiding hypos:

“I’m more likely to have a hyper because I hate hypos so much that I drink a lot of Lucozade to avoid them. I have a hyper about twice a week”

This was echoed by another participant whose blood sugar readings are routinely high:

“Sometimes diabetic nurses are saying you have to reduce your overall blood count. And I think ‘you don’t know what that’s like, to be having hypos all the time”

3.2.4 Severity

Given that different people can attach different levels of severity to similar experiences it is not possible to accurately assess the severity of attacks from anecdotal descriptions, but hypoglycaemic attacks appeared to vary quite widely in severity, both between and within diabetic types.

One woman, who had had Type 2 diabetes for nine years and tended to experience hypos at least once a month, described her attacks as 'quite bad at the time':

"I wake up feeling really shaky and a bit sick. My husband has to help me, a sugary drink usually does the trick."

A Type 2 participant who no longer has attacks gave a vivid description of the hypos she used to experience:

"I would begin to feel off and if I didn't get something fairly quickly, once they started it was like a snowball down a hill, it would take you over. They were quite frightening"

However, participants with both types of diabetes acknowledged that, because they could usually recognise the symptoms, they could also quite often treat them before the hypo became too disabling. Two Type 1 participants who have had some bad attacks were nevertheless confident that they could usually divert a bad hypo:

"It's quite good in that I still get warning signs. I kind of, my vision goes a little bit blurry. I feel a bit like I can't concentrate or process information quickly, and I get this kind of feeling in my stomach which I can't describe really. And sometimes I'll come over in a cold sweat so I know quite quickly once it drops below 3.9"

"Not too bad, they seem to go in phases where I'll have maybe two weeks of hypos while I readjust my insulin and then it settles itself down again. But I can normally feel them coming on as soon as my blood hits about 4"

Others, however, suffered severe hypos as a matter of course:

"Very. My husband has to deal with it because I am completely out of it"

3.2.5 Time of day

Most participants, regardless of diabetes type, had times of day when they were more likely to experience hypos, although for one Type 1 participant her hypos had become less reliable with time:

"I used to get nocturnal ones, mainly very early mornings . . . but now they are what I call 'Martini hypos' – any time, any place, anywhere"

Participants who experienced night time hypos acknowledged the difficulty of spotting and preventing an attack while asleep – which may explain why night hypos tended to be serious:

“At night, I get really bad, deep hypos. My husband wakes me up and I get really sweaty and completely out of it. If he catches it early enough and I am responsive, it’s ok because we have cereal bars by the bed and he makes me eat one. I’m never unconscious but I can be quite obstinate and refuse to eat it. I’m lucky if he’s around. Occasionally I’ve woken up and the bed’s been really damp with sweat and I know I’ve had one and come back. But if I have a hypo during the day it’s just a half-hour incident. I don’t go as low because I catch the symptoms”

Night hypos were very common among both groups, but some people were more likely to have hypos early in the morning or late in the afternoon – both times when blood sugar might be expected to be low without intervention.

For some people, the nature of the day’s activities had more effect than time of day on the likelihood of a hypo: one person who had a full time job and a young family at home was most likely to have a hypo at the weekend:

“During the week I have a mainly desk-based job but at weekends we tend to be more active”

For a Type 2 participant whose hypos had stopped as her management improved, churchgoing on a Sunday had once been a danger time for hypos:

“When I had them, it normally happened on a Sunday morning. I go to church at half past 10 and set up and then I’m busy through the service. I was having my normal breakfast but, where I would normally eat at work at half ten or something, I was going through until 12 o’clock. I actually tested my blood in church one Sunday morning and it was down to 2.2 – if it had gone any lower I’d have been out”

3.2.6 Causes

Most of the people we interviewed had a clear idea of what caused their hypos, and in most cases the primary cause was either a lack of food or an imbalance between food, insulin and exercise:

“Losing weight. Types of food that I eat, certain food has a higher GI so the insulin stays in longer than the food. And exercise”

“It depends on what I’ve been doing, sometimes it’s exercise or it could be that I haven’t had enough to eat and too much insulin. Too much exercise and not enough food really”

“Certainly this pregnancy it’s been to do with food – I just haven’t felt hungry, so I just haven’t been as good at eating at regular times so I’ve been letting it go a bit too long. And then sometimes I just get the equation wrong – or too much guesswork when you look at a plate and try and guess what the carbohydrate is in it, and you don’t always get it right”

“Sometimes I think it’s caused by sex – if we have sex when we go to bed, I’m a bit more likely to have a hypo a couple of hours later because it’s physical and I don’t always take that into account”

However, several participants identified other factors, notably stress and infections:

“Stress. Worry about my kids. And I think it’s when I’m not well, whether it’s an infection or I’m getting a cold, as well”

The Type 1 participant who had begun to have more hypos after taking on a more physically active job found that her hypos, which used to be infrequent and largely nocturnal for some years, have become much more frequent and likely to occur during the day since going from a job working the tills in a department store to a more active role on the shop floor :

“I’d say a couple a week at the moment. I was just basically on the tills, and I was doing insulin for being just in one place, but they’ve moved me up to photographic and electrical and I’m running around in the stockroom and being a lot more energetic and it’s messed my diabetes up”

Conversely, however, another Type 1 person had found that her hypos became more frequent when she changed from a physically active job to a more sedentary one:

“When I’m at work I get them a bit, especially now my job is quite sedentary. When I had a more active job, I’d spend the whole day up and down stairs, checking

spaces, talking to people, and was rarely at a desk, which would have meant that my metabolism was much higher, and also there was less change between weekdays and weekends so I had fewer hypos”

Another Type 1 participant, who has been extremely active and has achieved a number of sporting successes during nearly 50 years with diabetes, vividly described an afternoon when he was left alone to run a supermarket fundraising event for Diabetes UK:

“There were supposed to be five people helping us over the weekend and three of them cancelled and only two turned up in the morning. But the afternoon I was there totally by myself looking after these four buckets. And I had to run to the toilet, with the security guy looking after them for me and run back, I didn’t even manage to get a cup of tea. So I gave the shop and the staff a demonstration of a hypo, because the next thing I knew there was an ambulance there”

3.2.7 Aftermath of a hypo

We asked how people usually felt after a hypo, and how long it took them to feel they could function normally afterwards.

Extreme tiredness was the most common after-effect mentioned:

“Exhausted. I find that it wipes me out for the whole day really, so as much as I’m back on form within about 5 minutes of having the sugar, that’s not the end of the hypo really for me”

Headaches and disorientation were also mentioned, although some people (Type 1 and 2) said that they sometimes or always felt fine:

“If it’s just dropped down to between 3 and 4, then fine – you just get on with it. If it drops a bit lower, or at weekends where it’s been more activity-based, I actually end up sweating and having a proper hypo as opposed to just feeling a bit disorientated, then sometimes I need to sleep it off. It’ll leave me with a headache and just not feeling quite right”

“Absolutely fine, no symptoms because I think my hypo awareness is quite good, so I can treat it quick enough so I don’t have any side effects. In my life I’ve had two quite big hypos in 20 years. I did feel quite rotten afterwards but they were both when I was a

child. I've never had anything like that since and I never feel bad after one really now"

One participant, a self-employed electrician with Type 1 diabetes, had an unusual perspective:

"It's strange, but you feel refreshed in a way. It's a bit like when you get an electric shock, not a big dangerous one but a small 240v shock. It's like your heart gets a jolt and two or three minutes later you actually feel on top of the world, you feel better"

Almost everyone, regardless of the severity of an attack, claimed to be able to function normally after a hypo – often because there did not appear to be a choice:

"Yes. I'm quite high functioning with a hypo anyway, I tend to just get on with it. I have been known to sit in meetings and chair them and all sorts of things whilst having quite a low blood sugar. You just have to get on with it"

"Oh yes, I just get on with it. If you went for a lie down every time you dropped your blood sugar you would get nowhere fast"

"I have to function normally, I've got two kids and one of them is severely disabled so I don't have much choice. But if I haven't got the kids and they're at school for the day, I'll go and lie down and let myself deal with my hypo the way I should. I've got to deal with the hypo based on what my options are that day – if I've got two kids running round the house then my hypo has to just suffer itself"

3.2.8 Taking time off work after a hypo

Everyone interviewed for this report was aged 18 or over, and all except two were under 65. Two people had recently retired, one was on disability benefits and not working, three people were on maternity leave and one person was a full-time student. Everyone else was in full or part-time employment, or self-employed.

Very few people had taken time off work to recover from a hypo, and most of those who had, had done it very rarely:

"Once about four years ago I had to come home from work – it was such a bad hypo nobody could understand me. My dad had to come and get me. I

couldn't even manage to tell my boss I needed to go home, they thought I was drunk. That's the only time I've taken work off for a hypo"

"A couple of months ago I was unwell, I had a stomach bug. Because it had happened in the evening and because I had this bug I was eating food and I'd taken insulin but I wasn't digesting properly so then I had a hypo, I ate more food to try and bring the hypo up and that was making me feel more and more sick. So in the end, I just ended up being quite sick for a while and then I was able to recover the hypo. Because that had gone on for quite a while I didn't go to work the next day"

One participant, who now manages her Type 1 diabetes rigorously and also cares for a disabled child, admitted to having been neglectful of her condition before becoming a parent, and said she had taken time off to recover from hypos when she was younger:

"Not in my current job because I only work part time, and with not having them as often now I'm quite lucky. But before I had the kids, yeah, I've had to"

Another mother, whose condition began as gestational diabetes, had to begin her maternity leave early as a result of her diabetes:

"And with all that on top of the tiredness in pregnancy I would be quite wiped out for the next day. There was a few times I had to phone in sick, so I ended up going on early maternity leave because I just couldn't cope with it all the time"

Balancing work and the after-effects of hypos appears to be easier in some sectors than others; self-employment for example makes time off very difficult:

"No time off work to recover. Being self-employed, you can't. Nobody's going to pay you for being ill"

On the other hand, one participant who has worked mainly in the public and voluntary sectors has been able to exercise some flexibility:

"When it's taken a long time to recover I have occasionally taken a half-day off but normally I'm perfectly fine. I have very rarely had severe hypos at work where I've had to come home and I've had the odd morning where I've been maybe an hour late, probably

about twice a year. If I have a meeting that I just have to get to, then I tend to drag myself in”

For this participant, one of the factors affecting her decision to go into work after a hypo was road safety:

“The biggest thing for me is if I had to drive somewhere, I would be much more careful and I wouldn’t drive after a hypo, so if I was planning to have to do something the next day where I would have to drive – most of my jobs I haven’t needed to drive, but occasionally there has been a meeting or something I had to drive to – I wouldn’t go. I’d go in to work, but I wouldn’t drive a car”

Two people who had suffered complications that were either caused by, or led to, hypos at night, had had to miss work the next morning to recover from the combined effects; but both were at pains to point out that they would not normally have taken time off work after a hypo:

“That was an extreme. I’d never usually have to take time off to recover”

“Not if I’ve had one at work. But when I was having the seizures at night I was having them quite a lot because I was having to go into hospital with them, but not the ones I’m having during the day now”

For the people we spoke to, missing work after a hypo appeared to be either out of the question or something that only happened in extreme cases. However, one participant who has never taken time off from her job expressed frustration at other peoples’ perceived tendency to use diabetes as an ‘excuse’ for absenteeism:

“When I moved to the department I’m working in now I found out that one of the charge nurses had diabetes. I thought ‘oh great, something in common’. But he was quite put out by the fact that I was diabetic. I found out that was because he takes advantage of it quite a lot and it really frustrates me. He uses it as an excuse to be off on the sick all the time, he really takes the mick with it which frustrates the hell out of me. I get so annoyed I just feel like shaking him. He claims to have four hypos a day – he doesn’t at all, he just feels a bit hungry and goes for a Mars Bar. People always say to me ‘you’re not like that, why not?’ and it’s just not necessary to be like that”

3.3 The impact of diabetes on work and career

Most of the people we spoke to were adamant that diabetes neither had nor would affect their working life; one participant, whose previous post had involved managing a large and busy music venue, made the point that in fact her working life had impacted on her diabetes:

“I wouldn’t say my diabetes affected my job, I’d say my job affected my diabetes, because I tended to run my blood sugars slightly higher to make sure that I didn’t have hypos, because it wasn’t the sort of job where I could have a hypo. I was responsible for the venue and the safety of every person within it. I couldn’t flake out”

However, one person said that it had definitely affected her choice of career:

“For the career I’ve chosen I don’t think it’s made a difference at all, but when I left university, newly diagnosed, I had wanted to be a paramedic and it was a complete and utter no”

Another participant, leaving school in the 1970s, had had to fight to be allowed to pursue her chosen career :

“When I was 17, 18 and wanted to get into nurse training I found it quite difficult, they weren’t very keen to take an insulin-dependent diabetic”

However, she was eventually able to find a training hospital that would accept her:

“I went through my training no bother, and the rest was history – once I was in training and qualified, no bother”

One participant, who has been made redundant while on maternity leave from a teaching post, has had a very different and much more negative experience:

“There were complications with the pregnancy, because of my diabetes, and my doctor signed me off for quite a period of time. The head was quite unsympathetic. The same when I lost the sight in one of my eyes. I had about eight lots of surgery and they were very unsympathetic about that as well. They did things like changing my role to driving while I was off, knowing that when I came back I’d be unable to drive, they increased my marking load and gave me more coursework subjects – it was awful. So I

have no job to return to. I'm trying not to think about how to find another job after my maternity leave”

This was the most extreme experience related to us, but it was not the only difficulty described:

“I was offered this job [as a home carer], and then they withdrew the offer when they found I had diabetes. They were afraid I wouldn't be safe working in the community with old people. If I hadn't stuck up for myself and threatened to report them for discrimination, I wouldn't have got the job. Sometimes I have to ask for a break at work, because it's dangerous to drive. They don't like it, they always say 'But you said you had it under control'. But there have never been any complaints about my work, I've had a lot of praise. But I do know some people in the company who have been promoted and I never have. I sometimes think it might be because of my diabetes”

“When I was having [diabetes-related] seizures I'd just started a new job so I was having a lot of hospital appointments and I think that affected their opinion of me. I don't think they thought I was up to the job because of my health. I had originally worked for the company I'm with now, gone to work for the other company and I've come back now after the seizures, and I've stayed here basically because they've been really good to me and quite understanding of it all, whereas I didn't think the other company was”

All the people quoted above have Type 1 diabetes, and it is clear that Type 1 diabetes can create greater barriers than Type 2 in terms of working life. It is also clear, however, that many people with Type 1 diabetes experience no difficulties in pursuing their careers:

“I've been self-employed since I was 21, I had a five year apprenticeship before that so I've never been unemployed in my life”

“The insulin regime I'm on is designed specifically for shift work, and the doctors I'm under for my diabetes are very encouraging and very positive and never discourage me from doing anything. Occupational Health at work have been quite supportive as well, so it's fine”

While the impact of their condition on working life is generally less severe for people with Type 2 diabetes, several people with the condition felt that it could make, or had made, their working lives more difficult:

“I think it affects me at work, especially my memory. I am more forgetful than ever, I think it must affect that as well as not having enough energy”

“It’s mainly the fatigue – I’d like to have more energy and be more productive in my job as well as in other areas of my life”

In some cases, people with Type 2 diabetes found that diagnosis, and subsequent successful management of their condition, had actually helped them to overcome any difficulties it originally caused:

“I think it was affecting me before I was diagnosed, because I was listless and tired and I wasn’t sleeping very well either. I didn’t feel well in myself and that affected me at work. But it doesn’t affect me now”

“Before it was diagnosed I was driving for a living and I just couldn’t keep my eyes open. But I drive again now as part of my job – I just stopped until I got it diagnosed and sorted. But it’s fine again now. It’s fine, and I keep sweets in the glove box. If I’m going on a long run I know to have my meal before I go out and not take my medication before I get there. But I’ve never been discriminated against or victimised for having diabetes. The only downside is if I’m doing some really strenuous work I have to break off to have something to eat to keep myself right. But where I work, they are brilliant about it”

However, one person with a recent Type 2 diagnosis was aware of the difficulties his condition was beginning to cause:

“I’ve never had any problems with fitness, I led a very active life up to the point of being diagnosed. But I am having problems now when I’m looking at presentations, focusing. I’ve got to be at the front there to see a presentation and I find difficulty reading, which I think the eye screening next week will identify that”

Several people also mentioned the difficulty of fitting medical appointments, and courses like DESMOND or DAFNE [Dose Adjustment for Normal Eating], around a full time job – reinforcing the view that work can affect diabetes as well as vice versa :

“Fitting in appointments and getting to the GP for my prescription and then getting to the pharmacy out of working hours can be difficult. This is not a nine to five

job, and I've got three appointments to arrange at the moment. It's hard to fit in"

"It's fine. But my job meant that I couldn't go on any of the courses about managing diabetes because they are in working hours and I don't get enough leave to be able to take time off to go to them"

"I think the Dafne course is probably really good and exciting, but they only run it on weekdays during the day. If you work you'd have to take holiday to attend it, which I'm afraid I've always refused to do because I resent that. I think they should do something at evenings and weekends for people who work. Because surely the point is that they should be helping people to live normal lives? I have said it to them, and they're always very apologetic and say oh yes, but we only work 9-4 and you go, 'well that's nice, but that's kind of when I work too'"

3.4 Emergency treatment

Given that hypoglycaemic attacks can be dangerous as well as debilitating, we asked participants whether they had ever had to have emergency treatment for a hypo.

Six out of 12 Type 1 participants had had some kind of emergency treatment, while only one Type 2 patient had had this experience. In her case both admissions were the result of hypos experienced while suffering from other infections.

3.4.1 Admission to Accident & Emergency (A&E)

Five Type 1 participants had been taken to a hospital A&E department for a hypo, and one was admitted because of seizures.

One of these, who was experiencing a severe hypo for the first time, said:

"I didn't know what was wrong at that time, it didn't click that it was to do with the diabetes. They gave me some glucose and I gradually came back. It was quite frightening. I think people who don't have hypos don't really understand what it's like. You do think you're dying"

One participant, who was reluctant to go in to A&E in spite of severe symptoms, highlighted a very real fear that can affect people with diabetes:

“I nearly had to on the night I was ill because I was quite scared but we kind of said we’ll give it 20 more minutes and then it was ok. I think I was quite reluctant to go because once you’ve had an emergency admission for diabetes you have to put it on your forms, your DVLA and things like that – but it was getting to the point where I thought it might be necessary”

3.4.2 Admission by ambulance

Only two Type 1 participants had had to go by ambulance to A&E. In one case, this was shortly after her diagnosis at the age of 19:

“Twice, both a long time ago when I was newly diagnosed. It was at night and I couldn’t be woken up. I hadn’t been well and my blood sugar was all over the place. Friends were checking on me, and I was completely unrousable. So it was an ambulance both times”

In the other case, and that of the Type 2 participant who also needed an ambulance, the hypo was exacerbated by another illness:

“This year I went a bit dehydrated with a kidney infection and my blood sugars were going up and down. So I called NHS helpline and they told us what to do and then they rang me back and my blood sugars had gone up to 7 point something, then they rang us back about an hour later and it had gone back down to just over 1. So they told us to have a big bowl of cereal and some bread and it went up again but it went back down to 1.7 so they sent an ambulance”

The story of the other Type 1 participant who needed an ambulance reflects the difficulties some young people experience when they are dealing with diabetes as teenagers:

“Yes, I’ve been rushed in in ambulances and everything – at least 20 times. When I was teenage I totally rebelled against the diabetes, I didn’t want to do my injections, ate everything I shouldn’t, without telling anybody and without correcting my insulin for it, so when I was 14 or 15 I did everything I shouldn’t have. But the last time was 10 years ago, before I had my kids. I was newly married and my husband freaked out – he gave me an injection instead of food, sent me the other way again”

However, in recent years she has become much more responsible about her condition. She explained why:

“I had kids. I think it’s the fact of me being aware that if my husband’s not here and I have a hypo, what happens to my kids? My priority is my kids – in the past, I didn’t have a priority. I was daft, I was young, I did what I wanted. I didn’t look after myself as good as I should have, but I think when you’ve got kids and your priorities are different, you think ‘Well I’ve got to look after me to look after them’. So now I test more, I’m a bit more sensible in what I eat and what I’m doing in general, now it’s generally looking at diabetes as an illness rather than something I can forget about, since I had the kids”

3.4.3 Treatment by paramedics

Four people with Type 1 diabetes had been treated by paramedics at some point. One was a child when it happened, but in the other cases all three had been unusually busy, and unable to balance their food and activity levels sufficiently. One person had had a long day working in London before travelling home and being too tired to eat properly (another case of work affecting diabetes rather than the other way round):

“Partner brought me a cup of tea with loads of sugar but I fell asleep halfway through it. The next thing I knew, I think it was about 1 or 2, I woke up sitting on the edge of bed with two people in green overalls. It was the paramedics! I’d gone right out and my partner couldn’t rouse me so he called them. Normally he knows what to do, but I’d gone too far. So I just got canulated and had lots of dextrose and glucose in. I came round and then had something to eat, they disappeared and I went to work next morning”

Of two other events, one happened during a weekend shopping trip and the other was during the fundraising event described in 3.2.6:

“Yes, I was treated by a paramedic in the car park after the Tesco event and they had to put 300 mls of glucose into me intravenously that time”

3.4.4 Hospital admissions after emergency treatment

Three of the people who have attended A&E for hypos were admitted to hospital after treatment. All three stayed in for observation and were then released after two or three days. One of these was the lifelong Type 1 participant who rebelled against her condition as a teenager and had multiple emergency admissions:

“Most times for at least two nights. Normally with a telling off and everything else they could think of to stress how –

I don't think it worked to be honest, it just made me more adamant not to listen"

All three of the people treated by paramedics refused to go to hospital:

"No, the paramedics did ask me if I wanted to go in, but I told them I didn't have time. I had a meeting the next morning"

"No, they treated me on site. They wanted to take me in, but I didn't want to go. But they said if I felt unwell at all later on I'd have to go straight in"

"I got into the ambulance by myself. The ambulance guy said he'd never seen anyone so low but still able to function. They pumped the stuff into us and the manageress in Tesco brought me my dinner then I was back in action an hour and a half later"

3.4.5 Post-emergency follow-ups

Most participants who received emergency treatment had some form of contact with their diabetes care team after the event, although not all of them could remember who initiated it. Most people found the contact helpful:

"I don't mind hypos if I can figure out what happened, so I tend to be very proactive in finding out why. It helps to have someone else look at the situation and offer explanations, 'Oh well, you've lost a lot of weight or you were very active that day, or . . .', another pair of eyes. I lost a lot of weight recently and ended up having a lot more hypos, and it took someone else to point out that I was still taking the same amount of insulin I'd been taking when I was 10lbs heavier"

"Yes, I had an appointment with my own diabetes nurse afterwards. And the team from the hospital kept ringing me for several days afterwards to make sure I was all right. They were really good"

"Yes, every time. I've had follow up appointments straight after. My consultants have always been informed that I was in and they've always come to see us when I was on the wards. As I got older, it was less telling off and more of a 'how are we going to stop it happening?' And 'can we change to insulin, can we change the regime, can we change the type of insulin?' I've been on the pump, I've gone from having two injections to now five, I've gone down the path of changing everything throughout the

years to try and control it and stop things like this happening”

One participant, who was diagnosed as a very young child, differentiated between emergencies experienced as a child and as an adult:

“When I was admitted as a child, yes. But as an adult, what planet are you on? No, I casually rang them and they said just you know, get back into the routine so I carried on as normal”

This was not, however, expressed as a complaint.

One person chose not to contact her diabetes care team, but in this case it was because she felt she now understood what had happened and would be able to deal with it herself in future:

“No. I didn’t tell them, I think once I’d realised what it was – I probably wouldn’t have gone to hospital if I’d known. I would probably just have had some glucose. I have had one or two like that since. Not many, but I’ve known what it was and I’ve been able to get help at home”

3.5 Glucose levels

3.5.1 We asked whether people checked their blood sugar readings more often after a hypo than they usually would.

In general, opinion was divided between people who said they would check more often and those who would not. Four people said they definitely would:

“Yes, more often. Normally I would check my blood sugar before every meal and just before bed. When I’ve had a hypo I’d have checked it when I was actually thinking I was having one, and then half an hour and an hour after that, to check it’s coming back up”

“Normally I’ll do it twice a day but after a hypo – probably every time I eat something – 4,5 times, more. I end up with sore fingers!”

Those who said they would not check more often had clear reasons for saying no. In many cases this was because they did not need the extra information provided by a blood sugar test after the event, especially if they felt they were already frequent testers:

“Not really any more. I generally do about four a day anyway, give or take. I can trace why hypos happen so I don't really need to test after I've had one”

“I already test myself about seven times a day anyway, so I don't have to do it more often after a hypo”

Some people also pointed out that sugar levels can in fact 'bounce' after a hypo and that therefore it was not necessarily a good idea to test too soon afterwards:

“It's more a case of I do it a lot to start with. In fact, after a hypo you just know you're going to run high for a while so there's no point in checking it because it's not like I'm going to correct it to bring it down”

“I might do one extra test after a hypo but I often find that when I've had a hypo I bounce high after it so I try to avoid testing for a bit afterwards because it can make me think I've gone high when that's just a reaction and it will usually settle”

However, one Type 2 participant simply said:

“I'd rather not know!”

3.5.2 Blood sugar readings

When we asked what people's most recent blood sugar reading was, 11 of the 12 Type 1 participants could give an accurate reading taken earlier on the day of the interview. One person had tested 'this week' and was not sure of the precise reading.

Three people with Type 2 said they never tested theirs because their blood was still only being checked at clinic appointments. Two of these could not remember their last reading. Two other Type 2 patients said they hardly ever tested and could not remember their last reading, and one was not sure.

The full list of readings and times is included in Appendix 3.

Most people who tested their blood sugar levels said they were confident that they knew how to do it and understood the significance of the readings. This included people who in practice rarely or never test their blood.

However, one Type 2 participant commented on an apparent lack of interest in her blood sugar levels, although that had changed during both her pregnancies:

“I think the interesting thing is, as an individual I had annual appointments with a specialist, and if I’m very honest I’d say nobody really paid that much attention. Then, because I was trying for a baby I went on a pump for a year, and everybody got very very involved at that point, because obviously that was ‘interesting’. So I started having to email the diabetic nurses at the clinic weekly with my results, and the more involved we got with the pregnancies, the more of all that there’s been. The second I have the baby, everybody stops being interested”

3.5.3 Monitoring diaries

Perhaps as a sign of the times, very few people now keep paper monitoring diaries to record their blood sugar readings. Only two people did this (one, who is Chinese and spends some of her time caring for elderly relatives in Hong Kong kept a detailed record given to her by her doctor in Hong Kong that she shows to her doctors in the UK and Hong Kong).

However, most people recorded their readings in one way or another, and for many their blood sugar monitor was the most useful way to read, store and report on readings:

“That’s where I’m not so good, I actually don’t [keep a diary], but I’ve got a good meter that holds a thousand readings and I can download that onto my computer. I take the download to my reviews so I’ve got something to show them”

Two people used I-phone apps:

“I have an app. The machine holds them and then I download them on to my i-phone. I changed the meter about a year ago to one that would synchronise with my i-phone. You can have a trend chart that works out where you are. They always ask to see them at the clinic and they play around and look at the trends”

3.6 Medication and care

While every Type 1 participant we spoke to was using fast and/or slow-acting insulin in either injection or pump form, most Type 2 participants were being treated by tablets (usually Metformin, with or without other medicines). Three people were managing their condition by diet and were not on any form of medication.

A further four Type 2 participants were on insulin. Two of these were prescribed insulin after a relatively long time (12 and 15 years respectively):

“I wasn’t getting good sugar results (around 8 or 9), so the nurse referred me to the Newcastle General diabetic clinic. They suggested I tried this new medication that was being trialled, I can’t remember what it’s called now, but it’s a kind of inject pen. It was also supposed to help you lose weight. But that didn’t work for me, so after about 6 months the consultant suggested putting me on insulin”

“I’m still tweaking it just to get it right. I’m nearly there now, it’s took all these years to get this far. I was on tablets for ever and ever but I just got sick of trying out different tablets and some worked and then they didn’t and some made you feel sick. So last year I decided I wanted to go on insulin. The doctor said, ‘well try this other stuff first’, I forget what it was called, and I tried it and it just made me sick, and they’ve put me on this Miacin 3, which is marvellous. I didn’t want to go on insulin for a long time because I was afraid I’d lose my job and not be able to drive, but with type 2 they’re not bothered as long as you’re in control and not falling asleep behind the wheel”

The other two participants were given insulin after three and four years respectively. One, who has now been on insulin for many years, said:

“I obviously hadn’t been taking it that seriously, even though I’d been on the Desmond course and everything. But I wasn’t controlling it well, so I ended up on insulin”

The other person was the Chinese participant, whose doctor in Hong Kong prescribed insulin very recently, after three years of receiving most of her treatment in the UK. Her interpreter explained:

“She was having difficulty controlling her sugar levels, so needs a strong dose of insulin to bring it down”

This participant identified considerable differences in the way diabetes is perceived and treated in Hong Kong and the UK:

“There is a huge difference in approach between the UK and Hong Kong: doctors in UK do not generally advise patients to be on medication at the very beginning, but in Hong Kong they advise it straight away, including injections, to avoid all the possible side effects. People here think an injection means your condition is very severe, in Hong Kong it is much more common from the start. There is a lot of research in Hong Kong, indicating

that injections defer the side effects of diabetes. It is the second biggest killer in Hong Kong after heart disease, so doctors there advise treatment as early as possible and Type 2 is taken much more seriously than in the UK”

3.6.1 Making decisions about medication

Participants varied quite a lot in the extent to which they wanted to be involved in decisions about their medication. Twelve people were content to take no part in medical decisions at all, and while others liked to be involved in discussions most were happy to leave the final decisions to their diabetes specialists:

“Overall, I’m in their hands because they know what’s available and they make decisions about what to try when new things come up. But I think I’m party to those decisions – they’ll say ‘do you want to try this’ and occasionally it won’t work but we work it out”

“I’m involved in those discussions, but usually it is a case of doing whatever the consultant or whatever advises – after I’ve looked into it myself to make sure about side effects and so on. With having a child at home I don’t want to go on anything that has difficult side effects”

“I know a lot about managing my condition, but I don’t feel I have the knowledge to get involved in prescribing medication”

Some, however, were much more active in the decision-making:

“They wouldn’t dare [make decisions without me]. I decide what I’m doing and what I’m not. I’m an advisor to the Department of Health, on the retinal advisory committee. So if I don’t know what I’m doing . . . so basically they usually let me get on with it”

“I’m quite active – because I’ve had it so long rather than because I’m a nurse. I was always encouraged as a child to adjust my dosage of my fast-acting insulin. I know a lot of people are quite wary of that because they’re scared of the effects of too much or too little. But I’m quite confident with that and I’ll tell the diabetes team what I do and they are actually quite happy with it, they support that because it helps even out my control. If you are confident and you know what you are doing they are quite keen for you to do that, more than happy”

3.6.2 Fitting medication into everyday life

Most people we spoke to had become very used to taking medication for their diabetes, and had become adept at fitting it into their everyday life. This applied to injectable treatments as well as to tablets. People on medication alone found it particularly easy:

“I take it first thing in the morning and with my meal in the evening, so I don’t have to bring any medication into work, so that’s not a problem. On holiday this year I took all my medication and there wasn’t a problem with that, and my monitor as well and I think I probably ate better over there, because I had time to do so, than when I’m at work”

“Absolutely fine. It made me feel a bit sick when I first went on it, but they had warned me that might happen so I was prepared for it. And it’s fine now”

“I can handle the tablets and all that, but I think if I have to start having injections it will have an impact”

In practice, participants also tended to take injections largely in their stride, particularly after overcoming the initial embarrassment of injecting in public:

“There was a point when I just got old enough to stop caring what other people thought. When I was younger, and having to use syringes as opposed to the pen, I wouldn’t even test my blood sugars in front of people because I was quite self-conscious and then there’s a point at which you just go ‘this is stupid, people really aren’t watching, nobody cares’ so now I just do my blood sugars and injections in front of people, and nobody bats an eyelid. It’s much easier, and as a result I do believe I’ve got better control now”

“It doesn’t bother me, even if I’m out. Normally I’m either wearing trousers or a skirt so it’s quite easy to inject. My husband will sometimes joke about it and say ‘are you still on that methadone’ but it’s not a problem. I think it’s a lot more accepted now, and if people do comment I just say I’m diabetic”

People who used pumps tended to find them particularly convenient, although one participant who was being considered for an insulin pump was daunted by the prospect:

“It’s so much more convenient now with the pump. When I was a kid those needles got so blunt, it used to make me scream because the skin on my arms got very tough”

“Since being on the insulin pump it’s very easy”

“We’re kind of giving it a few more months to see if I can control it myself, and then we’re considering the pump. I’m not sure about that – I kind of want to talk to someone who’s got one, because it’s quite a life change”

3.6.3 Regular checks

Most participants had regular foot checks, usually as part of their regular review. However, some people had never had their feet checked:

“It should be yearly, but I’ve been asking for an appointment for the past three years and I still haven’t had one. I’m trying to get them checked”

“No, I’ve never been referred to podiatry. But my feet are quite healthy”

“My partner is quite a stickler about diabetes and she says you should never even cut your own toenail if you’ve got it, but if I’d waited for a podiatry appointment they’d have been growing out through my shoes by now”

Nobody reported serious problems with their feet, although the Chinese participant explained through her interpreter that she had experienced some discomfort:

“Every three months in Hong Kong, by a diabetes specialist. She has some pain in her right foot because of diabetes, she takes vitamin B to try and counteract and improve the sensation”

One person had regular checks to make sure callouses were not masking any loss of feeling.

Everyone we spoke to had regular appointments with their diabetes care team. In many cases this was an annual event, but for most people it was also supplemented with follow-ups every four or six months.

One person had begun to see the diabetes doctor at her local surgery because of the flexibility of GP appointments compared to the Diabetes Centre; but on the whole most participants were satisfied with the care they were receiving. One participant who has Type 1 diabetes stressed the importance of building up a relationship with a specialist:

“I have one specialist who ‘gets’ me now, and when I go to the clinic I’ll wait longer so I can see her, rather than having to start explaining everything all over again every time”

For most people, the gap between appointments felt right, and several people made the point that, if they had any concerns in the interim, they could and did contact a member of their care team. One person, however, found her schedule of reviews onerous:

“I have my annual review, and every three months for follow up. It feels like quite a lot, I don’t get much out of the follow-up appointments, I do think why are we bothering, what have I achieved from coming along and it’s a bit frustrating going for something you’ve had for years. I would prefer just an annual review and then if there were problems, the option of an extra appointment”

This was echoed by another participant whose reviews have been reduced from four times to twice a year, although her main concern was the impact of regular checks on her employment:

“Yes, it’s down to every six months. It was once every three months before, which was a pain. I get my blood taken one week and then I have to go back a week later to see her. I have to get out of work early so on those days I usually work through my lunch hour so I can go early. They [employers] moan, but I have to do it”

3.7 General reflections

After asking the same questions of every participant, we then gave everyone the opportunity to tell us about their personal experience of diabetes, and the issues, concerns or frustrations that were most important to them.

The full list of comments is included in Appendix 3, but some of the commonest or most striking themes are identified and set out below:

3.7.1 Non-specialist medical knowledge

While most people we spoke to were very happy with the specialist medical staff they encountered, five people identified a low level of diabetes awareness among non-specialist medics.

“You have within the health services people who are experts in particular conditions, but actually generic understanding across the board is fairly poor. And they don’t talk to each other!”

“Maybe it’s just me, but I’ve found you have to put your foot down if you are being treated for something else by

medics who don't know much about diabetes. I have friends with diabetes who had real problems while they were in labour. I didn't, but then I always tend to say 'It's my condition, I need to deal with it'. And they did, they just let me get on with it"

One person described a particularly distressing experience in the care of non-specialist medics:

"When I was having my baby I ended up having a four-hour hypo because they insisted on taking over the management of my insulin and giving me insulin. And I said 'I don't think I'm going to need any insulin, this is going to be quite active' but they insisted on giving me it and then they wouldn't give me any glucose. And you need about 50 grams of carbohydrate minimum to settle it, but they said 'oh no, we can't, the protocol won't let us' and it was excruciating. The common sense element and the thing about treating people as individuals went right out of the window"

This led her to an interesting observation about the future care of elderly people whose diabetes will probably be only one in a long list of medical conditions:

"This is purely on the experience I've been having recently because I've spent a lot of time in hospitals – but as the population is ageing and you end up with more insulin-dependent diabetics in hospital, and some will have dementia, I wonder whether Type 1 diabetics who may be starting to live with dementia and other conditions, and starting to live in care homes or hospitals, I do wonder what care they are going to get, and whether it's appropriate and whether anybody will actually look at them as individuals"

3.7.2 Public awareness

Several people expressed frustration at the low level of public understanding of diabetes, in particular the difference between Type 1 and Type 2. This was particularly galling for some Type 1 sufferers:

"I find the media's representation of diabetes offensive, partly because Type 1 and Type 2 diabetes are called the same thing – something you get when you're 10 as a result of an autoimmune deficiency or whatever it may be is very different to something that is likely to have been caused by lifestyle choices"

“There’s a lot of ignorance and discrimination out there. As a child it hits you harder than as an adult – you do get quite thick-skinned. But it’s frustrating, especially when people don’t understand the difference between Type 1 and Type 2, and start telling you you’ve got diabetes because it’s your own fault”

This was echoed to an extent by one Type 2 participant, who cheerfully stated that he thought his condition was his own fault:

“I am fully aware why I got diabetes – I heard a comedian on the radio recently. She said there are two types of diabetes – Type 1 and Type It’s Your Fault. I was very overweight, so I’m one of the ‘Your Fault’ people”

However, another person with Type 2 took the opposite view:

“There’s a lot of discrimination against people with Type 2. As soon as I mention anything about being Type 2, because I’m younger it’s automatically assumed that it’s my fault, that it’s a lifestyle thing. I’m not underweight but I do try to control my weight really well and I’m certainly not obese and I wasn’t before I had my baby either – obviously with me something triggered the gestational diabetes and it just didn’t go away, but I do try to have a good lifestyle”

3.7.3 Weight control and food regimes

Food looms large in the lives of most people with diabetes, and in particular the constant need to balance blood sugar levels with healthy eating and weight control.

Two people had managed to lose large amounts of weight since being diagnosed with diabetes – one person had lost over four stone since her Type 2 diagnosis just seven months before:

“I do feel much better and much fitter now, so in the long run although it was a bit of a shock, it’s been a good shock”

She had also used her diagnosis, and the incentive to lose weight, to become much better informed about nutritional issues:

“At first I said ‘I don’t eat much sugar, I’m not a sweetie person’. But then, looking at what was in different foods, the sugar content, I couldn’t believe it. Things you would never expect – like yogurts are really really high in sugar.

It's made me think differently about sugar content. So for now, my diagnosis has definitely improved my health!"

The other successful dieter was taking part in the Newcastle University research trial that is currently testing the effectiveness of a very low fat regime.

Other participants had had less success with weight control, and many people expressed their frustration at being caught in an apparently vicious cycle:

"I knew for years I was overweight, you go for help and you see a dietician, you go to the gym, you get a bit off, then you put it back on. If there was some way to get your weight under control before you got diabetes that would be a help but it seems you have to be morbidly obese before they offer you any help. And the side effect of insulin is that it makes me so hungry"

For another participant with a recent Type 2 diagnosis, the difficulty seemed to be eating enough food, after a lifetime of being a very light eater with a serious fizzy drink habit:

"I think what I'm very guilty of is I'm not your breakfast lunch evening meal man. I'm a cup of coffee and an evening meal man. That's my culture really, and my work ethos. I find it very difficult to drag myself away from the computer and sit down and have a sandwich. I've got a bit better at it, but I'm nowhere near doing what I should be doing, you know, three meals a day. But on the dietary side I have changed"

3.7.4 Physical activity

Most people recognised the value of exercise, both as a possible means of prevention and a way to maintain health with diabetes. However, there was also widespread awareness of the difficulties of balancing blood sugar levels with physical activity, and exercise proved to be an emotive subject. Several people expressed frustration at the difficulty of being as active as they would like:

"Exercise is a real problem for me now. It used to really help – if I wanted to lose weight or if my blood sugars weren't great, exercise was always the answer. It literally seemed to change overnight, I still don't know what caused it, where all of a sudden I became much more sensitive to insulin and exercise so now I do a lot less than I used to"

"Long term, exercise makes you have better control over your blood sugar, so obviously you want to do it. But it's just

such a nightmare. I often find myself avoiding it, even pilates. If I have my tea and insulin before I go, I get in the car afterwards and I'll be low even from very low-impact exercise like that”

The difficulty of getting good medical advice about balancing exercise and sugar levels was an issue with one participant:

“It’s quite hard if you are a bit unusual in that you want to be active – to get someone to give you proper advice about what to do if you’re hill-walking, or you’re going to be sailing for three months, you have to work it out for yourself. I don’t do anything particularly extreme, but there doesn’t seem to be a body of knowledge for those slightly different things. For me it’s been hard to get informed support to help me do slightly unusual things. Things like how to keep insulin cool enough when I’m doing x, y and z and I’m going to be out for seven or six hours, I’ve got much more support from websites and talking to other people, than from my healthcare team. They’ll discuss the issues with you, but they aren’t the ones with the answers. They don’t see enough people with diabetes who actually do stuff. You have to work it out yourself. You need to know things like for instance dextrasol jelly acts faster than dextrasol tablets when you’re in the middle of trying to change a sail and your blood is falling fast, that sort of practical advice. I’m too old for the younger person’s clinic now, and when you’re not attending that one people do tend to assume that you’re going to just sit and watch telly – and if you look round the clinic, you can see that it’s probably true of most people with diabetes”

However, another long-term Type 1 participant had managed to maintain very high levels of physical activity:

“I’ve been British national single-handed catamaran 3 times, I’ve also done motorbike trips to Istanbul and Asia and back in 6 days. My doctors don’t have a clue what I actually do . . . I had a jet ski for five years, I used to ride it round the Bass Rock off Edinburgh 6 miles out, and I’ve done over 100 miles on a jet ski in one go. I load up before days like that, you have to look after yourself. When I was in my 20s and 30s I’ve been windsurfing all over the place. I was sailing on a lake in Surrey the day of the big hurricane in 1987 and I was the last man off the water. Mind I had to get treatment off a doctor after that, but it was just basically a couple of Mars bars”

3.7.5 Emotional and psychological support

One long-term Type 1 participant felt that younger, more recently diagnosed diabetes patients are better supported than young patients in her day:

“I think there’s a lot more recognition now of the psychological, emotional effects. When we were kids it was quite a Victorian attitude – just get on with it”

However, a young woman who was diagnosed five years ago at 19 felt that more emotional support would have been helpful:

“I believe that you see a psychologist if you are diagnosed as a child, and I don’t know why they don’t offer that to everyone. Because it was such a shock. You know, you’ve got really high blood sugar, you go to A&E, you’re on a drip for several hours and then you’re discharged straight to the Diabetes Centre . . . I know it’s not the same as cancer, but in terms of the fact that it’s such a lifelong illness you need some support. I feel like I’ve had a lot of support from the Diabetes Centre, but not much sort of psychological support”

Another young woman who was diagnosed as a child had in fact sought psychological support on her own initiative since becoming an adult:

“I’ll be very honest. I’ve seen a psychologist fairly recently for help with more the mental side of it – feeling like a failure if I got it wrong, and all those sort of things. I feel that isn’t publicised enough. Even though I know I’m in much better control technically, I didn’t feel I really was overall. It had been mentioned to me before at the Diabetes Centre but I didn’t want to admit to the hospital that I wasn’t coping, I felt like I should be. But then I thought, if the support’s there I might as well take it. That was the best thing I ever did, so I would recommend it to anyone who is struggling with the mental side of it. Now I know I am doing well!”

3.7.6 Living a ‘normal’ life

Nobody we spoke to felt that their diabetes had prevented them from living a reasonably normal life, although there was widespread recognition that the condition imposed its restrictions on Type 1 and Type 2 patients alike.

One participant who has had Type 1 diabetes since childhood and has managed to live an extremely active life spoke of his determination not to let his condition hold him back:

“I remember when I was about 7, I was at my cousin’s and him and his mates were playing football so I started

playing football with them. And my cousin got my arm and he said 'Calm down xx, don't do it because you're diabetic'. Well that infuriated me and I thought 'Well, I've got to prove to you that I can run just as fast as you and beat you', and I was all over the place. And I remember that. I didn't want to be a lesser person"

This determination has carried him through a remarkable recovery from a stroke as well as a number of sporting achievements; but other people with Type 1 have found the barriers harder to overcome:

"I've always done a lot of sailing, and I would have liked to be the first mate of a boat but I had to take the decision that I wouldn't be. Because if you're in charge, and there's say 15 young people in your care, and you can't be in charge because you're having a hypo, then . . . so I never went up to that level"

"You can't really be spontaneous. I'd really like to travel more, and do backpacking kind of travel, but I don't think I could. I know that people with diabetes do, but I just think – how? It must be so incredibly complicated"

One participant, who leads a busy and successful life with a young family and a responsible job alongside longstanding Type 1 diabetes, spoke of her growing awareness of the impact of her condition:

"I would say that my perception of diabetes as I've got older has changed. In the early days I would never have described it as a disability, but I think now I probably would. There are now things that I know I can't do. It stops me from doing things. But that's fairly recent, as I've got older"

A participant with Type 2 diabetes eloquently described the fears and frustrations of her peers in a heartfelt outburst that encapsulates the insidiousness of a common but misunderstood and often underestimated condition:

"I had no idea about diabetes until I was diagnosed. Now I understand about it, but before I was diagnosed and started having hypos I had no idea. And then you start to take notice, but it's a shame you don't take notice before it's too late. You put a little bit of weight on, you don't think too much about it, but more attention needs to be drawn to these facts so people understand that yes, they are making themselves ill without realising it. You think you're living well, but you're not, you're making yourself ill"

3.8 Summary

One of the key messages to emerge from this research was that while common themes emerged both across and within Types 1 and 2, there were also some significant variations in the ways in which different people deal with, and are affected by, their condition.

To some extent, while both types of diabetes have a cumulative impact as symptoms become worse and patients grow older, most people tend to become better at managing their condition.

This is especially true of people who have been Type 1 since childhood: resentment at the restrictions of their condition had led in some cases to recklessness in adolescence or young adulthood, but most of the Type 1 participants we spoke to now took their condition very seriously and worked hard to manage it as well as possible.

It is perhaps not altogether surprising that Type 2 diabetics can struggle to make the lifestyle changes necessary to alleviate their condition or delay its effects. Most Type 2 participants were diagnosed at a later stage than their Type 1 counterparts, and lifestyles had in many cases contributed to the onset of the condition. However, those who took their diagnosis seriously and had made radical changes to their diet or lifestyle tended to cope well with their condition, avoiding or delaying some of the more debilitating health impacts.

But even those who managed their condition well were very clear that diabetes in all its forms is a difficult illness to manage – and one that has a significant impact on every aspect of the lives of people who are affected by it:

“Most people think it just has an impact on what you can eat and that’s it, but it literally has an impact on every aspect of your life, pretty much, it affects absolutely everything”

Appendices

Appendix 1

Participant profile

Gender

| | No. of participants | % of participants |
|--------------|---------------------|-------------------|
| Female | 20 | 76.9 |
| Male | 6 | 23.1 |
| Total | 26 | 100% |

Age

| | No. of participants | % of participants |
|--------------|---------------------|-------------------|
| 18-25 | 2 | 7.7 |
| 26-35 | 5 | 19.2 |
| 36-45 | 3 | 11.5 |
| 46-55 | 10 | 38.5 |
| 56+ | 6 | 23.1 |
| Total | 26 | 100% |

Diabetes Type

| | Number of respondents | % of respondents |
|--------------|-----------------------|------------------|
| Type 1 | 12 | 46. |
| Type 2 | 14 | 53.8 |
| Total | 26 | 100% |

Ethnic background

| | No. of participants | % of participants |
|---------------------------------------------|---------------------|-------------------|
| White British | 23 | 88.5 |
| White Irish | 0 | 0 |
| Any other White background | 0 | 0 |
| Mixed White and Black Caribbean | 0 | 0 |
| Mixed White and Black African | 0 | 0 |
| Mixed White and Asian | 0 | 0 |
| Any other Mixed background | 0 | 0 |
| Chinese | 1 | 3.8 |
| Asian or Asian British – Indian | 0 | 0 |
| Asian or Asian British – Pakistani | 2 | 7.7 |
| Asian or Asian British – Bangladeshi | 0 | 0 |
| Any other Asian or Asian British background | 0 | 0 |
| Black or Black British – Caribbean | 0 | 0 |
| Black or Black British - African | 0 | 0 |
| Any other Black background | 0 | 0 |
| Any other ethnic group | 0 | 0 |
| Total | 26 | 100% |

Diabetes Questionnaire

You are about to enter a market research interview. We are required to pass on to our client details of adverse events and/or product complaints that are raised during the course of market research interviews. Although this is a market research interview and what you say will, of course, be treated in confidence, should you raise during the discussion an adverse event/product complaint in a specific patient or group of patients, we will need to report this even if it has already been reported by you directly to the company or the regulatory authorities using the MHRA's 'Yellow Card' system. In such a situation you will be asked whether or not you are willing to waive the confidentiality given to you under the Market Research Codes of conduct specifically in relation to that adverse event/product complaint. Everything else you say during the course of the interview will continue to remain confidential. Are you happy to proceed with the interview on this basis?

ABOUT YOU

Gender

Female Male
 Transgender

Age

18 – 25 46 – 55
 26 – 35 56+
 36 - 45

Do you have Type 1 or Type 2 Diabetes? Type 1 Type 2

Please indicate your ethnic background

| White | ✓ | Asian or Asian British | ✓ |
|--------------------------------------------|---|-------------------------------|---|
| British | | Indian | |
| Irish | | Pakistani | |
| Any other White background | | Bangladeshi | |
| Mixed | | Any other Asian background | |
| White and Black Caribbean | | Black or Black British | |
| White and Black African | | Caribbean | |
| White and Asian | | African | |
| Any other mixed background | | Any other Black background | |
| Other ethnic groups | | | |
| Chinese | | | |
| Any other ethnic group (<i>write in</i>) | | | |
| ----- | | | |

INTRODUCTION

1 How old were you when you were diagnosed with Diabetes?

.....

2 How long have you had it?

Less than 5 years

5-10 years

10-15 years

Longer

HYPOGLYCAEMIA (HYPOS)

Hypos happen when your blood sugar is low, and they can cause shakiness, blurred vision, sweating and hunger

3 Have you ever had a hypo?

Yes

No

4 How often do you have them?

.....

5 When was your most recent hypo? (please give the month and the year)

.....

6 How severe are your hypos?

(what happens, how long, how do you overcome them at the time?)

.....

7 In your experience, what do you think causes YOU to have a hypo?

.....

8. Do you have them at any particular time of day, or more often on some days than others?

Some people experience hypos at night, but not everyone is woken up by a nocturnal hypo. Signs that you may have had a hypo while you were asleep include:

- Waking with a headache and/or a clammy neck
- Experiencing seemingly unprovoked sleep disturbance
- Feeling unusually tired, irritable or confused after waking up
- Waking with damp bed clothes and sheets from sweating

.....

9. How do you usually feel after a hypo?

.....

10. Are you able to function completely normally after a hypo?

(performing simple tasks, feeling tired or weak, ability to work etc) How long does it usually take for you to feel ok after a hypo?

.....

11. Have you ever had to take time off work to recover from a hypo?

(reiterate confidential nature of research)

.....

12. Do you think your diabetes has affected your ability to find work, to do your job well, or to keep your job?

.....

EMERGENCY TREATMENT

13. Have you ever been to a hospital Accident & Emergency (A&E) for a hypo?

Yes No

How many times?

14. 10 Have you ever been taken to A&E by ambulance for a hypo?

Yes No

How many times?

15. Have you ever been treated for a hypo by ambulance paramedics without being taken to A&E?

Yes No

How many times?

16. Have you been admitted to hospital after emergency treatment?

How long for?

17. Were you seen by your diabetes care team after this event?

Did you initiate this contact? What action was taken or suggested as a result?

GLUCOSE LEVELS

18. Do you test your blood sugar levels more often than usual, after a hypo?

Yes

No

How many times?

19. What was your last blood sugar reading, and when was it measured?

.....

20. Are you confident that you know how to measure your blood glucose levels?

Have you been told how to measure your blood glucose levels? How often should/do you do this? Do you keep a monitoring diary, do you use this to help manage your diabetes? Does your diabetes care team review your diary each time you visit, do they discuss the results with you?

MEDICATION AND CARE

21. What medication do you take for your Diabetes?

.....

22. Do you feel that you have any opportunity to make decisions about your medication?

Do you want to? Do you have enough information?

.....

23. *For type 2 patients on insulin only* How long between diagnosis and insulin prescription?

.....

24. How easy is it to fit your medication into your everyday life?

Difficulties, advice, which prescriptions are most difficult to work round?

.....

25. How often do you get your feet checked?

Is this often enough? Do you have to ask, or is it scheduled?

.....

26. Do you have regular scheduled visits to a healthcare professional to check and discuss your diabetes?

Often enough? Too often? Does your HCP initiate all contact, and does this meet your needs?

.....

27. Any other comments or observations about your experience of diabetes?

Appendix 3

Questionnaire responses

This section contains all the responses from face-to-face and telephone interviewees.

Do you have Type 1 or Type 2 diabetes?

| | Number of respondents | % of respondents |
|--------------|-----------------------|------------------|
| Type 1 | 12 | 46.2 |
| Type 2 | 14 | 53.8 |
| Total | 26 | 100% |

INTRODUCTION

1 How old were you when you were diagnosed with diabetes?

| | Number of respondents | | % of respondents | |
|--------------|-----------------------|-----------|------------------|-------------|
| | Type 1 | Type 2 | Type 1 | Type 2 |
| Under 20 | 10 | 0 | 83.4 | 0.0 |
| 20-40 | 1 | 5 | 8.3 | 35.7 |
| 40-60 | 1 | 9 | 8.3 | 64.3 |
| Total | 12 | 14 | 100% | 100% |

- I had gestational diabetes in 1986 when I was 29. Then it came back again four years ago, when I was 52

2 How long have you had it?

| | Number of respondents | | % of respondents | |
|-------------------|-----------------------|-----------|------------------|-------------|
| | Type 1 | Type 2 | Type 1 | Type 2 |
| Less than 5 years | 0 | 4 | 0.0 | 28.57 |
| 5-10 years | 2 | 2 | 16.7 | 14.29 |
| 10-15 years | 2 | 4 | 16.7 | 28.57 |
| Longer | 8 | 4 | 66.6 | 28.57 |
| Total | 12 | 14 | 100% | 100% |

HYPOGLYCAEMIA (HYPOS)

3 Have you ever had a hypo?

| | Number of respondents | | % of respondents | |
|--------------|-----------------------|-----------|------------------|-------------|
| | Type 1 | Type 2 | Type 1 | Type 2 |
| Yes | 12 | 9 | 100.0 | 64.3 |
| No | 0 | 5 | 0.0 | 35.7 |
| Total | 12 | 14 | 100% | 100% |

4 How often do you have them?

| | Number of respondents | | % of respondents | |
|-------------------------|-----------------------|-----------|------------------|-------------|
| | Type 1 | Type 2 | Type 1 | Type 2 |
| At least once a day | 2 | 0 | 16.7 | 0.0 |
| At least once a week | 5 | 0 | 41.6 | 0.0 |
| At least once a month | 2 | 2 | 16.7 | 14.29 |
| About four times a year | 1 | 2 | 8.3 | 14.29 |
| About twice a year | 2 | 1 | 16.7 | 7.14 |
| Once a year | 0 | 1 | 0.0 | 7.14 |
| Never had one | 0 | 5 | 0.0 | 35.7 |
| I no longer get them | 0 | 3 | 0.0 | 21.42 |
| Total | 12 | 14 | 100% | 100% |

Comment

- No, I don't think so. [*after hearing description of symptoms*]: Well, I do, then, I've just never put it down to that!
- Up until I was 35, I didn't have many, for several reasons, but probably partly because I didn't take quite enough care of myself. And also because at the age of 35 my body seemed to change. I went from being able to go to the gym for two hours at a time, climbing mountains, things like that, to a 10-minute warm-up sending me having a blood sugar reading that went from 14 to 2.
- Not that often. I am currently losing a lot of weight, which is affecting my blood sugars so I am going through fits and starts where I am having to adjust my insulin. But generally speaking, not that often. Usually, more like monthly
- I don't get them now. I used to have at least one a week, when I first went on the tablets. I was on three Metformin a day, but because I was so well controlled and completely cut out all the sugar, three tablets was too many
- I don't really get them, just slightly weak feelings, only after I haven't eaten for most of the day or something daft like that. I wouldn't necessarily see it as particularly out of the ordinary
- It depends on how busy I am, and how careless
- A couple of times a month, unless I'm coming down with something, then I get more. I'm more likely to have a hyper because I hate hypos so much that I drink a lot of Lucozade to avoid them. I have a hyper about twice a week
- It happens once or twice a week. I know that I've had a bad hypo when I've woken up and know that my sugar's low, but there have been a couple of times at night when it's been so low that I've had to get help. And once when I've ended up in hospital
- I kind of have them. I control my diabetes purely by food. My battery quickly runs out. I have a fairly high carbohydrate diet and I'm vegetarian. I have cereal in the morning, and then a lot depends on my energy levels and the extent to which it's used up, or if my immune system is fighting an infection. But by the middle of the morning I start to go, it feels like being drunk for free. My head goes fuzzy and I can't think straight so generally speaking I have a mid-morning snack or something. I try to avoid that, but I know that if I go into town and have say a croissant and a cup of coffee I can generally go until about 1 o'clock. Some days I can go further than that but anywhere from about half past 10 onwards I start to feel wobbly, so I guess it's a kind of a hypo. I know I'm not going to go into a coma – so I can have a bit of food and I recover

- Not very often now. I can normally tell roughly what time I need to check my blood sugar levels and when I need to eat – but sometimes when I'm out, if I don't eat regular I can start getting a little bit woozy and my wife knows because I might get a little bit snappy or a bit vague when I'm talking to her
- It varies really, depending on what I've eaten and how much
- I used to get hypos quite frequently because I was trying to lose weight and reduce the insulin I was taking. I was doing it with the nurse at the hospital, and I was getting frequent hypos. Not actually going, but the start where you go 'uh-oh' and you know it's coming and you have to have something to eat. Then my husband had a stroke in January and unfortunately he is no longer able to drive, it means I am now the only driver. So, in order that I can drive safely I do what a lot of people with diabetes do, I tend to eat something before I get in the car – which is putting the kibosh on my trying to lose weight. It means I am not getting any hypos, which is wonderful in a way but it's a fact that I would still be losing weight if I wasn't doing what I'm doing. You can't always drive at the same time of day straight after a meal, so you have to eat before you go, whenever that is. I was at a meeting this morning, about 11 o'clock so I had to have something to eat before I went because I knew I wouldn't be getting home before 1 and I usually have lunch at about 12. But the hypos have at least stopped for the time being
- I don't think I've ever had one. I feel lethargic at times but I can probably put that down to the day I've had and the job I'm in, rather than to the diabetes
- Not at all that I'm particularly aware of. I've never got to point where I've felt unwell and tested my sugar and found it to be very low. It has been down at about 3, but – I'm a fairly robust person
- I get shaky and lethargic a few times a week if I don't eat on time
- I have not had any attacks since I was diagnosed, but I do get a bit shaky in the night
- They aren't regular, but I tend to get them quite often. Usually it's every couple of weeks or so, but just lately I've been getting very high sugar instead of low, so it's about a month since my last one
- The bad hypos, when you go down to 2s and things, maybe once every eight months or so. But the 4s and 3s are a bit more common. I would say every three weeks or month. I know exactly when they're coming
- I've actually just changed departments at work and I've had quite a lot recently because I'm a lot more energetic at work so I'm trying to change my insulin regime to try and control that, but I'm not quite there yet. I'd say a couple a week at the moment. I was just basically on the tills, and I was doing insulin for being just in one place, but they've moved me up to photographic and electrical and I'm running around in the stockroom and being a lot more energetic and it's messed my diabetes up

5 How severe are your hypos?

- Not desperately. I get quite a lot of warning, and I seem to be able to function for quite a long time, so I can be as low as 2.3 or 2.4 and still functioning. I just drink Lucozade. Half a bottle's usually enough to bring me back up to normal. It depends how low it is – if it's in the 2s I'll probably drink a full bottle, then try and eat something a bit more solid

- Not too bad, they seem to go in phases where I'll have maybe two weeks of hypos while I readjust my insulin and then it settles itself down again. But I can normally feel them coming on as soon as my blood hits about 4
- Clinically I can go right down to about 1.2, 2 – but I've got good warning signs so I know what to do and I can move quick when it starts, get some sugar down the neck fairly pronto, no messing. So I can usually divert it by getting something to eat. I am accomplished enough. In 57 years I have only ever had two interventions when I've needed medical help
- Very bad when I get them. I hate them
- At night, I get really bad, deep hypos. [My husband] wakes me up and I get really sweaty and completely out of it. If he catches it early enough and I am responsive, it's ok because we have cereal bars by the bed and he makes me eat one. I'm never unconscious but I can be quite obstinate and refuse to eat it. I'm lucky if he's around. Occasionally I've woken up and the bed's been really damp with sweat and I know I've had one and come back. But if I have a hypo during the day it's just a half-hour incident. I don't go as low because I catch the symptoms. It's really like being slightly drunk, I don't know how else to describe it. If you go to pick up a glass and you miss it – it's that sort of misjudgment. And not being able to work things out. Sometimes it takes me a while to recognise it, usually if I'm playing tennis or something so you kind of expect to get a bit weary anyway, and I might put it down to that at first, or to not having had lunch, so it's harder to pick it up. But at work it's easier to recognise the symptoms when they start
- I wouldn't say they are severe because I do feel when the sugar's going. The other night it was 2.8 when I woke up and it did take quite a while for that to come back, but on the whole I feel as though I manage things quite well
- Not too bad, but it's more a question of how you relate to other people when you're feeling like that. And I wouldn't want to drive like that
- Not very
- Not very. I get very shaky and I feel sort of down in the dumps and exhausted
- I would begin to feel off and if I didn't get something fairly quickly, once they started it was like a snowball down a hill, it would take you over. They were quite frightening
- They were both really bad. I had to have an ambulance both times
- They aren't severe, because I can stop them. I can usually treat them early
- Quite bad at the time. I wake up feeling really shaky and a bit sick. My husband has to help me, a sugary drink usually does the trick
- Not very
Most of them aren't too bad, but my last bad one, I was doing a thing for Diabetes UK, a charity weekend with Tesco, I was a team leader. And they had 4 money boxes round the place. There were supposed to be 5 people helping us over the weekend and 3 of them cancelled and only 2 turned up in the morning. But the afternoon I was there totally by myself looking after these 4 buckets. And I had to run to the toilet, with the security guy looking after them for me and run back, I didn't even manage to get a cup of tea. So I gave the shop and the staff a demonstration of a hypo, because the next thing I knew there was an ambulance there
- It's quite good in that I still get warning signs. I kind of, my vision goes a little bit blurry. I feel a bit like I can't concentrate or process information quickly, and I get this kind of feeling in my stomach which I can't describe really. And sometimes I'll come over in a cold sweat so I know quite quickly once it drops below 3.9
- Very. My husband has to deal with it because I'm out of it

- I get hypo symptoms but not fully disabling hypos. I feel sweaty, shaky, that would be it really
- My blood sugar is usually about 2.5 and I recognise the symptoms quite quickly, but in theory I am more controlled now with my blood sugar, so my hypo is registering a lot lower than it used to. So I am quite shaky and my vision goes, that's one of my first symptoms, I get quite confused. I don't need other people to help me because I recognise my own symptoms so I'm quite lucky in that respect. I've always got dextrol tablets on me, especially since I've changed departments I carry them in my pocket, my boss said that was fine so I can handle it straight away rather than wasting any more time off the shop floor. So I have glucose tablets then something with some carbs, a slice of bread, something like that, to try and level off my blood sugar a bit

6 What do you think causes you to have a hypo?

- It varies, it can be to do with activity. Certainly this pregnancy it's been to do with food – I just haven't felt hungry, so I just haven't been as good at eating at regular times so I've been letting it go a bit too long. And then sometimes I just get the equation wrong – or too much guesswork when you look at a plate and try and guess what the carbohydrate is in it, and you don't always get it right. When I'm at work I get them a bit, especially now my job is quite sedentary. When I had a more active job, I'd spend the whole day up and down stairs, checking spaces, talking to people, and was rarely at a desk, which would have meant that my metabolism was much higher, and also there was less change between weekday and weekends so I had fewer hypos
- Losing weight. Types of food that I eat, certain food has a higher GI so the insulin stays in longer than the food. And exercise
- Generally, I've been careless. You can always trace a hypo to carelessness, usually when I've misjudged something. I probably haven't eaten enough
- I can usually trace back to why. I've played tennis, I've cycled, I've walked or done something, and just got the amount of sugar wrong. Or sometimes I'm getting over being ill. And sometimes it's just random
- Not keeping control of my blood sugars, and not checking them. And if I do exercise I'm very odd because the nurse said if I exercise my blood sugar would go down and not to take as much insulin. Well, my blood sugar goes up, and then about five or six hours later I have a quite a drastic drop. So if my sugar's a bit high after exercise I'll take a bit more insulin with my tea and then it'll have a massive effect later on
- Always food-related. I can guess when my blood sugar is dropping. Sometimes I've done a test then, and it's still shown all right. But I know for me it's not the level so much as the rate at which it starts to drop. Or if I've had my evening meal early, I might start to wilt a bit later. And I think sometimes if I'm fighting off an infection – although of course you don't always know that you are
- Not eating enough or at the right time, and being late with my medication
- Not enough food, depending on what insulin I've taken
- Not eating at the right time, leaving it too long between meals. I learned the lesson early that you eat carbohydrates, you don't try and lose weight without eating them because they keep you going
- They have both been when I had infections

- It depends what I've got on during the day, if I'm very busy and if I haven't had food. With working it's difficult to do things regularly. I usually stop it by eating sugary stuff. It happens when I've skipped a meal or not had anything for a couple of hours
- It's really hard to say. I always test my blood sugar levels in the evening, and if they are low I'll have a piece of toast before I go to bed – but sometimes I still get a hypo in the night, even if I've eaten something before I go to bed. Sometimes I think it's caused by sex – if we have sex when we go to bed, I'm a bit more likely to have a hypo a couple of hours later because it's physical and I don't always take that into account. But other times it just seems random – there's never really a pattern. If there was, I think I'd be able to control it better. I put a lot down to hormones
- It's probably my own fault because a lot of times I miss breakfast, and if I'm not eating at regular intervals, that's what does it with me. I just get busy and I get engrossed and I lose track of time and ...
- Work, and what is the worst that gets me is stress. You don't realise you're under stress but I'm an electrician and if there's a fault I've got to find it in some electric circuit and the next thing you're working away and before you turn round you're getting hot you think right I'd better check me blood. I never know when I get up for work in the morning what I'm going to be doing, whether it's up in ceilings or up ladders, whatever. it's totally different every day
- Me miscalculating how much carbohydrate is in food. I am quite good at it, but sometimes it might be that it's got a lot of sugar or fat in it. Exercise – if I exercise or not even proper exercise, it could be just going shopping. So walking round the shops I often have a hypo in the MetroCentre. If I do any sort of physical exertion in the hour or two after I eat, because it speeds up the absorption, that usually causes me to have a hypo. Me misjudging, for example, if I take some insulin to counteract having chocolate. If I check a couple of hours later, me misjudging that high when it's just a sugar high I can panic and take insulin and then it'll drop down later. The heat, the cold . . . pretty much everything causes hypos
- Stress. Worry about my kids. And I think it's when I'm not well, whether it's an infection or I'm getting a cold, as well
- It depends on what I've been doing, sometimes it's exercise or it could be that I haven't had enough to eat and too much insulin. Too much exercise and not enough food really
- Physical activity. I've done a carb counting course through a hospital so I balance my carbs with my insulin – I've got a bit of a ratio with that, but with the physical activity as well, if I get that wrong, basically, that's why I'm having the problems at the moment
- Before, when they were in the night: I'm on two different types of insulin, glargine the 24-hour insulin and also humalog at every meal. I was basically on the wrong dose of glargine, I was taking it at the evening meal so I was having too much insulin in the evening and that was affecting my blood sugar at night. But I'd started having seizures because of it, and that's how they worked it out. They'd given me a meter that was attached into my stomach so they were testing my blood sugar every five minutes for three days and it was registering that it was going below 1 through the night and that was why I was having seizures. So I've completely flipped my insulin regime round after that, so I don't I don't have as severe hypos as that now
- Sometimes diabetic nurses are saying you have to reduce your overall blood count. And I think 'you don't know what that's like, to be having hypos all the time'

7 Do you have them at any particular time of day, or more often on some days than others?

- First thing in the morning, after low sugar levels overnight. And quite often mid-late afternoon, teatime-ish. And at weekends – during the week I have a mainly desk-based job, but at weekends we tend to be more active
- Night time are most common. I wake up hypo
- When I had them, it normally happened on a Sunday morning. I go to church at half past 10 and set up and then I'm busy through the service. I was having my normal breakfast but, where I would normally eat at work at half ten or something, I was going through until 12 o'clock. I actually tested my blood in church one Sunday morning and it was down to 2.2 – if it had gone any lower I'd have been out
- I used to get nocturnal ones, mainly very early mornings – 4,5,6 o'clock after my blood sugar has dropped overnight. But now they are what I call 'Martini hypos' – any time, any place, anywhere
- I get them more at night, or first thing in the morning, than during the day. Sometimes I've been woken up in the night with it. And I get night hypos when I'm on a diet and I've not had enough carbohydrate. I'm always on diets. But I do sometimes get them during the day, too.
- I usually get them at night. During the day I might get a symptom, but I'll recognise it and treat it
- Usually in the night. That's probably my own fault because I don't check my blood sugars as much as I should in the evening. I do check it regularly during the day. But sometimes before you go to bed you can't be bothered and then I wake up about two hours later and think 'Oh, I should have done that'
- It's usually mid to late morning, not every day but that's most regularly. I have had it late at night – going to bed and I suddenly feel wooshy. What I generally do is I carry round some Scottish oatcakes. People implore me to take sugary things but I try to avoid those. I prefer to eat complex carbohydrates, and they tend to work within about half an hour
- Not particularly. I know when my low times are, which is normally about three o'clock in the afternoon and then again about 9 at night. But if you eat before then and look after yourself, you can normally control it
- Usually first thing in the morning
- Usually it was morning or lunchtime, but to be honest it could be any time. I'd just grab the Lucozade which was strategically placed all over the house. And occasionally I would wake up in the night not feeling well because I hadn't had supper, with trying to lose weight. But now I have a little bowl of cornflakes before I go to bed, and I'm all right until breakfast time
- Only really during the day, I don't get them at night
- Always at night, usually midnight or 1am
- Probably late afternoon
- More in the afternoon, about 3 o'clock in the afternoon if anything. Because some days I can't quite judge it
- It changes because I do a lot of monitoring now I'm backwards and forwards to the diabetes centre because I'm quite sensitive to insulin. So say for example I'm having highs, which I do have as well, at a certain point in the day I change one of my mealtimes or my overnight long-lasting insulin, even just by a half or one unit that can make me go low at a different time of the day, as a knock-on effect. Say for example the holiday I just went on, and I've been back nearly three weeks and I'm still getting back to normal. I went to America so with the time difference I think my

body's still getting back in the right cycle so I'm going high at a different time of the day that I didn't used to

- I only get them during the week, I don't get them during the day
- The most common time for me to experience hypos is through the night, it wakes me up. Depending on how bad the symptoms feel I would I check my BM or go straight for the glucose if I felt particularly bad. I always have something beside my bed, years of habit. I look like a midnight binge eater
- I was mostly having them in the middle of the night when I had the less active job and was able to control it better during the day, but now I'm having them in the middle of the day and not at night

8 How do you usually feel after a hypo?

- If it's just dropped down to between 3 and 4, then fine – you just get on with it. If it drops a bit lower, or at weekends where it's been more activity-based, I actually end up sweating and having a proper hypo as opposed to just feeling a bit disorientated, then sometimes I need to sleep it off. It'll leave me with a headache and just not feeling quite right. But I think I'm quite lucky from that point of view. I have friends who have hypos and the effects are very severe – they have to be off work afterwards
- Tired, heavy-eyed. That sort of thing
- Knackered. It used to take me the rest of the day to recover
- A bit washed out, tired, a bit headache, but after years of practice you just move on with what you're doing
- Rotten. Really tired, and I get a bad head
- I feel groggy the next day. It's not quite as bad as a hangover, but it's very similar. Often I get it wrong so my blood sugar then goes too high after being too low, so you're playing this rebound thing to get right. And after being really sweaty I get really cold so I have to have a shower to warm me up. It takes me ages to get going, the coldness lasts for ages
- I suppose within half an hour I'm back to normal. I have felt recently that I'm taking longer to come back. It used to be I'd have a glucose sweet or a glass of orange and within 5 or 10 minutes I'd feel ok again, but now it's taking more like half an hour
- OK, because I tend to head it off
- You feel ok after about 20 minutes but you do get a blinding headache right behind the eyes
- Usually I'm exhausted, and I still feel weak afterwards. But then sometimes you feel fine
- It takes a while for you to get your energy levels back. You just feel tired and lethargic and then you eat so much before you get your levels back.
- I have to resist the urge to shovel food down before the hypo's completely gone. But afterwards, I just want to sleep
- A bit tired
- It's strange, but you feel refreshed in a way. It's a bit like when you get an electric shock, not a big dangerous one but a small 240v shock. It's like your heart gets a jolt and two or three minutes later you actually feel on top of the world, you feel better

- Really tired, I often get a headache, I often feel quite – because obviously I have to have sugar sweets and then something with carbohydrate in, if that's not long after a meal and I'm full anyway, I feel a bit sort of nauseous
- I'm horrendous. I feel drained, tired, very lethargic, I just want to sleep, I don't want to see anybody. I just want to lie down and stay in bed
- Absolutely fine, no symptoms because I think my hypo awareness is quite good, so I can treat it quick enough so I don't have any side effects. In my life I've had two quite big hypos in 20 years. I did feel quite rotten afterwards but they were both when I was a child. I've never had anything like that since and I never feel bad after one really now
- Exhausted. I find that it wipes me out for the whole day really so as much as I'm back on form within about 5 minutes of having the sugar, that's not the end of the hypo really for me

9 Are you able to function completely normally after a hypo?

- Yes. I'm quite high functioning with a hypo anyway, I tend to just get on with it. I have been known to sit in meetings and chair them and all sorts of things whilst having quite a low blood sugar. You just have to get on with it
- Oh yes, I just get on with it. If you went for a lie down every time you dropped your blood sugar you would get nowhere fast
- I wouldn't say I can't function, but I feel really tired. I just want to lie there
- I am usually back to normal after about half an hour
- Not really. I still feel really tired and want to sleep forever the next day, and I feel so fuzzy-headed all through the day. Sometimes the school run in the morning is really hard if I've had a hypo in the night, because I'm still feeling very much . . . and it's just trying to remember everything to get ready in the morning. But usually after I've had a walk out in the fresh air it does tend to clear your head a bit – you just feel tired for the rest of the day
- It's not too long to feel normal. It depends how low I've got but I don't usually drop below 3. I went through a stage last year where I had quite a bad time, I was having a lot more hypos so I was losing my warning signs a bit and having bad ones, but at the moment I am noticing straight away and doing something about it, so I would say within an hour I'm all right. I'm probably more tired than I would be for the rest of the day, and a bit crap, but in general I can carry on. If it happens at work, at the time I can't really function too well, hold a conversation or a meeting or anything, but I can still respond. I wouldn't have to go home or anything
- I have to function normally, I've got two kids and one of them is severely disabled so I don't have much choice. But if I haven't got the kids and they're at school for the day, I'll go and lie down and let myself deal with my hypo the way I should. I've got to deal with the hypo based on what my options are that day – if I've got two kids running round the house then my hypo has to just suffer itself
- I have in the past very rarely had a series of hypers (if I'm coming off being ill where I've been very high because I've had extra insulin) where it can sometimes take a day or so to recover
- The only thing I've ever had is overtreating where I've gone a bit high, but usually I'm fine
- Yes, even though I'm feeling rubbish
- Yes, although I'm very tired

- Yes x 6
- Yes, within about 20-30 minutes x 4

10 Have you ever had to take time off work to recover from a hypo?

- I'm a teacher so I've had to take time out of a lesson. But my students are 16-18, so I can explain to them, then set them some work and sit down for a while
- No, because I only ever had them on Sundays
- Once about four years ago I had to come home from work – it was such a bad hypo nobody could understand me. My dad had to come and get me. I couldn't even manage to tell my boss I needed to go home, they thought I was drunk. That's the only time I've taken work off for a hypo
- When it's taken a long time to recover I have occasionally taken a half-day off but normally I'm perfectly fine. I have very rarely had severe hypos at work where I've had to come home and I've had the odd morning where I've been maybe an hour late, probably about twice a year. If I have a meeting that I just have to get to, then I tend to drag myself in. But the biggest thing for me is if I had to drive somewhere, I would be much more careful and I wouldn't drive after a hypo, so if I was planning to have to do something the next day where I would have to drive – most of my jobs I haven't needed to drive, but occasionally there has been a meeting or something I had to drive to – I wouldn't go. I'd go in to work, but I wouldn't drive a car
- Yes, it started as gestational diabetes and in the end I had to take early maternity leave because of everything that was happening, and because I was put more or less straight on to insulin and trying to get the levels right, it would happen a lot more frequently then because I was overdoing it rather than the other way round because you were always so conscious of trying to keep the levels really low, I would have them quite often. And with all that on top of the tiredness in pregnancy I would be quite wiped out for the next day. There was a few times I had to phone in sick, so I ended up going on early maternity leave because I just couldn't cope with it all the time
- No time off work to recover. Being self-employed, you can't. Nobody's going to pay you for being ill
- A couple of months ago I was unwell, I had a stomach bug. Because it had happened in the evening and because I had this bug I was eating food and I'd taken insulin but I wasn't digesting properly so then I had a hypo, I ate more food to try and bring the hypo up and that was making me feel more and more sick. So in the end, I just ended up being quite sick for a while and then I was able to recover the hypo. Because that had gone on for quite a while I didn't go to work the next day. But that was an extreme. I'd never usually have to take time off to recover
- Not in my current job because I only work part time, and with not having them as often now I'm quite lucky. But before I had the kids, yeah, I've had to
- Not if I've had one at work. But when I was having the seizures at night I was having them quite a lot because I was having to go into hospital with them, but not the ones I'm having during the day now
- When I moved to the department I've working in now I found out that one of the charge nurses had diabetes. I thought 'oh great, something in common. But he was quite put out by the fact that I was diabetic. I found out that was because he takes advantage of it quite a lot and it really frustrates me and he uses it as an excuse to be off on the sick all the time, he really takes the mick with it which frustrates the hell out of me. I get so annoyed I just feel like shaking him. He claims to have four

hypos a day – he doesn't at all, he just feels a bit hungry and goes for a Mars Bar. People always say to me 'you're not like that, why not?' and it's just not necessary to be like that.

- No x 8

11 Do you think diabetes has affected your ability to find work, to do your job well, or to keep your job?

- Once I had to see an Occupational Therapist before they would offer me a job. And certainly all the time I was a house manager, I wouldn't say my diabetes affected my job, I'd say my job affected my diabetes, because I tended to run my blood sugars slightly higher to make sure that I didn't have hypos, because it wasn't the sort of job where I could have a hypo. I was responsible for the venue and the safety of every person within it. I couldn't flake out
- Yes. I've been diabetic for a long time, so I've had complications like retinopathy, which leads to a lot of appointments. In a teacher's role they don't like you taking time off like that. And being diabetic I tend to get colds and things more often than other people, and it takes longer to get over them. I was made redundant from my last job while I've been on maternity leave. There were complications with the pregnancy, because of my diabetes, and my doctor signed me off for quite a period of time. The head was quite unsympathetic. The same when I lost the sight in one of my eyes. I had about eight lots of surgery and they were very unsympathetic about that as well. They did things like changing my role to driving while I was off, knowing that when I came back I'd be unable to drive, they increased my marking load and gave me more coursework subjects . . . it was awful. So I have no job to return to. I'm trying not to think about how to find another job after my maternity leave. And I'm worried about trying to get a reference from them. The pregnancy and the eye problems are all sorted now, they're historic events. My eyes are settled, the surgeon says the chances of it happening again are unlikely, I'm not going to get pregnant again. But I'm still concerned about getting a reference and that sort of thing
- I'm currently looking for another job. I haven't told them yet that I've got it [diabetes]. The form only asked if I had anything that affects my ability to do the job and I don't think it does because I'm aware of how to control it properly, so I haven't declared it yet. If they asked specifically if I had diabetes I would tell them because I wouldn't want to keep it back, but . . .
- Yes I do. When I was 17, 18 and wanted to get into nurse training I found it quite difficult, they weren't very keen to take an insulin-dependent diabetic. But in the end I found a training hospital that would, and went through my training no bother, and the rest was history – once I was in training and qualified, no bother. And of course this was 30-odd years ago
- I was offered this job [as a home carer], and then they withdrew the offer when they found I had diabetes. They were afraid I wouldn't be safe working in the community with old people. If I hadn't stuck up for myself and threatened to report them for discrimination, I wouldn't have got the job. People need to be much more aware of diabetes, especially employers. Sometimes I have to ask for a break at work, because it's dangerous to drive [from one elderly person's home to another]. They don't like it, they always say 'But you said you had it under control'. But there have never been any complaints about my work, I've had a lot of praise. But I do know some people in the company who have been promoted and I never have. I sometimes think it might be because of my diabetes

- For the career I've chosen I don't think it's made a difference at all, but when I left university, newly diagnosed, I had wanted to be a paramedic and it was a complete and utter no. But I've always been involved with different charities and it has made a difference to what I can do. I can't drive a minibus for them, for instance. I have a restricted licence, so there are the odd jobs with charities where driving a minibus might have been involved and I couldn't have applied. My control is good enough for it not to make a difference most of the time. There's been the odd meeting where I've had to leave when I've realised I'm really not functioning, but it hasn't had a big impact. I use my brain quite a lot at work, and if I've got a list of numbers and I can't add them up, then I know I'm heading for a hypo, but I don't go as low as I do at night, because I catch the symptoms. And I always have Lucozade in my drawer. I reckon if I had been in a job where I was physically responsible for people, if I'd been a teacher or something, it would have been a problem. But that's different from flying a desk.
- No, not my diabetes. I have other conditions that probably affected it more
- Before it was diagnosed I was driving for a living and I just couldn't keep my eyes open. But I drive again now as part of my job – I just stopped until I got it diagnosed and sorted. But it's fine again now. It's fine, and I keep sweets in the glove box. If I'm going on a long run I know to have me meal before I go out and not take my medication before I get there. But I've never been discriminated against or victimised for having diabetes. The only downside is if I'm doing some really strenuous work I have to break off to have something to eat to keep myself right. But where I work, they are brilliant about it
- I don't think it will have any effect on my career. I just want to live a normal life
- No, because you fit yourself around what you have to do. But like I say, you always have a biscuit in your bag, or those little bags of sugar that I filch from cafes. You know your symptoms and the minute you feel like that, you stop and have a biscuit. It's just coping mechanisms, and this is what you do
- No, I came out of the army after 2010 and I've pretty much walked straight into a job here after doing some volunteering here. I came out of the army on the Friday, and on the Monday I was working here. But fitting in appointments and getting to the GP for my prescription and then getting to the pharmacy out of working hours can be difficult. This is not a nine to five job, and I've got three appointments to arrange at the moment. It's hard to fit in
- I've never had any problems with fitness, I led a very active life up to the point of being diagnosed. But I am having problems now when I'm looking at presentations, focusing. I've got to be at the front there to see a presentation and I find difficulty reading, which I think the eye screening next week will identify that. What GPs do now, which is very good, they send you the paperwork and you book the appointment on your availability
- When I was first diagnosed I was in full-time employment and it didn't make any difference that I was aware of, I told colleagues I'd been diagnosed. And I asked them to let me know if I was displaying any bad temper or anything like that that they should tell me – because that's one of the indicators. And I identified myself in my employers' monitoring forms as a disabled person in the sense that I had a long term chronic illness. I took early retirement at 54 and worked on employment tribunals, and I always made a point of identifying myself and explaining about the breaks I would need and so on. It was never a problem. Now I'm a councillor I have less control over my own diary, but I do make sure I have fruit with me if I'm going to be a meeting over the middle of the day, things like that

- I think it was affecting me before I was diagnosed, because I was listless and tired and I wasn't sleeping very well either. I didn't feel well in myself and that affected me at work. But it doesn't affect me now
- I think it affects me at work, especially my memory. I am more forgetful than ever, I think it must affect that as well as not having enough energy
- It's mainly the fatigue – I'd like to have more energy and be more productive in my job as well as in other areas of my life
- I found that I just couldn't keep a clear head after I'd had a hypo, it was just one of those things where you just couldn't function properly. But I really don't think it would be a problem now because I know the warning signs. The hypos happen at night anyway, but I think even at work I would be able to cope with the fuzzy-headedness and that now, and I'd just be able to get on. I really don't think it would be an issue at work now. But at the time when I was first diagnosed, if I hadn't gone onto early maternity leave it would have caused problems while I was adjusting
- Not really, apart from occasional bouts of extreme fatigue. Then it's just a case of, as soon as I go home I go straight to bed
- I've been self-employed since I was 21, I had a five year apprenticeship before that so I've never been unemployed in my life
- It's never affected me getting work. I have never put it down on a form – until recently I didn't know it was counted as a disability. I would put it down now, but when I have interviews I always tell people I am diabetic, but I say it doesn't affect my work. I've been quite lucky, especially in my current job in that they are quite flexible and really understanding. Obviously I have more hospital appointments than most, especially when it's a bit up and down but they are absolutely fine with that. And they are aware that I might have to stop and check my blood sugar. Hospital appointments they are good about. It could just depend on my manager because they can make you take lieu time for them. In my previous job that wasn't NHS, it was a private company, I did have to make the time back up. I guess, because I've been able to control it relatively well I can still drive, which I have to do for my current job and my previous one. If it got to the point where I couldn't drive – I hope that won't ever happen – I think it would affect me then. But beside that I can't see it ever affecting me. There have been a couple of times at the start of the year when I was actually with a client when I had a hypo, which was a bit traumatic. One of the times I actually had to say I'm going to have to check [my blood sugar]. I work with learning disabilities, but luckily I was with a family member rather than the client themselves. She was quite nice, she gave me a Mars Bar. But fortunately that's not happened since
- I was first diagnosed as a student. When I was at university, because I was undiagnosed for a couple of months, it was going on at the time we had course work so I was really like lethargic and it did have an effect on my coursework I think. But they did allow me to put in personal extenuating circumstance forms
- No, not in the work that I've done in the past. I worked for the government and they were quite understanding about hospital appointments and diabetes as a whole, I've been quite lucky
- The insulin regime I'm on is designed specifically for shift work, and the doctors I'm under for my diabetes are very encouraging and very positive and never discourage me from doing anything. Occupational Health at work have been quite supportive as well, so it's fine
- Yes, when I was having seizures I'd just started a new job so I was having a lot of hospital appointments and I think that affected their opinion of me. I don't think they thought I was up the job because of my health. I had originally worked for the

company I'm with now, gone to work for the other company and I've come back now after the seizures and I've stayed here basically because they've been really good to me and quite understanding of it all, whereas I didn't think the other company was

- It's fine. But my job meant that I couldn't go on any of the courses about managing diabetes because they are in working hours and I don't get enough leave to be able to take time off to go to them
- Dafne (Dose Adjustment for Normal Eating) courses: I think it's probably really good and exciting – but they only run it on weekdays during the day – if you work you'd have to take holiday to attend it, which I'm afraid I've always refused to do because I resent that. I think they should do something at evenings and weekends for people who work. Because surely the point is that they should be helping people to live normal lives? I have said it to them, and they're always very apologetic and say oh yes, but we only work 9-4 and you go, 'well that's nice, but that's kind of when I work too'

EMERGENCY TREATMENT

12 Have you ever been to a hospital A&E department for a hypo?

| | Number of respondents | | % of respondents | |
|--------------|-----------------------|-----------|------------------|-------------|
| | Type 1 | Type 2 | Type 1 | Type 2 |
| Yes | 4 | 1 | 33.3 | 7.1 |
| No | 8 | 13 | 66.7 | 92.9 |
| Total | 12 | 14 | 100% | 100% |

- Yes, once, a couple of years in to being a diabetic. It was the first one where I'd been unable to function. I woke up and just couldn't do anything. I felt completely drunk. My foster son was there and he phoned my partner and he came and took me to hospital, I was literally crawling along the landing. I didn't know what was wrong at that time, it didn't click that it was to do with the diabetes. They gave me some glucose and I gradually came back. It was quite frightening. I don't think people who don't have hypos don't really understand what it's like. You do think you're dying. I was there for observation for about 6 hours, then once we realised what it was I was ok to go home
- Yes, about five years ago, because I had gastroenteritis and that just totally dehydrated us. My blood sugar had been fine first thing and I didn't fancy any breakfast, then I got a bit hungry at about 10 in the morning and I sat down with the grandkids and a packet of crisps and then I never knew anything until the paramedics were there trying to wake us up. My daughter rang the helpline and they said to give me spoonfuls of sugar, but she said as quick as she was spooning it in I was spitting it out because I hate sugar. I was in hospital about three or four days
- No. I nearly had to on the night I was ill because I was quite scared but we kind of said we'll give it 20 more minutes and then it was ok. I think I was quite reluctant to go because once you've had an emergency admission for diabetes you have to put it on your forms, your DVLA and things like that – but it was getting to the point where I thought it might be necessary
- Not for hypos as such, but for seizures I ended up in A&E, but once they realised it was diabetes-related they began to sort it out

13 Have you ever been to A&E by ambulance with a hypo?

| | Number of respondents | | % of respondents | |
|--------------|-----------------------|----------|------------------|-------------|
| | Type 1 | Type 2 | Type 1 | Type 2 |
| Yes | 2 | 1 | 50.0 | 100.0 |
| No | 2 | 0 | 50.0 | 0.0 |
| Total | 4 | 1 | 100% | 100% |

Responses only from those who had answered Yes to the previous question

- Twice, both a long time ago when I was newly diagnosed. It was at night and I couldn't be woken up. I hadn't been well and my blood sugar was all over the place. Friends were checking on me, and I was completely unrousable. So it was an ambulance both times
- This year I went a bit dehydrated with a kidney infection and my blood sugars were going up and down. So I called NHS helpline and they told us what to do and then they rang me back and my blood sugars had gone up to 7 point something, then they rang us back about an hour later and it had gone back down to just over 1. So they told us to have a big bowl of cereal and some bread and it went up again but it went back down to 1.7 so they sent an ambulance
- Yes, I've been rushed in in ambulances and everything – at least 20 times. When I was teenage I totally rebelled against the diabetes, I didn't want to do my injections, ate everything I shouldn't, without telling anybody and without correcting my insulin for it, so when I was 14 or 15 I did everything I shouldn't have. But the last time was 10 years ago, before I had my kids. was newly married and my husband freaked out – he gave me an injection instead of food, sent me the other way again

14 Have you ever been treated for a hypo by ambulance paramedics without going to A&E?

| | Number of respondents | | % of respondents | |
|--------------|-----------------------|-----------|------------------|-------------|
| | Type 1 | Type 2 | Type 1 | Type 2 |
| Yes | 4 | 0 | 33.3 | 0.0 |
| No | 8 | 14 | 66.7 | 100.0 |
| Total | 12 | 14 | 100% | 100% |

- On my 50th birthday I had to rush down to London to be interviewed for breakfast television about retinal screening, and it was a case of pack up the office and go. I went down, had an overnight in London, was up about 30'clock for GMTV, and then was interviewed two or three times from about 6 until 9, then got on the train about 10 to come home and I was shattered. I thought no, come on. Thought I'd had enough to eat on the train but hadn't, came home, rang the office, then was going to have some soup at about 5 but it was off. So I was sick all over the place, knew I should eat something but fell asleep because I was so tired. Partner brought me a cup of tea with loads of sugar but I fell asleep halfway through it. The next thing I knew, I think it was about 1 or 2, I woke up sitting on the edge of bed with two people in green overalls. It was the paramedics! I'd gone right out and my partner couldn't rouse me so he called them. Normally he knows what to do, but I'd gone too far. So I just got canulated and had lots of dextrose and glucose in. I came round and then had something to eat, they disappeared and I went to work next morning

- I was away in Glasgow for the weekend and I'd spent the whole day walking about and shopping. I hadn't really had enough to eat, and in the night I just lost consciousness and I was having a fit. My boyfriend couldn't wake me up so he dialled 999. I was woken up by paramedics injecting glucose. I do have an emergency supply, but I didn't take it to Glasgow with me because I'd had it for years and never had to use it
- Yes, I was treated by a paramedic in the car park after the Tesco event and they had to put 300 mls of glucose into me intravenously that time. But I got into the ambulance by myself. The ambulance guy said he'd never seen anyone so low but still able to function. They pumped the stuff into us and the manageress in Tesco brought me my dinner then I was back in action an hour and a half later
- Once, as a child. I was at school and I had quite a severe hypo. We couldn't get to the bottom of the cause, it may have been because I was a teenager and hormones were affecting my diabetes. That's the nearest I've got to any kind of intervention or treatment from another person. I was 14, so it was more embarrassing than frightening

15 Have you been admitted to hospital after emergency treatment?

| | Number of respondents | | % of respondents |
|--------------|-----------------------|-----------|------------------|
| | Type 1 | Type 2 | |
| Yes | 2 | 1 | |
| No | 10 | 13 | |
| Total | 12 | 14 | 100% |

Comment

- No, the paramedics did ask me if I wanted to go in, but I told them I didn't have time. I had a meeting the next morning
- No, they treated me on site. They wanted to take me in, but I didn't want to go. But they said if I felt unwell at all later on I'd have to go straight in
- Yes, I had to stay in for 24-hour observation both times
- Yes, for three days with a drip on
- Yes, most times for at least two nights. Normally with a telling off and everything else they could think of to stress how – I don't think it worked to be honest, it just made me more adamant not to listen

16 Were you seen by your diabetes care team after this event?

- When I was admitted as a child, yes. But as an adult, what planet are you on? No, I casually rang them and they said just you know, get back into the routine so I carried on as normal
- Yes, I can't remember who initiated it. I think I phoned them afterwards and arranged to see someone. I don't mind hypos if I can figure out what happened, so I tend to be very proactive in finding out why. It helps to have someone else look at the situation and offer explanations, 'Oh well, you've lost a lot of weight or you were very active that day, or . . .', another pair of eyes. I lost a lot of weight recently and ended up having a lot more hypos, and it took someone else to point out that I was still taking the same amount of insulin I'd been taking when I was 10lbs heavier

- No. I didn't tell them, I think once I'd realised what it was – I probably wouldn't have gone to hospital if I'd known. I would probably just have had some glucose. I have had one or two like that since. Not many, but I've known what it was and I've been able to get help at home
- Yes, I had an appointment with my own diabetes nurse afterwards. And the team from the hospital kept ringing me for several days afterwards to make sure I was all right. They were really good
- Yes, every time. I've had follow up appointments straight after. My consultants have always been informed that I was in and they've always come to see us when I was on the wards. As I got older, it was less telling off and more of a 'how are we going to stop it happening?' And 'can we change the insulin, can we change the regime, can we change to type of insulin?' I've been on the pump, I've gone from having two injections to now five, I've gone down the path of changing everything throughout the years to try and control it and stop things like this happening
- I spoke to them on the phone, I was still under the paediatric team at the time. They were very good, they knew everyone by name and had a good individual relationship with all the patients. They were very helpful and they tried to help me get to the bottom of why it happened, but we couldn't
- Yes, once they realised it was to do with my diabetes, to see how to change my regime and keep me under watchful eyes

GLUCOSE LEVELS

17 Do you test your blood sugar levels more often than usual, after a hypo?

Comment

- Not really. I've been in the habit of testing 8-10 times a day – I had nearly five years on IVF and it was important to get my blood sugars absolutely right – and now I'm just in that habit. So it's more a case of I do it a lot to start with. In fact, after a hypo you just know you're going to run high for a while so there's no point in checking it because it's not like I'm going to correct it to bring it down
- About the same – around four times a day
- Not really any more. I generally do about four a day anyway, give or take. I can trace why hypos happen so I don't really need to test after I've had one
- Yes. Most of the time I just check once a week because I sort of know how my body is and I don't need a reading. But I would check it after a hypo
- I'm not the world's best tester of my blood sugars. I'll test it if I think it's high or I think it's low. So, if I have had a hypo I'm more likely to test afterwards, especially if I'm doing something, if I'm going to play tennis or go walking, or do anything that will inconvenience anybody else, then I'll test. If I'm just at home and it's Saturday afternoon then I probably won't. I don't know why, it's not difficult and I don't dislike it, it's just a reluctance to bother
- I would check immediately afterwards until it was normal. But once it's back to normal, I'd do it the same as usual – about three times a day. I'm supposed to check it four times a day
- Yes, but mainly before if I'm concerned. Normally you're supposed to test them morning and night. But it hurts your fingers. So maybe in the morning if I can be bothered I'll do my bloods. But if I'm feeling a little bit woozy I'll test them then just to double check. But it hurts like hell to do them and your finger ends get a bit

scarred and then it's even harder to get the needle though, so I do it mainly if I'm concerned. You normally find after a hypo, if you take your jelly babies whatever and you take your blood 10 minutes later, you're creeping back up to 4 or 5, and you just feel better in yourself. You're not shaky, your breath isn't laboured, you just know your blood sugar levels are coming right

- Yes, I do – I check when I feel I'm having one, and then after, to see if it's any better. And if it's not any better I treat it again and then do it again
- I do it about twice a day but if they tend to be a bit on the low side I'll do them about four times a day. If it's about 7 I won't check until teatime unless I feel a bit wishy washy and not 100%. Then I'll check just in case to be on the safe side
- I don't have to test them myself yet – they just did them for me when I went for my first six-monthly check-up
- No, I hardly ever test it anyway. I think I last tested it about six weeks ago
- No, I test it several times a day anyway
- At the moment I test four times a day so because I test first thing in the morning and my hypos are at night it doesn't really change my testing because I would still test as normal when I get up. But if it was still fairly low in the morning I might take an extra reading at some point during the day, but generally I don't really need to do an extra test after a hypo because I already do it quite a lot
- No, I'd rather not know
- I already test myself about seven times a day, so I don't have to do it more often after a hypo
- I didn't used to check it much because when I was first diagnosed. I had what they call a honeymoon period where I was still producing a bit of my own insulin so I was quite stable for the first year, and for a while after that I didn't really test that much, but since things have gone a bit more unstable I test about seven times a day. It can range between possibly five and seven times, and I probably could get away with testing it slightly less but I think probably for me I like to be sure
- I might do one extra test after a hypo but I often find that when I've had a hypo I bounce high after it so I try to avoid testing for a bit afterwards because it can make me think I've gone high when that's just a reaction and it will usually settle
- Yes. Normally I'll do it twice a day but after a hypo – probably every time I eat something – 4,5 times, more. I end up with sore fingers!
- Not really, because there is usually a reason for a hypo so it's not like it's unexplained
- Yes, more often. Normally I would check my blood sugar before every meal and just before bed. When I've had a hypo I'd have checked it when I was actually thinking I was having one, and then half an hour and an hour after that, to check it's coming back up

18 What was your last blood sugar reading, and when was it measured?

Type 1:

- 3.3, this morning about four hours ago. With the pregnancy I'm trying to test between an hour and an hour and a half after meals
- 6.4 this morning
- 4.8 this morning

- 6.7 this afternoon at work. I walk home from work, it takes an hour and a half to two hours, so I need to be sure it's high enough for that. I have a snack in the afternoon because I know I'm going to walk for an hour or so
- 4.8 this morning. That's very good for me in the morning!
- 6 this morning. That's about normal for me before breakfast
- 8.5 this morning after breakfast
- 7.9 before lunch, 7.9
- 7.1 this morning, 7.1
- 7.2 this morning
- 5.5 at lunchtime. I test it first thing in the morning, then every time I eat
- 12-13, this week. That's a lot higher than it should be, but that's because I'm paranoid about not having hypos and I keep it high

Type 2:

- Just less than 6, about two weeks ago
- I took it this morning, it was 7.3. I'm happy with that, I was up to 35, 36 at one time
- 6.2, this morning
- My most recent test was 13.1 this morning. 13.1 is still very high but I will get it down further, I know I will
- My most recent test was 7.2 yesterday
- It was about 8, six weeks ago or so
- 20.1 this morning, straight after breakfast
- I think it was 5.9. I just get it done whenever I go to the doctor's which might be about twice a year. But they always say that I've still got really good control
- 4.6, at my last regular check-up
- I can't remember – I never do it, but my mum checked mine when she was doing hers. I think it was about 8 or 9

19 Are you confident that you know how to measure your blood sugar levels?

Comment

- I think the interesting thing is, as an individual I had annual appointments with a specialist, and if I'm very honest I'd say nobody really paid that much attention. Then, because I was trying for a baby I went on a pump for a year, and everybody got very very involved at that point, because obviously that was 'interesting'. So I started having to email the diabetic nurses at the clinic weekly with my results, and the more involved we got with the pregnancies, the more of all that there's been. The second I have the baby, everybody stops being interested
- What I would say is that I have developed good practice [in measuring blood sugar] because of key things that have happened a lot later in life. So there's a lot of stuff that maybe if it had been tackled more when I was in my teens – I'm perfectly functioning and fine, but I do have effects from the diabetes. I've had to have laser eye treatment and other little bits and bobs – the joints in my fingers are a bit stiff – which are all to do with poor control
- Yes, I know how to work out GIs and change my insulin. I do understand it all quite well, but they don't tell you. They give you a load of leaflets with it all on and how to do it, but they never actually sat and talked me through it. They do comment on my readings though.

- Yes, it's just one of those things. When I was diagnosed I just thought there's nothing I can do about it, I've got to get control of it and I did that quite quickly
- Yes, I've made it my purpose to understand my diabetes as well as I can
- Yes, and every six months at the clinic we get it all checked – but you know toughly what's what. My mam was diabetic, so you know roughly from her what to expect. And there's plenty of literature
- Yes. The only one I panic about is when it goes really high and it won't go down – but that's usually when I've been on antibiotics or steroids. But they tell us not to worry about it because it will go down when I stop taking the steroids. And it usually does
- *Through an interpreter:* Yes, every morning, before and after food. Then again a few hours after lunch and again before and after evening meals. Walks for an hour after meals, as advised by doctor, to control sugar levels. Readings in the UK tend to be higher than those in Hong Kong because she does more exercise (better weather!) in Hong Kong
- Yes. And I'm really impressed with the advancements in meters now
- Yes. I review it with the care team as long as I remember to take the book with me
- Yes x 11
- No, I just let them [*diabetes team*] do it x 3

20 Do you keep a monitoring diary of your blood sugar levels?

- I use an i-phone app to record my levels and I have to say, my first pregnancy round I was very very very good at filling in. This time I have been less good at maintaining it, but it's really useful whenever you can see things are changing. You can use it to spot the trends and it does graphs and the more information you put into it the more it splurges back out, and the better your control can be. I don't use it all the time to its full extent, but when I do it is brilliant. At the minute I email the results across to the Diabetes care team while I'm pregnant. They won't withdraw that offer after this pregnancy ends, but they will stop checking to see that I'm doing it. That's down to me – if I wanted to I should just keep doing it – but the occasional nudge from somebody saying 'come on we haven't heard from you for a while' would actually be quite helpful
- I don't keep a diary, I tend to just use the machine for that, and it's quite easy to pick up a pattern. I write it out for them when I go and visit and we discuss the results. I do get a response from them, but I know my doctor quite well now and he's happy for me to make suggestions and adjust things myself because I've had it for so long
- I don't keep a diary, no. I couldn't write it down anyway (*participant has diabetic retinopathy*) – but generally I know what I'm running at, and what I'm doing and not doing
- I have an app. The machine holds them and then I download them on to my i-phone I changed the meter about a year ago to one that would synchronise with my i-phone. You can have a trend chart that works out where you are. They always ask to see them at the clinic and they play around and look at the trends
- No, I just use the monitor
- No, just what's on the machine
- Yes, I keep a diary and take it in to the nurse at the clinic
- Yes, I've got a monitor and I do it morning, lunchtime and evenings. My GP practice is very personal, they'll phone you up and go into a lot of detail and tell you about

the risks and what can happen. I write my readings down in a book and take it to the GP with me when I go

- Yes, a detailed record in a notebook supplied by the doctor in Hong Kong
- Not probably as well as I should. I did used to do it religiously when I first got my diagnosis but now I tend to rely just on the meter itself because it does keep a record for so long as well. So if I need to check back it can give me a 7 day or 4 day record. The diabetes care team goes through the results with me when I see them
- I used to but I'm on a pump now so all the information's in there. It's downloaded on a computer and the nurses sort it all out
- I am at the moment. I tend to when it's unstable, or when I have a review coming up. I tend to do a diary for about a month beforehand
- No, I get told off for that at the diabetes centre. I do check but I don't write it down, I think because I've had it so long I know how to respond to the different readings. I just get on with it and don't see the need for recording it for the doctors
- That's where I'm not so good, I actually don't. but I've got a good meter that holds a thousand readings and I can download that onto my computer. I take the download to my reviews so I've got something to show them
- Yes
- No x 8
- N/a (don't have to test it yet) x 3

MEDICATION AND CARE

21 What medication do you take for your diabetes?

See main body of report

- *Via an interpreter:* There is a huge difference in approach between the UK and Hong Kong: doctors in UK do not generally advise patients to be on medication at the very beginning, but in Hong Kong they advise it straight away, including injections, to avoid all the possible side effects. People here think an injection means your condition is very severe, in Hong Kong it is much more common from the start. There is a lot of research in Hong Kong, indicating that injections defer the side effects of diabetes. It is the second biggest killer in Hong Kong after heart disease, so doctors there advise treatment as early as possible and Type 2 is taken much more seriously than in the UK

22 Do you feel you have any opportunity to make decisions about your medication?

- No, but I wouldn't want that. I know a lot about managing my condition, but I don't feel I have the knowledge to get involved in prescribing medication
- Yes. I wouldn't have it any other way. It's my condition and my responsibility. It did take some time [to get that level of trust with my doctor] and I know other people who go to the same doctor who don't have that level of relationship with him, but I find it quite scary just to put yourself in a doctor's hands. I know diabetics who don't even know how to count carbs. They just give themselves the same amount of insulin regardless of what they eat and then they wonder why they have a hypo
- When I went about my hypos, the doctor said to drop my Metformin down to one, but that doesn't give me any leeway even to have just the odd bit of sugar, like my

marmalade in the morning – so I decided to keep it at two a day, even though he kept the prescription at three a day. I haven't had any hypos since then

- They wouldn't dare. I decide what I'm doing and what I'm not. I'm an advisor to the Department of Health, on the retinal advisory committee. So if I don't know what I'm doing . . . so basically they usually let me get on with it.
- Overall, I'm in their hands because they know what's available and they make decisions about what to try when new things come up. But I think I'm party to those decisions – they'll say 'do you want to try this' and occasionally it won't work but we work it out
- I know to a certain extent what my tablets do, but I don't know enough to make those decisions. My actual dosage has been increased, and I think it is working. There was a stage, early on, when it was 19, it was 23, very very high. And the figure 23 meant nothing to me at that point. But with the assistance of Google these days you can find out more and take ownership of it, and that's what I've tried to do. But I don't want to be making the decisions about it
- We do try things out. Originally when I first had my baby I didn't go straight back on to insulin. It ended at the end of the pregnancy and they decided to put me on some other tablets for a few weeks but they didn't really control anything, I was starting to get really high readings again. So we decided I should go back on insulin because that really controlled things. And there's been a couple of times where I changed to exenatide injections. The first time it was great and I lost 10 kilos within the first couple of months. But it didn't control my sugars as well as the insulin and I was also trying to get pregnant again so I came off it. I went back on it after I'd had a miscarriage but the second time it didn't suit me – my sugars went crazy. Since then I've just been on insulin and Metformin. I may have to go on to a faster acting insulin. I'm involved in those discussions, but usually it is a case of doing whatever the consultant or whatever advises – after I've looked into it myself to make sure about side effects and so on. With having a child at home I don't want to go on anything that has difficult side effects
- I'll argue if I don't agree with what they're saying I'll tell them. I think after all these years I'm not frightened to say I don't want to that, or that's not what I want. And if I hear about something I'll ask about it. I feel I've got to be involved, it's my life. I feel if I can make the decisions then if it's wrong, fair enough. But if they make the decision and it's wrong I'd not be happy
- I'm quite active – because I've had it so long rather than because I'm a nurse. I was always encouraged as a child to adjust my dosage of my fast-acting insulin. I know a lot of people are quite wary of that because they're scared of the effects of too much or too little. But I'm quite confident with that and I'll tell the diabetes team what I do and they are actually quite happy with it, they support that because it helps even out my control. If you are confident and you know what you are doing they are quite keen for you to do that, more than happy
- I normally leave it to them and give it a go, then I'll say if it's not working for me. But I trust them to know what's best for me after all this time
- No, I let the doctor decide x 12

23 How long after your Type 2 diagnosis were you prescribed insulin?

- 12 years. I'm still tweaking it just to get it right. I'm nearly there now, it's took all these years to get this far. I was on tablets for ever and ever but I just got sick of trying out different tablets and some worked and then they didn't and some made

you feel sick. So last year I decided I wanted to go on insulin. The doctor said, 'well try this other stuff first, I forget what it was called, and I tried it and it just made me sick, and they've put me on this Miacin 3 (insulin), which is marvellous. I didn't want to go on insulin for a long time because I was afraid I'd lose me job and not be able to drive, but with type 2 they're not bothered as long as you're in control and not falling asleep behind the wheel

- About 4-5 years. I obviously hadn't been taking it that seriously, even though I'd been on the Desmond course and everything. But I wasn't controlling it well, so I ended up on insulin
- Probably about 3 years ago (after 15 years as a diabetic). I wasn't getting good sugar results (around 8 or 9), so the nurse referred me to the Newcastle General diabetic clinic. They suggested I tried this new medication that was being trialed, I can't remember what it's called now, but it's a kind of inject pen. It was also supposed to help you lose weight. But that didn't work for me, so after about 6 months the consultant suggested putting me on insulin. So I went through a programme of advice and counselling then eventually I went on insulin. They reduced the level of Metformin I was taking, from 1000mg twice a day, to 600mg twice a day plus the insulin. And during the training programme they advised me about adjusting my dose of insulin. As it happens I have more or less settled at a fairly fixed dose
- *Through an interpreter:* She has now been on medication for about four years. Nine months ago she was also put on insulin injections. She has difficulty controlling sugar levels so needs a strong dose of insulin to bring it down

24 How easy is it to fit your medication into your everyday life?

- Fine. There was a point when I just got old enough to stop caring what other people thought. When I was younger, and having to use syringes as opposed to the pen, I wouldn't even test my blood sugars in front of people because I was quite self-conscious and then there's a point at which you just go 'this is stupid, people really aren't watching, nobody cares' so now I just do my blood sugars and injections in front of people, and nobody bats an eyelid. It's much easier, and as a result I do believe I've got better control now
- Since being on the insulin pump, it's very easy. In the past when I was having to do injections I've had people asking me to go to the toilet to do it. Obviously I'd say no, but you do get discrimination from people, like in a staffroom. They can't cope with it. It's not hygienic to do it in a toilet. You're sticking a needle under your skin, and a toilet's not the right place to do that. When I was at school I had teachers trying to get me to do it in a cupboard – my parents had to go in and speak to them about it
- Very easy. I take with meals, breakfast and evening meal. It suits me best to take it after, although the prescription says you can take it with or after
- It's quite easy, because there's a framework and then you add on to that
- I have to inject, so it's difficult if you go out to eat or I'm out shopping. People do stare at you when you're at the table and you pull out a needle. But I prefer not to have to use a toilet, it's a bit uncomfortable
- Relatively easy. I've got a flexible plan that I can adjust to when I eat. I've been on all sorts of regimes over the years, and when I had the sort where I had to take a dose in the morning and then I had to have lunch at a set time, for the sort of job I was doing that was really hard. Somebody would have a 12 o'clock meeting, or a 1 o'clock meeting, and if you had to eat lunch at 12, it didn't give me the flexibility I

needed. Whereas now, because I can inject as I eat, I can delay food by an hour or half an hour. It gives me more flexibility. But I do have to have lunch, I can't skip it completely

- It doesn't bother me, even if I'm out. Normally I'm either wearing trousers or a skirt so it's quite easy to inject. My husband will sometimes joke about it and say 'are you still on that methadone' but it's not a problem. I think it's a lot more accepted now, and if people do comment I just say I'm diabetic
- No problem, I get up in the morning and do it [insulin], then when I get home I make myself a cup of tea and I sit down and do it then. The wife puts me tablets out in advance on a tray. I don't think I could do it any better, unless they come up with some miracle cure where I can come off everything altogether
- It's fine, I'm just that used to it now
- It's not a problem to me, because I'm just used to taking meds. I don't enjoy sticking needles in, but I know there's no alternative. I've got to do it
- I take if first thing in the morning and with my meal in the evening, so I don't have to bring any medication into work, so that's not a problem. On holiday this year I took all my medication and there wasn't a problem with that, and my monitor as well and I think I probably ate better over there, because I had time to do so, than when I'm at work
- I have a dispenser thing, so normally on a Sunday teatime I take the bedtime ones out and fill a little pot then I take the whole lot out and put them in the dispenser for the week. That stops me getting confused about what I've taken
- Fairly easy because my family and friends all know I'm an insulin-dependent diabetic so they are quite used to me whipping out my inject pen in front of them – or I'll turn my back if I think anyone might be a bit squeamish. But it's important for medics who are responsible for treating diabetes, to be as open and transparent as they can about the side effects of any treatment
- Absolutely fine. It made me feel a bit sick when I first went on it, but they had warned me that might happen so I was prepared for it. And it's fine now
- Ok, but I'm a bit forgetful these days so I do sometimes take it a bit too late
- I do take them regularly. I may be a bit blasé about other things, but I never miss that
- *Through an interpreter:* It's ok, although the needle does feel a bit blunt sometimes
- It's pretty easy, I'm so used to doing the injections now and to be honest I've been on other medication since my teens, for a thyroid problem and also for polycystic ovaries, so I'm just in the habit. I used to think it was hard to find somewhere to inject insulin if we were out anywhere, but now I don't really find it that bad to inject in front of people so it's ok
- It's no problem, I just have it as soon as I get up in the morning then it's over and done with
- It's so much more convenient now with the pump. When I was a kid those needles got so blunt, it used to make me scream because the skin on my arms got very tough
- It's a bit tedious, but the actual act of taking it is not a hardship unless it hurts a bit, which it sometimes does. It's more the thing of being quite limited in when you can eat, because I've found if I go out for a meal and it's a bit later than normal that has a knock-on effect. So I end up in this routine of eating the same time every single day, which in terms of eating out is ridiculous. I find that really hard, because I was in the habit of eating out a lot because I love food, it's just impossible to tell what's in it. Even going to a friend's house, having to say 'Can I weigh my potatoes please?' it's just a bit awkward doing that so you guess and you might not get it

right. My partner's just moved in in the last five months. I find that when we have a meal he's sat down and halfway through his tea before I've had a chance to test my blood sugar and worked out what insulin I'm going to take for it. But you get used to it. It's just every now and again you kind of go, 'Really? Do I have to?'

- Not easy. It's quite easy to go out in the morning and think you're going to be back in time for injections at lunchtime and you're not, but you've still got to have your lunch. So it's remembering to take things with you, or having a set in the car, or in my bag. And when you've got two kids, one with severe cerebral palsy and the other one who was 12 weeks prem and on oxygen for a year and you're struggling with your own health, it's mine that gets left. It's getting better now that they're getting older, but it's still really hard when you work and you've got a life. It's a struggle to do it, but if you don't it's like they keep threatening you, you'll die. There's days when you just think I can't be bothered to do this any more and you don't, but then you start getting the bad head and the uncomfortableness and the mood swings and you think it's probably easier just to do them
- Very easy. I don't have many problems with people being offended. I don't make a big scene about my injections, I'm quite discreet. But I will do it in front of people and not hide it. I'm not embarrassed and I prefer people, if they see me, to ask what I'm doing and why. But I don't want to cause a show
- It's easy now. I've changed my routine that much, but what I'm on now really suits me. I've never had a problem with doing my actual injections, it's more the organisation around diabetes
- We're kind of giving it a few more months to see if I can control it myself, and then we're considering the pump. I'm not sure about that – I kind of want to talk to someone who's got one, because it's quite a life change. But I just feel like it would be helpful to my health. My highs and lows aren't constant, I do have stable periods, but I can't imagine that this many highs and lows can be good for my health in the long run. But I'm not at that stage yet
- I can handle the tablets and all that, but I think if I have to start having injections it will have an impact

25 How often do you get your feet checked?

- At my annual check. It's not one of my problems, but I would go and get it looked at if I was losing sensation or anything
- It should be yearly, but I've been asking for an appointment for the past three years and I still haven't had one. I'm trying to get them checked
- Once a year. I don't have any problems with my feet, so that's fine
- I mean it's been very patchy in the last few years. I had quite a regular routine when I lived in South Tyneside, but that seemed to start to fall apart. And then when I moved to Morpeth in 2010 – I may have had my feet checked once since then, but I'm not entirely sure. I have paid privately to see a podiatrist recently, partly because I've had some problems with planter fasciitis. But I've lost weight now, and since I've lost weight it has entirely gone away. And he checked me over and my feet seemed to be fine. I recently had diabetic eye screening at the new doctor's surgery, but I'm not sure where I'm supposed to for podiatry. I have had doctors say I'll put you down for podiatry, but then I've never heard from anyone again, I suppose because they are so stretched. [my partner] is quite a stickler about diabetes and she says you should never even cut your own toenail if you've got it,

but if I'd waited for a podiatry appointment they'd have been growing out through my shoes by now

- Every 3 months. I find that's enough, but then I look after my feet. And I know what to do if anything's not quite kosher
- Yearly, as part of my regular checks and my eye screening. Nothing has come up so far
- Every six months, as part of my regular check-up
- Once a year as part of my regular check-up, and then a couple more times to keep an eye on an ingrown toenail
- Once a year, I call it my MOT and they do it. But I do take care of my feet, I pedicure them myself and make sure they're not getting any spots or scabs or cracks, if I do think they aren't right I just go to the doctor and get some powder to put on, to nip it in the bud. But they are checked once a year when I go in
- Every six months or yearly, I can't remember. But I don't have any problems with them
- I get them done three times a year and then again at the annual check. It used to be four times, but the podiatry services are so hard-pressed, the girls themselves are very good but the service can't really cope with the demand. They've told me if I have any problems I must ring them so they can see me as soon as possible
- It's every six months. And I know that a lot of diabetics have problems with their feet. But I think that, being in the military, I look after my feet. I've always kept them clean, powdered. And I was very conscious of my footwear when I was on holiday. Before I was diagnosed, in Turkey last year, my feet burnt. So I've learned this year to wear shoes and protect my feet and wear sandals in the sea and so on
- They do it every six months at the diabetic review then go I to the chiropodist every six weeks for hard skin on my heels
- For me it's about six monthly. It's fine. I did have, or I have some problems orthotically and it builds up callouses on my feet, which they think might be diabetes-related. It has the potential if you've got lots of callouses, for you not to see that you're losing feeling. So they keep a closer watch on me because I'm diabetic
- At least once a year. I have an annual check-up where they measure whether the blood is flowing, and they do a tingle test. And I'm supplied with foot cream. But I am very careful with them and I avoid bad habits
- I had them done for the first time at my check-up. Everything was ok
- No, I've never been referred to podiatry. But my feet are quite healthy
- I had them done about a year ago. They seem ok
- *Through an interpreter:* Every three months in Hong Kong, by a diabetes specialist. She has some pain in her right foot because of diabetes. Takes vitamin B to try and counteract and improve the sensation
- At my annual review
- Yes, annually at a regular test. They are ok at the moment but I did have a period where I did have some sensory loss. So I was put in touch with a podiatrist because I have one foot that was pretty calloused. I saw the podiatrist for about nine months and that seems to have rectified the situation now
- A minimum of once a year. I've got pretty good sensations. I've still got tickly feet!
- I didn't know I was meant to have them, nobody's ever told me. I think I had them checked once before, then recently my practice sent me an appointment to go and get them checked. So it's just starting, I've no problems with my feet so far

- Every time I go to the diabetic clinic, and it they think there's an issue or I want to see the podiatrist I can book an appointment. But I haven't got any issues with my feet
- Yearly. For years I'd never seen anyone apart from the diabetes people and doctors. They would check my feet at my annual review. Then when I was in my early 20s I started getting appointments randomly to see a podiatrist yearly, which I did, then apparently policy changed with regard to podiatrists and they didn't need to see me any more. And now it's just purely the diabetes team once a year. That seems fine, I don't have any problems with my feet
- I go to the hospital for a diabetes check-up every six months, and I have it then, they're in quite good shape

26 Do you have regular scheduled visits to a healthcare professional to check and discuss your diabetes?

- I have an annual check, but have just changed from seeing a specialist at the hospital. After the last pregnancy, I had trouble getting and keeping the appointment and it just got delayed for ever and ever. So I ended up going to see the diabetes doctor at my local GP's instead, who I've actually got on very well with. And they do regular appointments so at the moment because she doesn't know me that well, she's seeing me six-monthly and then that will go to annual. There's an element of it just being a bit easier, because you can plan when you want to go, which at the hospital you can't do – you have to go when they tell you, and if you can't make that appointment you can get a four or six month delay – whereas at the doctor's, they'll see you next week. And if I want referring back to the hospital I can ask for that at any point
- Yes, I see the diabetes doctor every 6 months, and my eye specialist every 6 months
- Yes, it's down to every six months. It was once every three months before, which was a pain. I get my blood taken one week and then I have to go back a week later to see her. I have to get out of work early so on those days I usually work through my lunch hour so I can go early. They [employers] moan, but I have to do it
- I have a yearly review, but also probably 3-4monthly visits to the Diabetes Centre as well
- Yes, it's down to once a year now. I used to have to go every six months, but once a year is fine
- Yes, every six months. It's about right – and if I was concerned about anything I'd ring them
- Once every six months
- Yes, every six months
- Once a year. It's fine, and again they say I must ring if I need them
- They have a morning diabetes clinic and I have to take a day off to go to it, that's a nuisance. This company will be fine with it, but I know if I worked with another employer I'd have to take a day's sick
- Six months, that's fine. If I have any problems she said to ring up and they'll see me in a couple of days
- I have an annual review then often another one about 6 monthly. I have a specialist who I know and trust and who 'gets' me now, and when I go to the clinic I'll wait longer so I can and see her, rather than having to start explaining everything all over again every time

- It used to be quarterly, but I've adjusted it down to every 4 months, which suits me better
- Yes, I'll be going every six months
- Yes, I have a six monthly check at the specialist doctor and then I see my GP. And I also have retinal checks
- Once a year. I'm happy with that as long as they are
- *Through an interpreter:* Every three months in Hong Kong. Most of her treatment is in Hong Kong because she is spending so much time there looking after her parents. She contacts her GP in UK when she is here, but has to be reassessed because it's so long since she has been in UK to see him. She has an appointment next week
- It's usually an annual review, but because I'm trying to get pregnant again I am also going to a pre-conception advice clinic and I can discuss things there. They really take a good look at the blood sugar readings – we're always going over them and it's really closely monitored
- I usually go to see the practice nurse who does my bloods and we have a good chat about everything. She's good, but she's never asked us if I have these funny turns and I've never associated them with diabetes before just now
- Normally every 4, 6 months. Basically that's fine. I've got loads of diabetic nurses' emails, which is ideal if I want to ask any little questions I can always get support. The nurses are spot on. If they left I would have to start with somebody else, and they'd have to build up an understanding of what I'm like
- An annual check with six month follow-up, then if I'm struggling they give me more appointments. I'm in the middle of a lot of appointments at the moment, just to see how I'm getting on because I do change so much
- Annual review plus a six monthly visit. Any more would be hard to fit in. With appointments for me and both of my kids, and my husband's got coeliac disease so trying to fit more appointments in, with work and school and life, would be too much. I know if there's been issues in the past, I ended up with retinopathy I had more frequent appointments, so if there's an issue they'll ask for us every three months but if there's nothing that anybody's worrying about six months is fine. The retinopathy's ok now. I get me eyes tested regularly and for the last few years there's been no change. Which means I can keep my driving licence
- I have my annual review, and every three months for follow up. It feels like quite a lot, I don't get much out of the follow-up appointments, I do think why are we bothering, what have I achieved from coming along and it's a bit frustrating going for something you've had for years. I would prefer just an annual review and then if there were problems, the option of an extra appointment
- Every six months. I used to have four a year but the two at the moment suits me

ADDITIONAL COMMENTS

Public awareness and stigmatisation

- It tends to be type 2 that's featured in the news and the media don't bother to explain, so people just lump the two together. I think they put it across very badly. They talk about it being on the increase. Type 2 quite possibly is on the increase because of lifestyles, but it's not the same. And a lot of people don't understand about gestational diabetes. I had people who'd known me before I got pregnant and even they were asking if it would get better after I'd had the baby

- There's a lot of discrimination against people with Type 2. As soon as I mention anything about being Type 2, because I'm younger it's automatically assumed that it's my fault, that it's a lifestyle thing. I'm not underweight but I do try to control my weight really well and I'm certainly not obese and I wasn't before I had my baby either – obviously with me something triggered the gestational diabetes and it just didn't go away, but I do try to have a good lifestyle. I'm active and I eat well, and I do find a lot of the time that I get a lot of prejudice from people who assume that it's my fault. Even within the Diabetes Centre itself, I've been in a few groups, with the Women's Health for the pre-conception, and obviously a lot of the other women were round about my age and all the others in the group were Type 1 diabetes, I was the only one who had Type 2 – and I think even they looked at it as, well, you know, at your age – I do find, more than the medication or the side effects or anything, that that's really hard. I know in some cases it is due to weight and a bad lifestyle, but there are lots of people who do that and don't end up with diabetes, so there's obviously something else there – but I hate the way people assume that if you've got Type 2 it's your fault
- There's a lot of ignorance and discrimination out there. As a child it hits you harder than as an adult – you do get quite thick-skinned. But it's frustrating, especially when people don't understand the difference between Type 1 and Type 2, and start telling you you've got diabetes because it's your own fault
- I think a lot of type 1s would actually prefer it if type 2 wasn't actually called diabetes, because they are different. I put on a lot of weight when I was pregnant, not because of I ate too much sugary food, but people assume that's why I was diabetic, they actually say that to you
- I had no idea about diabetes until I was diagnosed. Now I understand about it, but before I was diagnosed and started having hypos I had no idea. And then you start to take notice, but it's a shame you don't take notice before it's too late. You put a little bit of weight on, you don't think too much about it, but more attention needs to be drawn to these facts so people understand that yes, they are making themselves ill without realising it. You think you're living well, but you're not, you're making yourself ill
- Another thing is people not understanding, particularly friends not understanding. I didn't go out drinking loads before, but I was 18, 19 and I did go out every other weekend. Now I can still drink but it's obviously not good for me and it just has such a knock-on effect, like for example I go out on a Saturday night, for some reason hangovers make me feel like I'm having a hypo and it's just impossible to keep control of your blood sugar when you've got a hangover. I always feel I don't want to waste a whole day of my weekend like that, so I tend not to go out so much any more. Or if I do I tend not to drink as much. Some friends have been very understanding of that, but some friends just can't comprehend that I'm not boring, it's just that I don't like – I care about my health. So just in general other people's understanding of it does affect you
- I am fully aware why I got diabetes – I heard a comedian on the radio recently. She said there are two types of diabetes – Type 1 and Type It's Your Fault. I was very overweight, so I'm one of the 'Your Fault' people

Non-specialist medical knowledge

- Because I've been in contact with hospitals a lot with my two pregnancies, I've come up against the sheer ignorance within the medical profession about diabetes. At the point where I'm on the maternity ward, I've got access to the diabetes nurse if it's between 9 and 4 and they can get hold of her. But you take your own Lucozade in, you take your own snacks, because if anything happens there is nothing there

that you can get access to and nobody who knows what to do if you're having a hypo. And of course, in the world where doctors get sued, they have protocols. Now, protocols are good and I know they are based on best practice for an average person, but when I was having my baby I ended up having a four-hour hypo because they insisted on taking over the management of my insulin and giving me insulin. And I said 'I don't think I'm going to need any insulin, this is going to be quite active' but they insisted on giving me it and then they wouldn't give me any glucose. And you need about 50 grams of carbohydrate minimum to settle it, but they said 'oh no we can't, the protocol won't let us' and it was excruciating. The common sense element and the thing about treating people as individuals went right out of the window

- You have within the health services people who are experts in particular conditions, but actually generic understanding across the board is fairly poor. And they don't talk to each other!
- Maybe it's just me, but I've found you have to put your foot down if you are being treated for something else by medics who don't know much about diabetes. I have friends with diabetes who had real problems while they were in labour. I didn't, but then I always tend to say 'It's my condition, I need to deal with it'. And they did, they just let me get on with it
- Years ago I had an infection in my penis, and eventually it was identified as a side effect of undiagnosed diabetes. GPs don't know about connections like that. I think more needs to be done about ensuring GPs know more about it so they can identify it. I know they can't be experts in everything but there is a lot of undiagnosed diabetes about
- My sister's diabetic and we almost lost her last year. She had a very bad hypo, her blood sugar went right down to 1, and when the paramedics came they poured masses of orange juice down her, so in the end her blood sugar shot up and she went hyper. It made me wonder whether paramedics understand enough about diabetes
- This is purely on the experience I've been having recently because I've spent a lot of time in hospitals – but as the population is ageing and you end up with more insulin-dependent diabetics in hospital, and some will have dementia, I wonder whether Type 1 diabetics who may be starting to live with dementia and other conditions, and starting to live in care homes or hospitals, I do wonder what care they are going to get, and whether it's appropriate and whether anybody will actually look at them as individuals

Other people with diabetes

- I'm surprised at how little some people know about their diabetes. I did the Dafne course and that really surprised me. There was a group of 8 of us there. I wasn't the oldest, probably in the middle, and I was probably one of the ones who had had diabetes the longest. But there were people there who had had it for 30 odd years who knew nothing, didn't even really know how to treat a hypo. One said she'd had porridge with loads of raisins on it, and wondered why her blood was so high. And then she'd have a salad and take the same amount of insulin and wonder why it was so low. I find it a shame – everyone should know how to do this. It's day to day living, it's not something you just have to do for six months and then stop
- You shouldn't use things like diabetes as an excuse. One day you might need to, and people won't believe you. I didn't become a diabetic nurse, because other diabetics annoy me! They have excuses for everything and then they have really bad health because they've not looked after themselves and it really does frustrate

me. I said I would never work with diabetic patients! If you want to have a normal life and not let it get in the way that's fine

Weight control and food regimes

- I knew for years I was overweight, you go for help and you see a dietician, you go to the gym, you get a bit off, then you put it back on. If there was some way to get your weight under control before you got diabetes that would be a help but it seems you have to be morbidly obese before they offer you any help. And the side effect of insulin is that it makes me so hungry
- One thing I would like is – I'd like to lose weight, but I know that's down to me. But at one point you could get free gym membership if you were diabetic and that was really useful to me. I love swimming but I can't afford £5 every time I want to go swimming
- I've volunteered for the Newcastle University MRC research trial under Professor Roy Taylor. You start with less than 800 calories a day for 8 weeks. You have to do what motivates you. Professor Taylor has said he thought only about 10% of subjects would be able to stick with the regime. I'm quite flattered to be one of the 10%. I've lost a lot of weight, before and while I've been on the trial, but I do have reservations about a low fat regime – I believe sugar is the real villain. I'm very passionate about the food industry's negative impact on food, and its tendency to peddle rubbish to consumers
- The big problem I have found with it [insulin] is that it's absolutely piled more weight on me. I understand why, because it uses a human growth hormone, but I was quite unhappy about that although it has improved my sugar levels to under 8. So I've now undergone a Why Weight 3 programme to get that side of things under control. I am having to suffer mobility problems because of the weight, but I'm working on that
- At first it was a bit of a shock, I didn't expect anything like that. As time's gone on, with changing my diet and everything to cut the sugar, I've lost 4 ½ stone [in seven months since diagnosis] just through cutting down on sugar. I do feel much better and much fitter now, so in the long run although it was a bit of a shock, it's been a good shock. At first I said 'I don't eat much sugar, I'm not a sweetie person'. But then, looking at what was in different foods, the sugar content, I couldn't believe it. Things you would never expect – like yogurts are really really high in sugar. It's made me think differently about sugar content. So for now, my diagnosis has definitely improved my health!
- I think what I'm very guilty of is I'm not your breakfast lunch evening meal man. I'm a cup of coffee and an evening meal man. That's my culture really, and my work ethos. I find it very difficult to drag myself away from the computer and sit down and have a sandwich. I've got a bit better at it, but I'm nowhere near doing what I should be doing, you know, three meals a day. But on the dietary side I have changed
- They do keep telling me to lose weight. I'd love to, but I'm a taxi driver and it's hard to control if you sit down all day. I did Why Weight and it was good but I had to stop for a month over Ramadan. I want to go back on it, but they haven't answered my messages yet
- The only thing it's made me do is certainly be a lot more conscious of what I eat and what I drink. It's made me look at my diet a bit more at that, and my exercise because I think that with any sort of illness exercise tends to play a big part anyway. It does make me feel better, although it does give me the shakes so I go all wobbly and I have to go for the sugary stuff afterwards. But other than that there's been no major impact, except I occasionally find it a bit of a pain in the butt

- I had my hysterectomy when I was very young, 29, 30, and I battled with my weight ever since that. I always think that might have been a bit of a contributory factor in the diabetes as well. I used to be a size 12 and it has just gradually crept up since then. If I'm totally focused I can get about a stone off but it's a constant battle
- When I was diagnosed it was a shock, but it's what you do with it. It's taking ownership of it in all walks of life. My granddad had it and he did go on a downward spiral once he had it. I'm not strict with it, I'll have the occasional dessert if I go out for a meal, but you do have to try and balance it out so you don't get too embroiled in it. The biggest thing for me was cutting out the fizzy drink – I can't think how much Lucozade I used to drink, thinking it was good for me and kept me awake. But I will constantly monitor it and get it [my blood sugar] down. But my key goal is not to go to Type 1. That would have a real impact on my life whereas now I can manage. But my GP recommends me to try and maintain and manage it, so as not to go to Type 1

Exercise

- I think it's important to prevent it, and I think doctors should give out free prescriptions to the gym, especially where there is a family history, to prevent it – because a lot of people can't afford to pay for themselves to go
- There is less opportunity in this country [than in Hong Kong] to do outdoor exercise, because of the weather. I would like more support in this country to help diabetes patients do more exercise – either indoors or outdoors – to supplement our medication. Without help it costs £3.50, with concessions, to go swimming
- I've been British national single-handed catamaran 3 times, I've also done motorbike trips to Istanbul and Asia and back in 6 days. My doctors don't have a clue what I actually do. My doctor's Type 1 like me and I met him one day when I was working in Eldon Garden and he couldn't even pick up my toolbox. I had a jet ski for five years, I used to ride it round the Bass Rock off Edinburgh 6 miles out, and I've done over 100 miles on a jet ski in one go. I load up before days like that, you have to look after yourself. When I was in my 20s and 30s I've been windsurfing all over the place. I was sailing on a lake in Surrey the day of the big hurricane in 1987 and I was the last man off the water. Mind I had to get treatment off a doctor after that, but it was just basically a couple of Mars bars
- Exercise is a real problem for me now. It used to really help – if I wanted to lose weight or if my blood sugars weren't great, exercise was always the answer. It literally seemed to change overnight, I still don't know what caused it, where all of a sudden I became much more sensitive to insulin and exercise so now I do a lot less than I used to
- Exercise is just – I've spoken to other people with diabetes and they say exercise is really a problem. Once I was at a dance class, it was my first time and I didn't even get through the warm-up, I just plummeted. Sometimes you just know you've done everything right and you still have a hypo. But another girl there who had diabetes came and spoke to me. I asked her how she coped and she said 'I don't. I just stuff my face before the class and then deal with the high later.' But that's not good for you either. And it actually makes you ache for days afterwards because your muscles aren't getting what they need. But then, long term, exercise makes you have better control over your blood sugar, so obviously you want to do it. But it's just such a nightmare. I often find myself avoiding it, even pilates. If I have my tea and insulin before I go, I get in the car afterwards and I'll be low even from very low-impact exercise like that
- It's quite hard if you are a bit unusual in that you want to be active – to get someone to give you proper advice about what to do if you're hill-walking, or you're going to

be sailing for three months, you have to work it out for yourself. I don't do anything particularly extreme, but there doesn't seem to be a body of knowledge for those slightly different things. For me it's been hard to get informed support to help me do slightly unusual things. Things like how to keep insulin cool enough when I'm doing x, y and z and I'm going to be out for seven or six hours, I've got much more support from websites and talking to other people, than from my healthcare team. They'll discuss the issues with you, but they aren't the ones with the answers. They don't see enough people with diabetes who actually do stuff. You have to work it out yourself. You need to know things like for instance dextrasol jelly acts faster than dextrasol tablets when you're in the middle of trying to change a sail and your blood is falling fast, that sort of practical advice. I'm too old for the younger person's clinic now, and when you're not attending that one people do tend to assume that you're going to just sit and watch telly – and if you look round the clinic, you can see that it's probably true of most people with diabetes

Emotional and psychological support

- One thing that I was a bit puzzled about was – I was only 19 when I was diagnosed and I believe that you see a psychologist if you are diagnosed as a child, and I don't know why they don't offer that to everyone. Because it was such a shock. You know, you've got really high blood sugar, you go to A&E, you're on a drip for several hours and then you're discharged straight to the Diabetes Centre. Obviously you are told at some point then you're told you've got Diabetes and then you go home with insulin – all within 24 hours. For me, even though I had background knowledge from my mum [a diabetes nurse], it was really hard. So I can't imagine for someone who's heard of diabetes but doesn't really know what it is, it must be such a major life change. I know it's not the same as cancer, but in terms of the fact that it's such a lifelong illness you need some support. I feel like I've had a lot of support from the Diabetes Centre, but not much sort of psychological support. I've always just wondered why, because any other sort of major lifelong illness you do get that
- I'll be very honest. I've seen a psychologist fairly recently for help with more the mental side of it – feeling like a failure if I got it wrong, and all those sort of things. I feel that isn't publicised enough. Even though I know I'm in much better control technically, I didn't feel I really was overall. It had been mentioned to me before at the Diabetes Centre but I didn't want to admit to the hospital that I wasn't coping, I felt like I should be. But then I thought, if the support's there I might as well take it. That was the best thing I ever did, so I would recommend it to anyone who is struggling with the mental side of it. Now I know I am doing well!
- I think there's a lot more recognition now of the psychological, emotional effects. When we were kids it was quite a Victorian attitude – just get on with it. I'm fairly lucky because I'm a survivor. All my friends of roughly the same age with diabetes are all dead now with complications. I'm 57 and I always say 'well done' to myself. But on the other hand I've looked after myself. I have been naughty, but the bottom line is, you just have to get on with it. And you don't get a day off from diabetes – although, if you look after yourself most of the time you can have a bit of a lapse now and then

Living a 'normal' life

- You can't really be spontaneous. I'd really like to travel more, and do backpacking kind of travel, but I don't think I could. I know that people with diabetes do, but I just think – how? It must be so incredibly complicated. I'd also like to go and live in another country, but then there's the health insurance when you aren't somewhere with a health service. It's generally a difficult illness to have

- Most people think it just has an impact on what you can eat and that's it, but it literally has an impact on every aspect of your life, pretty much, it affects absolutely everything
- I had a stroke in 2005, and I was in hospital for six weeks. But I was determined to get better. I'm self-employed so I can't be ill and I didn't want to slow down. I want to play football with my son and stuff, I couldn't be bothered with having a stroke so I got over that. But when I've had a hypo I do limp a bit. I used to get wrong in hospital off the nurses for wearing the carpet out – but I was determined to educate my brain so I was like I didn't have a one [stroke]. It's worked big style, but it had to, with my job
- I remember when I was about 7, I was at my cousin's and him and his mates were playing football so I started playing football with them. And my cousin got my arm and he said 'Calm down xx, don't do it because you're diabetic'. Well that infuriated me and I thought 'Well, I've got to prove to you that I can run just as fast as you and beat you', and I was all over the place. And I remember that. I didn't want to be a lesser person
- In my personal life it's probably had more of an impact than at work. I've always done a lot of sailing, and I would have liked to be the first mate of a boat but I had to take the decision that I wouldn't be. Because if you're in charge, and there's say 15 young people in your care, and you can't be in charge because you're having a hypo, then . . . so I never went up to that level. I've always been third in command so there's another two people available. I did my second mate training and they were encouraging me to do my first mate certificate and it was only then, only because the first mate didn't turn up, and I was acting up – and then the skipper became incapacitated so suddenly I was in charge. Now I didn't have a hypo or anything but it suddenly brought up the reality of it, being the only person who's got the knowledge on this boat, and you can't be at risk then, you can't. I've always gone ahead and done things, I've never let my diabetes stop me. And I've always had a Mars bar or something in my pocket, so you could get through a few hours. But you don't really have the time to concentrate on you in that situation, so you might put someone else at risk

Other comments

- I would say that my perception of diabetes as I've got older has changed. In the early days I would never have described it as a disability, but I think now I probably would. There are now things that I know I can't do. It stops me from doing things. But that's fairly recent, as I've got older
- It find it perfectly normal now, because I've had it such a long time. But if I got it now, I think I would find it difficult because it's such a lot of work, controlling your bloods and stuff
- You can never turn your back on it, because the outcomes would be quite serious. It's always in my mind but I feel I suppose a bit resilient in being able to deal with it
- You kind of just want someone to come along and say 'Here's the answer', or you just want a break from it. I think if I had been younger when I was diagnosed, I might have done that, just drinking and things in excess, possibly more than even my peers
- It's horrible, life changing, most people don't realise how serious it is. And there's not a lot of support from the government. They don't treat it as the serious illness that it is. I hear so many people who have had their DLA for their diabetes taken away because they say it's not serious

- I've always thought that, as much as the people who treat you and know about the area and are very knowledgeable about it, because they don't have diabetes they never really know. And every person with diabetes gets different symptoms, and they are completely and utterly different in terms of symptoms, how sensitive they are to insulin – and sometimes they are just like 'I don't know'. Or you'll ask them something and they're like 'Oh, I've never heard that before'. They suggest doing something and you're like, that's not really practical. I don't necessarily expect them to know everything, but it's just hard when you're getting advice from someone who hasn't ever actually experienced it
- My priority is my kids – in the past, I didn't have a priority. I was daft, I was young, I did what I wanted. I didn't look after myself as good as I should have, but I think when you've got kids and your priorities are different, you think 'Well I've got to look after me to look after them'. So now I test more, I'm a bit more sensible in what I eat and what I'm doing in general, now it's generally looking at diabetes as an illness rather than something I can forget about, since I had the kids