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Living with Type 2 Diabetes
A report for Bristol-Myers Squibb

October 2012

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Section 1: Introduction

1.0 Introduction

This report, which has been compiled by Involve North East (INE) for Bristol-Myers Squibb Group (BMS), analyses the findings of research into the experiences of patients in Newcastle with Type 2 diabetes.

This project originated in discussions between BMS and NHS Newcastle West CCG, in which there was recognition of the value of qualitative evidence of local people's experiences of using diabetes services.

1.1 Involve North East

Involve North East (formerly Community Action on Health) 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 experience of patients with type 2 diabetes, in order to provide commissioners and other stakeholders with:

- better knowledge of patients' experience of type 2 diabetes
- greater understanding of the factors influencing patients' experiences
- information to help shape services that support better outcomes

In particular, the research aims to shed light on the daily realities of balancing the management of high blood sugars with the risk of hypoglycaemia. We were also asked to assess the impact of this balance on quality of life and patient safety.

1.3 The context

Type 2 diabetes accounts for between 85% and 95% of all people with diabetes and usually appears in people over the age of 40. However, it often appears at a younger age in people of South Asian or Black origin and is becoming increasingly common in children, adolescents and young people of all ethnicities.

Type 2 diabetes is often wrongly perceived as a 'mild' form of the disease – a perception that in itself can lead to poor management of the condition. In its early stages it can often be managed with a healthy diet and increased physical activity, but as the condition progresses most patients need medication and/or insulin and can become susceptible to complications such as blindness, heart attack, kidney disease and stroke.

In order to meet the overall aims of the research, we asked participants to tell us about their experience of living with the condition, focusing in particular on the management

of hypoglycaemic episodes ('hypos') and other symptoms; experience of medication; and the impact of type 2 diabetes on daily life, including working life.

Section 2 - Methodology

2.0 Methodology

In order to gain in-depth information about the views and experiences of a range of type 2 diabetes patients, we chose to take a primarily qualitative approach, giving participants the opportunity to describe their experiences and identify priorities that would inform future commissioning and treatment approaches.

2.1 Participants

Fifty-five people in total took part in this research project. Most were recruited with the help of GP practices from NHS Newcastle West Clinical Commissioning Group, but INE also recruited participants from its own networks to achieve as representative a cohort as possible.

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

2.2 Focus Groups

We convened and ran five focus groups to gather personal and anecdotal information about patients' experience of living with type 2 diabetes. In all, 20 people participated in focus groups.

2.3 Questionnaire

We also used a questionnaire, to collect the views of a more substantial cohort and help us attach appropriate weight to findings.

We developed the questionnaire to address exactly the same issues as the focus group, using a combination of multiple choice boxes and free comment sections.

Fifteen people completed the questionnaire on paper or online.

The questionnaire is included in this report as Appendix 2.

Questionnaire responses are set out in Appendix 3.

2.4 Telephone interviews

Some participants who were unable to attend a focus group were willing to talk about their experiences in more detail, and more anecdotally, than our questionnaire respondents. We conducted 20 telephone interviews with patients in this category.

We asked telephone participants exactly the same questions as questionnaire respondents, and entered their replies into the same database.

Their responses are also included 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 Diagnosis and learning about diabetes

We asked participants to tell us how long they had had a Type 2 diabetes diagnosis, and to describe their experience of being diagnosed.

3.1.1 Age at diagnosis

The majority of our 55 participants (34 people) were diagnosed between the ages of 40 and 60. Ten people were over 60 at diagnosis, and 11 were diagnosed between the ages of 20 and 40.

Sixteen people had had their diagnosis for 5-10 years, a further 16 for 10-15 years, and 14 for more than 15 years. Nine people had been diagnosed for less than five years.

3.1.2 Experience of diagnosis

Patterns of diagnosis varied: while some participants recognised their own symptoms and already suspected the cause (see 3.1.3), others experienced unexpected, almost 'accidental' diagnoses while they were being treated or tested for other conditions:

“My GP said I had a blocked sweat gland but when I went into hospital they said 'Why is your diabetes so out of control?' It was a diabetic abscess. That was a big shock. I realise now I had classic symptoms, but I had four year-old twins at the time and I was so busy I just didn't think about the symptoms.”

“I had ovarian cancer, I'd gone in – it was just a pre-op check since I was in the hospital, ready for my op and they said, 'Oh we're the diabetic team, do you know you're diabetic?' and I said, 'No and I don't care. If I'm still alive at Christmas, tell me then'.”

“I had a new doctor and I was being treated for cellulitis and she asked me to have a blood test which showed borderline diabetes. At the same time I was also diagnosed with an underactive thyroid and it was upsetting to be diagnosed with diabetes and the thyroid problem.”

A participant who had had two major heart attacks in the past was admitted to hospital with chest pains:

“I was in casualty at the General and this Scottish male nurse said ‘Are you diabetic?’ and I said no but he took the reading anyway and came in and said ‘Your reading’s very high. You’re a diabetic.’”

For some patients, the diagnosis came during routine check-ups:

“I had a medical at work and the nurse had just done a urine sample, and she just turned round and said, ‘You’re diabetic’.”

3.1.3 Existing knowledge

Although some participants were shocked and taken unawares by their diagnosis, many were unsurprised to be told they had diabetes. Some had an existing understanding of the condition, either because of family experience or their own professional knowledge:

“I roughly knew myself, because of the symptoms.”

“My father struggled with diabetes so the doctor checked me as a precaution and found I had it as well.”

“I work within the NHS, and a lot of my work is about heart disease and diabetes. So I knew quite a bit - and other family members have it too.”

“I work with elderly people, so I had some knowledge already. And my mother had it too, so I recognised the symptoms.”

“I’m a nurse, so I know a bit about it. And my mother had type 1 diabetes too.”

Others had been warned of the likelihood of developing the condition:

“I had been warned that I was drinking too much and that might lead to diabetes, so I wasn’t surprised when it was diagnosed.”

Two women, both of Asian British origin, had had gestational diabetes and were able to recognise the symptoms when they recurred several years later.

3.2 Information and advice at diagnosis

Participants had varied experiences of receiving advice and information about their conditions after diagnosis.

Most people were happy with the support they received after diagnosis:

“My practice has its own Diabetic Centre. I get excellent information and regular reviews so I have always been very happy with the information and advice I get.”

“Great doctor, he explained to me that I had to change my diet and lose weight if it was possible. Got the Metformin tablets straight away.”

“The nurses from the diabetic centre, they were all great.”

Several people praised their Diabetes Centre, and one person referred to a diabetes ‘fact file’ she was given:

“The practice used to give you a diabetes fact file, that you kept with you and took to all your medical appointments - optician visits, podiatry, everything. It had a record of blood results, weight and other things, and it was updated at every visit. It was brilliant, really useful.”

However, her practice no longer provides the file:

“I imagine it's because of funding, but I found it so useful in keeping track of things.”

Some participants felt they had been given very little information at diagnosis: seven survey respondents said they either could not remember receiving information or did not get any, and others were unimpressed by the information they received:

“I saw somebody at the General and they said, ‘Oh you’ll have to take tablets’ and that was about it, there wasn’t a lot said.”

3.2.1 Course information

People who had attended DESMOND (Diabetes Education and Self-Management for Ongoing and Newly Diagnosed) or similar courses after diagnosis had varied experiences. Five people identified the course as their most useful source of initial information, and others felt it had been helpful:

“Fortunately for me they had just started a one afternoon a week six-session course for diabetics, so I linked straight on to that and found it very informative.”

Others had reservations:

“It’s a lot of information to take in in ten weeks for something you’re not used to, you’ve never had before.”

“Because there’s a lot of you in the group you hold back on questions because you don’t want to take all the time up.”

One source of frustration was the lack of guidance people felt they received about blood sugar; some people who attended the DESMOND course felt that

its emphasis on healthy eating came at the expense of better explanations about sugar levels and blood testing:

“All we seemed to do was talk about food.”

“It was all about weight and what you eat and what you don’t eat – I think I would have liked to know about how to know when your sugar is high or low, and what was the impact of it. Like if you were poorly how would you know if it’s got something to do with diabetes?”

However, patients who have taken insulin and had been on courses to help them take it were generally very positive in their assessment of the insulin courses:

“When I was first put on insulin, I had a four-week course to show me how to use it. It also covered adjusting the dose, diet, reading blood tests and things. I felt fully informed at the end of it.”

“I went to the General last year...diabetes was getting that bad so tablets wasn’t good enough. But we did a course there and I think it was on for four weeks and it was really good, went through the medication, how to take insulin and what it does and also the food I could and couldn’t eat, like the diet coke, it was really, really good. Really impressed.”

3.2.2 Alarming information

Other people were alarmed by the information they received:

“The nurse [at the diabetes centre] frightened me as she started talking about toes, feet and legs being amputated. She also told me to check bathwater with my elbow and to always check for stones and nails in case of loss of sensation. It frightened me.”

“Practice nurse was very negative, warned me about going blind or losing my legs. She was rather harsh.”

“It’s frightening when you get diagnosed with diabetes; they tell you you could lose your sight or a limb.”

However, one focus group participant felt that scare tactics were important to drive home the seriousness of type 2 diabetes:

“I just think people at the beginning, they should spend some time actually at the Diabetes Centre going to the place where they’re dealing with the people who have got quite serious ... I think you should hold people by the ear and drag them into the waiting area and say ‘that’s what you’re going to end up like.’ What made me rigidly disciplined was sitting in the waiting room and they were

coming in on wheelchairs and they had the big boots on and I was thinking ‘I hope that’s not – I’d kill myself.’”

3.3 Hypoglycaemic episodes (hypos)

When we recruited participants for this study, we were looking for type 2 diabetes patients who had experienced at least two hypoglycaemic attacks in the last two years. In the event, five questionnaire respondents and two focus group members had not suffered from hypos. Another focus group participant was not sure whether he had them:

“I don’t even know what a hypo is. I’m epileptic and it’s the same procedure to taking an epileptic fit, so I don’t know the difference. The doctor at the hospital tried to explain but he went through all the Latin names and things like that.”

Some people experienced only mild symptoms, but others were severely affected. One focus group participant, who was struggling to balance her medication, food intake and lifestyle, was experiencing frequent severe attacks:

“My whole body just seems to want to shut down from head to toe, you can’t control it, and my speech and then my vision goes and then the sweats come and I get palpitations.”

3.3.1 Frequency of attacks

The vast majority of participants had experienced hypos and most had them at least once a month. One person was experiencing daily hypos at the time of the discussion, and weekly hypos were common.

3.3.2 Causes

Seven survey participants and five focus group members said they did not know what caused their hypoglycaemic attacks, but most people had identified at least one trigger.

Mealtimes

The most commonly identified cause, from a list we offered, was missing meals: 17 survey participants highlighted this, either alone or alongside eating the wrong food (four people), exercising a lot (four people) and drinking too much alcohol (one person).

However, when asked for more details both focus group members and telephone participants said they felt the problem was not just missing meals but leaving too big a gap between meals:

“If you don’t get that time spot on from having breakfast time to dinner time to tea time, it’s crucial because that’s the worst thing I’ll do – I

have my breakfast in the morning then, if I get put off and I'm doing things I'll think 'oh I'll hang on until my dinner' but your diabetes won't let you do that because straight away you get a hypo because you've let yourself go too long."

"It's the timing. I can't go any longer than four hours [without meals]."

"I'd been out working all day and when I came in at night I would be shaking like that because I had gone without food all day and I was just eating cake, biscuits, absolutely stuffing them in ..."

"I have to have meals at regular intervals ... I used to get irritated when my father-in-law insisted on having his dinner at noon every day, but I'm a bit like that now, because it helps me to control my diabetes."

Exercise

Although four questionnaire respondents ticked 'Exercise' as a cause of hypos, other participants recognised that exercise alone was rarely the cause. They felt the real issue was balancing food intake with calorific output:

"It's Catch 22 for me – we walk, we cycle, we exercise. But if we just go from here to Newburn, I have to take a sandwich."

"We do a lot of walking, and I always carry something with me because sometimes I can feel I'm starting to shake ..."

"If I exercise without eating [I get hypos]."

"Not eating enough before exercise."

Medication

Some participants who were, or had been, on insulin or other injectable treatments had found it particularly difficult to avoid hypos:

"I've never had a really bad 'crash' but I used to get them several times a week. I've reduced my insulin now and that has helped to reduce the hypos."

"The big problem, with having a family, is that I have to have a meal an hour after my [Byetta] injection - not less than an hour and not longer. But if the kids are late getting back from a club or something, then I am likely to have a hypo. It's difficult managing an injection regime with family mealtimes."

"It was being on insulin [that caused hypos], with my existing diabetes meds."

However, one person felt that insulin had helped to reduce the frequency of attacks:

“I’m on insulin now, and the hypos seem to be a lot less frequent since I started.”

Other people had identified links between hypos and other medication:

“The nurse has cut down my Gliclazide and I don’t take Pioglitazone now, to try and control my hypos.”

Stress

A number of people highlighted stress as a significant factor in diabetes management, including frequency and severity of hypos:

“If I don’t eat ‘little and often’, or if I am worried about something, I get shaky and lethargic.”

“I think stress can cause hypos.”

“I find the best way for me to avoid hypos is to avoid stress.”

3.3.3 Managing hypos

Several focus group members identified Mars bars as their most effective method of treating hypos, although most were aware that this was not medically approved:

“I really do get wrong off the nurse, ‘oh you can’t touch them, you can’t touch them’ – but it’s the only thing that pulls me round.”

Other remedies included different brands of sweets, sugar cubes, jam and bread, Lucozade, bananas and sandwiches. Some participants consciously tried to avoid very high levels of sugar when they were having hypos:

“Cup of coffee with sugar in and a sandwich or something like that and you’re all right.”

“I always carry a satsuma and a banana.”

“When I’m about to have a hypo I see ‘floaters’ in front of my eyes. If I take orange juice as soon as that happens, I can usually prevent the hypo.”

“I have a slice of toast.”

3.3.4 Emergency treatment for hypos

Only three people (all survey respondents) had been hospitalised for a hypo, and in each case this had been the attack that led to their diagnosis. One of these had been taken to hospital by ambulance.

Nobody had been treated 'on the spot' by a paramedic for a hypo, although one focus group participant described an occasion where she had to be helped home by neighbours who drove her home, took her inside and gave her sugar.

3.4 Medication taken

All but one of our participants was on some form of medication, the exception being a telephone interviewee who had only been recently diagnosed:

"I have a prescription for Metformin but I'm waiting for my six month check-up. I'm hoping to deal with this without medication."

Thirty-two survey respondents were on Metformin. Twenty-one took Gliclazide or similar, six were on Pioglitazone and seven were on an injectable treatment.

Changes and adaptations to medication were common:

"I was recently put on slow release Metformin as my potassium levels were high."

"I used to take three Metformin a day, but I've lost a lot of weight so I don't need so much now. I only take it twice a day, morning and night."

"I used to take Gliclazide, but since I've lost over a stone through Slimming World I don't need it any more. So I just take three Metformin."

"Gliclazide made me feel hungry, so the doctor told me to reduce my dosage."

"The nurse has cut down my Gliclazide and I don't take Pioglitazone now, to try and control my hypos."

"I was on Rosiglitazone and was having a bad reaction, so the doctor changed my medication to Pioglitazone."

"Pioglitazone gave me heart problems, which is why I don't take it now."

It was not possible to record precise medication in focus group discussions. Broadly speaking their medication matched that of the survey respondents,

although more focus group participants than survey respondents spoke about having 'lizard saliva' (exenatide) injections.

3.5 Problems with medication

When asked whether they had problems with their medication, 27 of the 34 survey respondents (and most focus group members) who took medication said that they had no serious difficulties. One interviewee was especially positive about the effects of prescribed medicine:

"I am better now I am on medication. I used to get blinding headaches and a really bad thirst, but they've all gone now I'm on medication."

However, a number of people mentioned problems which they felt they had overcome, and in conversation several people described a range of difficulties.

3.5.1 Metformin

Metformin was frequently identified as the cause of bowel problems; one focus group participant who also had Crohn's disease had to be taken off Metformin, and a number of other people mentioned its side effects:

"I'm so used to it now, but Metformin gives you terrible wind."

"I find I can't take Metformin as soon as I get up, so I take it to work with me. But that means I sometimes forget to take it, and only remember it when I start to feel ill."

Slow release Metformin had alleviated the problem for several people:

"Metformin makes my bowel movements loose, but now I am on a slow release version it's better."

3.5.2 Injectable treatments

Insulin seemed to divide patients between those who found it effective and relatively trouble-free and those who experienced problems. Four survey respondents said they thought insulin caused their hypos, while another respondent said:

"I'm on insulin now, and the hypos seem a lot less frequent since I started."

Exenatide injections had created difficulties for some people who had used them. These included the timing difficulties created by having to eat at an exact interval after injecting (which one patient felt were eradicated by moving to a weekly, rather than twice-daily, dosage) and the difficulties of travelling with a drug that has to be refrigerated.

Two people also said that exenatide has to be injected via a bigger needle than the one used for insulin.

One focus group member was managing well on exenatide, but admitted that he was learning to 'get round' its appetite suppressing properties and wondered whether he should come off it to save money.

Three focus group participants had experienced problems with exenatide. One had found it almost too effective:

"I would cook a meal, I would serve it, I would sit down and I'd go 'nah', so I stopped taking it ... I lost weight, it was terrific, but that one particular side effect was too much so we spoke about it at the diabetes clinic and they agreed yes the best thing you can do is stop."

However, when he regained all the weight he had lost and persuaded his doctor to prescribe exenatide again, it caused severe digestive problems and he had to stop.

Two people (one of whom also had Crohn's disease) had suffered from constant sickness as a side effect:

"It makes you feel sick every minute of the day ... I really wanted it to work but I couldn't."

"I was sick from morning to night and I had to come off it and go back on the tablets."

3.5.3 Compliance with instructions

Asked whether they take their medication exactly as prescribed, 29 survey respondents said 'Yes, always' and the remaining six said 'Most of the time'. This was echoed by the focus group participants, most of whom were happy to comply exactly with instructions:

"I find medicine works best if you do it the way they tell you. For me."

"I take a lot of tablets for a lot of things, so I just set them all out together and take them when I need to. I trust the doctor."

"If you try to be clever, you're going to come unstuck."

People who said they complied 'most of the time' blamed forgetfulness for most of their lapses, particularly if they were busy. One person, who found it difficult to eat breakfast and therefore tended to take his first medication later in the day, said:

"It has to be taken with food, and if I skip breakfast because I'm busy, I don't take my medication in the morning."

Only one person said she had decided not to take her medication as directed:

“The Gliclazide, I only take two of them instead of four because I think they were causing the hypos.”

Asked if she had discussed this with a medical professional, she replied ‘I think I told the nurse.’

When we asked if anything would make it easier for people to take their medication, almost everyone said that, on the whole, their medication was not difficult to take. One survey respondent and two focus group members said it would help if the tablets were smaller, but on the whole nobody raised any serious concerns.

“The complications are all to do with work and family, and you can’t change that!”

3.5.4 Understanding medication

Our participants varied quite widely in the degree to which they took an active interest in their condition and its treatment.

Most people were content simply to take their medication without question, but others had asked their doctor or diabetes nurse for more information. Two people had used the internet to inform themselves. However, some were frustrated by the lack of information they were given:

“I take about nine tablets a day and I haven’t a clue what half of them are for ... I think they should explain.”

3.5.5 Consultations about medication

Most of the participants in this research had spoken at some point to their GP or nurse about concerns or questions they had regarding their medication. Most people were satisfied with the outcome of their conversations, although the response was not always what they wanted:

“I mentioned to Dr T a few times about why I am on so much medication, and then you get the stock answer – I don’t bring the subject up any more ... but you’ve got to be guided by the people who know what they’re doing.”

“I said I thought the tablets were a waste of time. They didn’t agree. I told them in no uncertain terms, but I just take them now.”

“She went to her doctor when he prescribed medication, she said that although it suits her can he not reduce it and he said no, you have to take whatever you are given.” (interpreted conversation)

On the whole, however, although one person said she felt her GP ‘never seems to have time to explain things, or isn’t interested’, most people had had productive negotiations when they raised queries about their medication:

“I was having hypos about 10 minutes after taking Gliclazide. You’re supposed to wait an hour after taking it before you eat, but now I take it closer to the time when I eat.”

“They’ve always listened to my concerns.”

“I spoke to my consultant because I thought the insulin was causing me to have hypos. He was happy for me to reduce the insulin and he said I could reduce it faster than I was doing.”

3.6 Managing type 2 diabetes symptoms

We asked participants what, apart from their medication, they had found helpful in managing their condition and alleviating symptoms.

Common symptoms included tiredness, pains in the hands and feet, deteriorating eyesight, lack of concentration, susceptibility to temperatures and, of course, hypos. Three male survey respondents and one focus group member talked about the loss of libido caused by their condition or its treatment.

3.6.1 Diet and weight control

There was widespread recognition of the importance of diet in managing type 2 diabetes and its symptoms:

“Food is the best medicine for your body. I’d like to see more research on this.”

Two telephone interviewees had recently lost weight through Slimming World, and were evangelical in describing the effect it had had on their diabetes. Others had also benefited from losing weight:

“When I was ill with pancreatitis I went down to 10 stone and I didn’t need to take any diabetes meds. I really struggle with my weight and I’ve finally admitted I need help with it. I’m going to Weightwatchers and I’ve lost a stone so I hope my diabetes symptoms will keep getting better.”

“The nurse and I argue like hell – she gives me hell about my weight. But she’s pleased with me now I’ve lost two stone.”

However, interpretations of healthy eating for the condition varied quite widely, and many people found the nutritional advice they received confusing:

“They tend to say ‘that’s not enough for breakfast, you’ll have to have more’, and then they turn round and say ‘you’re putting on weight’. You

can't win with some of the things. They all seem to tell you different actually."

"She told me, the diabetic nurse, when I was first diagnosed and I had my sugar under control, she said 'now don't be too hard with yourself, you can have a sweetie now and then.' Well, she shouldn't have said that to me!"

"The stupidest piece of advice I got was from the nurse: 'If you feel you'd like a piece of gateau now and again, do have a piece, but always have it at the end of your meal.'"

One person talked about the need for reliable, accessible nutritional advice:

"I would really like to see a dietician for advice on what to eat and how I can control it that way. But when I went to see one, she said she wasn't really supposed to work with diabetics because there's no funding for it. That made me feel bad about asking, but if I could have a dietician to help me I think it would be easier to manage. I don't want to keep going on courses, I just want advice when I need it."

In practice, many people found the dietary restrictions frustrating:

"I am very single-minded, so when I decide to do something I do it properly. But I hate it and it does get to me. Like when I'm in Asda and I can only eat about a quarter of what I can see on the shelves."

"Yes, you understood them [the healthy eating principles outlined by health professionals] but then when you went out it's a different thing, and when you're in the house it's 'well I haven't got that so I'm just going to have this', you know?"

Food was also a common outlet for rebellion against the condition and its restrictions:

"When you go through so many problems in life you think, 'Well that seems trivial, leave me alone, I've got more important things to deal with than you telling me I can't'. I know I shouldn't, but it's just a biscuit, but she [the nurse] would say, 'Do you know with that one bite you could lose a limb?' and I'd think, 'Well thanks very much'."

Six interviewees of Asian origin identified bitter melon (also known as bitter melon or karela) as a useful aid in controlling symptoms. It is said to contain a hypoglycaemic compound that some people believe may be beneficial in lowering sugar levels in blood and urine:

"If I have bitter melon as part of a meal, I don't need to take Metformin. Other people find the same."

3.6.2 Exercise

Participants varied widely in their attitude to exercise. One focus group participant, who had multiple health problems, was a regular walker and gym user, controlling her condition in spite of a catalogue of health complications.

People who did exercise were very aware of its beneficial effects, even when their capacity was limited:

“I can’t go to a gym because of my weight, but I do feel better if I walk more and faster, things like that.”

“When I have the time to exercise regularly, I do feel much better – less lethargic, and much more energy. But the problem is fitting the gym into a busy life.”

“When I went to Aquafit I found it really good.”

3.6.3 Avoiding stress

There was widespread agreement that stress could exacerbate diabetes. Some people felt that it had helped to cause their condition in the first place; two Asian ladies said they believed the sudden deaths of close relatives had actually brought on their diabetes, and several people referred to being very stressed before they were diagnosed.

Stress was also frequently mentioned as a factor in bringing on hypos and there was general agreement that avoiding stress was important. However, as one participant put it:

“Every GP tells everybody who is diagnosed with diabetes, to avoid stress, and I immediately ask, how?”

3.7 Living with type 2 diabetes

3.7.1 Perceptions of diabetes

Participants varied in their attitude to having type 2 diabetes. To some, it was a minor inconvenience that they had learned to control and that had very little effect on their lives.

Other people were more concerned about other conditions they had, that they perceived to be more serious than diabetes. When we asked how diabetes affected daily routines, it was clear that this varied from person to person:

“It doesn’t. I don’t make any changes.”

“I try not to let it. When I got my diagnosis, I was told the trick is to manage it so it didn’t manage me. You have to watch your diet, and be careful about getting infections.”

“It’s hard to say because I have so many other problems and you don’t know what causes what.”

Other respondents felt much more seriously affected:

“All my lifestyle has changed.”

“I had to stop work due to ill health, and I have stopped going to church.”

“It’s a very bad thing to have. It wasn’t so bad at first, but it affects you more and more as time goes on. You always have to be very careful. Nobody can see you have diabetes, but it makes you feel bad pains in your legs and eyesight problems. It becomes more worrying as it gets worse. It is depressing if you have worked hard all your life because now I have to be so careful about what to eat, how to work, taking tablets. And you can’t always join in with your friends and family, you just want to sit down.”

In general, perceptions of the disease’s seriousness tended to increase over time. One focus group participant who had been diagnosed less than ten years ago said:

“I knew a lot of people suffered with it and I knew there were two types, type 1 and 2, and I knew 1 was more dangerous than 2. So I wasn’t really that concerned.”

However, a survey respondent who had had the condition for some time said:

“When I was first told I had diabetes I was not told all the different things it could affect. I have since been told that my lost sight, quadruple bypass and stroke are all down to my diabetes.”

3.7.2 Making lifestyle changes

Asked how easy it had been to make changes to their lifestyle to manage their condition, eight of the 35 survey respondents said they found it easy most of the time but occasionally fell ‘off the wagon’. One respondent, however, had had a salutary lesson in the importance of managing diabetes sensibly:

“I used to cheat a bit, but never again. My sister nearly died, and that changed my approach and encouraged me to change my lifestyle. These days I find it easy to change my lifestyle because I want to stay healthy and keep off insulin.”

Another respondent was a firm believer in keeping busy:

“ ... so I am not always thinking about food and reaching for the fruit bowl. I think being on insulin makes you think about food all the time, so being busy keeps you away from that. I get much better readings when I'm busy because it keeps my blood sugars down.”

3.7.3 Tiredness

Apart from hypos, the difficulty most commonly identified was tiredness:

“It’s a funny kind of tiredness, it’s not the kind where you’ve done any hard work, it’s just – for me – it just seems to come over you, you know?”

“I don’t have the energy to do all the housework like I did before. I can’t stand very long either.”

One survey respondent who complained of being tired said:

“I get very tired, more exercise would probably help me a lot.”

3.7.4 Ramadan

Most of the interviews for this study were conducted shortly before or during Ramadan 2012. Muslim participants who were interviewed during this period were naturally focused on the Ramadan fasting regime and its impact on their diabetes.

While the Koran requires Muslims to fast during the month of Ramadan from sunrise to sunset, it does allow for some exceptions. One of these is that people who are ill or have medical conditions do not have to fast. This definition can of course include people with diabetes.

The four Muslim participants interviewed before or during Ramadan were aware that they have the option not to fast, but in practice only one was considering taking up this dispensation. All four acknowledged that type 2 diabetes creates particular complications during Ramadan, but opinions about its impact varied:

“Ramadan is very difficult because your energy levels get so low. It's OK in the morning, but by the evening I am very tired from not eating or drinking.”

“I am generally OK with fasting, although at the moment, because Ramadan is in the summer, the extra length of time between meals makes it harder. The important thing is to focus on what you have to do, and put other things on the back burner. For example, I normally take a brisk walk after breakfast, but I don't do that at Ramadan. Some people swap their meds over in Ramadan, and take their

evening dose in the morning and vice versa. But I just take mine a bit earlier, with my early meal.”

“The only time I have to be careful is Ramadan. But I have learnt to adapt my eating and cut down my exercise in Ramadan, and I amend my medication for that period with my doctor's support. Strangely enough, I felt better last Ramadan than usual! But I know a lot of people who can't manage their diabetes well in Ramadan”

3.7.5 Varying degrees and quality of information

While some people seemed to have arrived at a way to control their diabetes (or were still at an early and relatively mild stage), others were frustrated at the lack of sound advice or information available.

Two people found the Diabetes UK website very helpful, and most had faith in health professionals:

“The specialist nurse at the Diabetes Centre is great. She's on a crusade to get people managing their diabetes well and she's great. She can be a bit of a demon if you don't do what you're supposed to do, but I really trust her.”

Others, however, were frustrated by the difficulty of controlling their symptoms, and their feeling that it was hard to find reliable, consistent advice. Sometimes this stemmed from conflicting advice from health professionals:

“They all seem to tell you different.”

“The doctor said ‘right, let's see what tablets you're on’ and he had a look at the tablets and he said, ‘The diabetic nurse gave you the wrong tablets, you can't take them.’”

“Even your doctor and your nurse that does your blood, they don't always agree with your dietician, they conflict and you don't know where you are.”

Other people were more frustrated by the lack of any explanation about their condition:

“Nobody will explain things. I've been monitoring my bloods, but when you show the information to the nurse or doctor, they don't explain what it means or give you any advice about your reading - so you're none the wiser. That's stupid.”

“It's difficult knowing what I need to do. I don't do stupid things, but I must be doing something wrong because my bloods are always so high.”

There was also a sense, particularly among women with weight problems, that their size prevented them being taken seriously by health professionals:

“It's actually very hard to get good information or advice. I think the GP, and the nurses, don't really look past your size. I know I need to lose weight, but it's not as easy as that. And when I did lose five stone, my bloods were still seven and above. I don't feel I really understand, even now. The dietician tells me one thing, I do it and then I have hypos. Nobody can give you a straight answer, that's the problem.”

“I didn't get much useful information. And I felt – still do – that my weight was more of a problem to them than my diabetes. If you're fat, your other symptoms aren't taken seriously.”

3.7.6 Rebellion and frustration

While eating restrictions and lack of information were a common source of frustration, one participant (who in fact managed her condition quite well) expressed her irritation at being part of the diabetes 'system':

“I hate the fact that diabetics are popped in a box and told what to do. it isn't serious, and I don't want to be on databases for students to look at. I just want to get on. I won't go to the Diabetes Centre for my foot checks, for example, I just go to an ordinary clinic. Why should I have to go to the extra expense and pain of specialist services? And the constant blood checks . . . I refuse to get in the box!”

3.8 Summary

Our research demonstrates that experience of diabetes varies significantly between patients, and that its impact depends to some extent on levels of proactive self-management and compliance with medical guidance.

The difficulties of managing blood sugars while avoiding hypoglycaemic attacks, and the varying impact of medication on different patients, complicates the picture.

However, some clear themes have emerged through this research. These include the very different levels of understanding of type 2 diabetes among patients, which affects the degree and effectiveness of self-management.

Access to consistent advice and information was identified as a common need, particularly among patients who were not regular internet users.

The next section of this report contains recommendations for supporting higher levels of understanding and information, and better management of the condition.

Section 4: Recommendations

4.0 Recommendations

This section contains recommendations, based on the findings of our research, to support better management of type 2 diabetes by patients in Newcastle upon Tyne.

4.1 Knowledge and information

4.1.1 Introduction to type 2 diabetes

Given the variation between the depth and quality of information given to newly diagnosed patients (and the frustration felt by some patients who did not feel they had been given enough information), there seems to be a strong case for developing an effective, coordinated induction programme for newly diagnosed patients.

The DESMOND course is clearly designed to meet this need, but in its current form it appears not to provide all the information, or answer all the questions, participants felt they had needed at the outset.

The course could be amended and developed in consultation with existing patients, whose experiences and opinions constitute a valuable resource that would in many cases be willingly offered. Alternatively, it might be advisable to develop a locally focused course that provides information but also signposts patients to local resources.

4.1.2 Consistent nutritional and dietary support

Participants in this research demonstrated variable levels of understanding of the nutritional issues affecting type 2 diabetes; and it was clear that much of the information and advice offered was contradictory and inconsistent.

Given the importance of diet in controlling the condition, a coordinated programme of introductory and ongoing nutritional advice would be invaluable and could be delivered as part of the locally developed course recommended above.

4.1.3 Information about blood sugars

Although some participants had either taught themselves or been given good information about blood sugars, a significant proportion felt they had little or no understanding of the significance of their regular readings.

Better understanding of the significance of different readings could potentially lead to better management of blood sugar levels.

4.1.4 Informal sharing of information

Participants at focus groups commented on how helpful it had been to share experiences and compare notes with each other. The opportunity to talk to other type 2 diabetes patients, with or without professionals present, was identified as a potentially useful opportunity. In many cases, participants felt this would meet their needs better

than participating in Diabetes UK meetings, but where the capacity to convene meetings is not present in practices, there could still be real benefit in actively signposting patients towards local Diabetes UK groups.

Appendices

Appendix 1 – Participant profile

Gender

	No. of participants	% of participants
Female	36	65.5
Male	19	34.5
Total	55	100.0

Age

	No. of participants	% of participants
16-30	0	0
31-59	23	41.8
60+	32	58.2
Total	55	100.0

Ethnic background

	No. of participants	% of participants
White British	40	72.7
White Irish	1	1.8
Any other White background	1	1.8
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	0	0
Asian or Asian British – Indian	3	5.5
Asian or Asian British – Pakistani	8	14.5
Asian or Asian British – Bangladeshi	1	1.8
Any other Asian or Asian British background	1	1.8
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	55	100.0

Where do you live?

	No. of participants	% of participants
Benwell	2	3.6
Blakelaw	1	1.8
Byker	1	1.8
Cowgate	1	1.8
Cruddas Park	3	5.4
Dumpling Hall	2	3.6
Elswick	7	12.7
Fenham	10	18.2
Forest Hall	1	1.8
Gateshead	1	1.8
Gosforth	4	7.3
Heaton	1	1.8
Jesmond	1	1.8
Lemington	8	14.5
Montague	2	3.6
Newburn	1	1.8
North Kenton	1	1.8
Shieldfield	1	1.8
Throckley	2	3.6
Walbottle	1	1.8
West Denton	3	5.4
Winlaton	1	1.8
Total	55	100.0

Type 2 Diabetes Questionnaire

Involve North East (formerly Community Action on Health) is collecting information about the experiences of people with Type 2 Diabetes.

We are particularly keen to learn more from patients who sometimes have Hypoglycaemic episodes ('hypos'), to help us improve the services we offer. Hypos happen when your blood sugar is low, and they can cause shakiness, blurred vision, sweating and hunger.

The information we gather will be fed back and used to improve the treatment and care we can give to you and other patients.

We would really appreciate it if you could take some time to complete this questionnaire.

ABOUT YOU

Gender

- Female
- Male
- Transgender

Age

- 16 – 30
- 31 – 59
- 60+

Where do you live? E.g. Elswick, Throckley, Fenham

.....

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>)			

Diagnosis and Learning about your Diabetes

1 How old were you when you were diagnosed with Type 2 Diabetes?

- Under 20 20-40
40-60 Over 60

2 How long have you had it?

- Less than 5 years 5-10 years
10-15 years Longer

3 When you were first diagnosed, what information or advice were you given to help you understand the condition? (you can tick ✓ more than one box)

- I can't remember if I was given any information or advice
I wasn't given any information or advice
My GP/practice nurse gave me some leaflets
I was put on a DESMOND course
My GP/practice nurse gave me other information (please specify below)

Other (please describe below)

.....

4 What was your most useful source of help or information? (please tick ✓ just one box)

- My GP
The practice nurse
The DESMOND course
Talking to other people with Type 2 Diabetes

Other (please specify below)

.....

Hypoglycaemic episodes (Hypos)

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

5 Have you ever had a hypo?

Yes No

6 How often do you have them?

At least once a month
About four times a year
About twice a year
Once a year
I've only ever had one

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

.....

8 In your experience, what do you think causes YOU to have a hypo? (you can tick more than one box)

I don't know
If I miss meals or eat too late
If I eat the wrong food
If I have been exercising a lot
If I drink too much alcohol
The diabetic medication that I take

Other (please specify below)

.....

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

Yes No

How many times?

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

Yes No

How many times?

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

Yes No

How many times?

Medication

12 What medication do you take for your Diabetes?

Metformin
Gliclazide / Glimpiride / Glibenclamide
Pioglitazone
An injectable treatment

Other (please state below)

.....

13 Do you have any problems taking your medication?

No Yes - side effects
Yes – timing of medication Yes – how I have to take it

Other (please state)

.....

14 Do you take your medication as directed by your GP?

Yes No Most of the time

15 If you do take your medication as directed, what are your reasons for this? (you can tick more than one box if you need to)

I have been told to take them
My medication keeps me well / makes me feel better
I know I will feel worse if I don't take it as directed

Other (please state)

16 If you don't take your medication as directed, why is this?

- | | | | |
|--|--------------------------|---------------------------|--------------------------|
| Side effects | <input type="checkbox"/> | I forget to take it | <input type="checkbox"/> |
| Inconvenient / complicated | <input type="checkbox"/> | I don't think it helps me | <input type="checkbox"/> |
| I don't like taking medication | <input type="checkbox"/> | | |
| I prefer to manage my symptoms in other ways | <input type="checkbox"/> | | |

Other

.....

17 Have you ever spoken to your GP or practice nurse about any concerns you have with your medication?

- Yes No

If so, what happened?

.....

.....

18 Is there anything that would make it easier for you to take your medication?

.....

.....

Managing your Diabetes symptoms

19 Apart from your medication, is there anything that makes your symptoms better?

.....

.....

20 How did you find out about the things that make your symptoms better? (you can tick more than one box if you need to)

- | | | | |
|-------------------------------|--------------------------|---|--------------------------|
| By accident / trial and error | <input type="checkbox"/> | Support group / other people with Type 2 Diabetes | <input type="checkbox"/> |
| GP / Consultant | <input type="checkbox"/> | Practice nurse | <input type="checkbox"/> |
| Leaflets / Internet | <input type="checkbox"/> | | |

Other (please state)

.....

21 How easy do you find it to make changes to your lifestyle in order to manage your symptoms? (please tick just one box)

- There isn't anything I can change
- Easy because it keeps me well
- Easy most of the time but sometimes I 'fall off the wagon'!
- Difficult, but I do it anyway
- There are things I should avoid but I enjoy them
- I take medication to manage any problems

Other (please state)

.....

22 Is there anything that makes your symptoms worse?

.....

23 How do you manage this? (you can tick more than one box if you need to)

- Avoid things that make me worse
- Take medication to prevent symptoms
- I just deal with it
- Other (please state)

.....

Living with Type 2 Diabetes

24 How does Diabetes affect your daily routine?

.....

25 What symptoms do you find most difficult in terms of carrying out daily activities?

.....

26 Are there any activities that you no longer do or are unable to do as a result of having Type 2 Diabetes?

.....

27 How does this make you feel?

.....

.....

28 What is your most useful source of support or information to help you live with Type 2 Diabetes? (tick just one)

- | | | | |
|-------------------|--------------------------|-----------------------------------|--------------------------|
| GP/Consultant | <input type="checkbox"/> | Practice nurse | <input type="checkbox"/> |
| My family/friends | <input type="checkbox"/> | Other people with Type 2 Diabetes | <input type="checkbox"/> |
| The internet | <input type="checkbox"/> | Leaflets | <input type="checkbox"/> |

Other (please state)

.....

29 Please use the space below to tell us anything else you would like to share about living with Type 2 Diabetes

.....

.....

.....

.....

Thank you for taking the time to complete this questionnaire.

Please return it in the stamped, addressed envelope provided

Appendix 3 - Questionnaire responses

This section includes responses from telephone interviewees as well as respondents who completed the questionnaire on paper or online.

1 How old were you when you were diagnosed with type 2 diabetes?

	Number of respondents	% of respondents
Under 20	0	0
20-40	7	20.0
40-60	18	51.4
Over 60	10	28.6
Total	35	100.0%

2 How long have you had it?

	Number of respondents	% of respondents
Less than 5 years	8	22.9
5-10 years	9	25.7
10-15 years	9	25.7
Longer	9	25.7
Total	35	100.0%

3 When you were first diagnosed, what information or advice were you given to help you understand the condition? (tick all that apply)

	Number of responses	% of responses	% of respondents
I can't remember if I was given any	6	13.3	17.1
I wasn't given any	1	2.2	2.9
Leaflets from my GP/Practice nurse	9	20.0	25.7
I was put on a DESMOND course	7	15.6	20.0
Other information from my GP/Practice nurse	6	13.3	17.1
Other	16	35.6	45.7
Total	45	100.0	

Number of respondents answering this question: 35

Other

- I started by controlling it through diet, then I went on to medication
- I was sent to the Diabetes Centre. The nurse frightened me as she started talking about toes, feet and legs being amputated. She also told me to check bathwater with my elbow and to always check for stones and nails in case of loss of sensation. It frightened me
- Practice Nurse was very negative, warned me about going blind or losing my legs. She was rather harsh
- I worked for years with the elderly so I knew what to do. I go to the Diabetic Clinic once a year which keeps me on track
- My practice has its own Diabetic Centre. I get really excellent information and regular reviews so I have always been very happy with the information

and advice I get

- The practice used to give you a diabetes fact file, that you kept with you and took to all your medical appointments - including optician visit, podiatry, everything. It had a record of blood results, weight and other things, and it was updated at every visit. It was brilliant, really useful - but they don't do them any more. I imagine it's because of funding, but I found it so useful in keeping track of things
- I was put on tablets straight away, and sent to the hospital for eye tests
- I found the Diabetes Awareness 'purple book' very useful
- The nurse told me I need to lose weight, and gave me advice about healthy eating (fruit and veg) and exercise
- I was given advice about sensible eating. Basically, everything you like is bad for you
- The course, and all the nurses at the hospital, were very helpful
- I didn't ask for any advice because my mother and sisters had it and I knew all about it from them
- A great doctor, he explained to me that I had to change my diet and lose weight if it was possible. I got the Metformin tablets straight away. He told me that I had to wear shoes and not walk about in my bare feet in case I got my feet cut
- Diagnosed at hospital and given information there
- Not answered x 2

4 What was your most useful source of help or information (tick just one)

	Number of respondents	% of respondents
My GP	9	25.7
The Practice nurse	5	14.3
The DESMOND course	5	14.3
Talking to other people with Type 2 Diabetes	0	0
Other	16	45.7
Total	35	100.0%

Other

- I didn't get much useful information. And I felt - still feel - that my weight was more of a problem to them than my diabetes. If you're fat, your other symptoms aren't taken seriously
- Information I was given at check-ups by the nurses at the Diabetes Centre. They reassured me about my fears from the previous information I was given, and gave me general advice
- Internet, especially Diabetes UK - changed doctors and found new doctors' practice very helpful
- My own personal knowledge
- Over a period of time I got advice from the Diabetic Centre at the General Hospital. I used to go every three months, but it's down to twice a year now.
- The diabetes fact file
- The Diabetes Centre
- My family
- My own experience

- The course was very helpful, and I work with elderly people so I had some knowledge already. And my mother had it too, so I recognised the symptoms
- The internet
- The nurses from the Diabetic Centre, they were all great
- The chiropodist gave me some information, but it wasn't any good
- I don't think they know much - you get lots of different answers
- I had a really good dietician who was very helpful. But then I was given another dietician and she spoke to me as if I was a child or an idiot. I really hated that

5 Have you ever had a hypo?

	Number of respondents	% of respondents
Yes	30	85.7
No	5	14.3
Total	35	100.0%

6 How often do you have them?

	Number of respondents	% of respondents
At least once a month	11	36.7
About four times a year	9	30.0
About twice a year	4	13.3
Once a year	4	13.3
I've only ever had one	2	6.7
Total	30	100.0%

7 What do you think causes you to have a hypo? (tick all that apply)

	Number of responses	% of responses	% of respondents
I don't know	7	13.0	23.3
If I miss meals or eat too late	17	31.5	56.7
If I eat the wrong food	5	9.3	16.7
If I have been exercising a lot	4	7.4	13.3
If I drink too much alcohol	1	1.8	3.3
The diabetic medication I take	4	7.4	13.3
Other	16	29.6	53.3
Total	54	100.0%	

Number of respondents answering this question: 30

Other

- Snacks at work, to stave off boredom and help me concentrate. But then if they are the wrong sort of snacks, I can end up with a hypo
- The big problem, with having a family, is that I have to have a meal an hour after my injection - not less than an hour and not longer. But if the kids are late getting back from a club or something, than I am likely to have a hypo. It's difficult managing an injection regime with family mealtimes
- It was being on insulin, with my existing diabetes meds

- I think stress can cause hypos. And in my case, I think my last one may have been brought on by chemotherapy. But I'm on insulin now, and the hypos seem to be a lot less frequent since I started
- And also if I forget my medication
- Insulin levels in my case
- In the morning I am OK if I wake up slowly, but if I wake up with a start, I feel bad for the rest of the day
- Doing too much and not looking at the time, so I leave too big a gap between breakfast and lunch
- If I don't eat 'little and often', or if I am worried about something, I get shaky and lethargic
- Not eating enough before exercise
- I have a bottle of wine with a takeaway most Friday nights, and I often get them on a Saturday
- If I exercise without eating
- To tell the truth I can't quite remember what caused it
- I used to carry Lucozade tablets with me when I went walking, but the doctor suggested I should just take one when I got in from my walk. But I can tell when it's coming on, so I'm going to start taking the Lucozade out with me again so I can take one as soon as the feeling starts
- The nurse has changed my medication and I've lost two stone since January, so my hypos don't seem so bad now
- If I don't eat something last thing at night

9 Have you ever been to A&E with a hypo?

	Number of respondents	% of respondents
Yes	3	10.0
No	27	90.0
Total	30	100.0%

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

	Number of respondents	% of respondents
Yes	1	3.3
No	29	96.7
Total	30	100.0%

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

	Number of respondents	% of respondents
Yes	0	0
No	30	100
Total	30	100.0%

12 What medication do you take for your diabetes? (tick all that apply)

	Number of responses	% of responses	% of respondents
Metformin	32	42.1	91.4
Gliclazide/Glimepiride/Glibenclamide	21	27.6	60.0
Pioglitazone	6	7.9	17.1
An injectable treatment	7	9.2	20.0
Other/none	10	13.2	28.6
Total	76	100.0%	

Number of respondents answering this question: 35

Other

- I was recently put on slow release Metformin as my potassium levels were high
- I was on Pioglitazone, but now I take Saxagliptin
- I used to take three Metformin a day, but I've lost a lot of weight so I don't need so much now. I only take it twice a day, morning and night
- I used to take Gliclazide, but since I've lost over a stone through Slimming World, I don't need it any more. So I just take 3 Metformin
- Simvastin for cholesterol, Amlodine for high blood pressure
- Cholesterol tablets and aspirin
- The nurse has cut down my Gliclazide and I don't take Pioglitazone now, to try and control my hypos
- Something for the cramps in my feet. I'm not sure what it's called
- Humulin
- I have a prescription for Metformin but I'm waiting for my six month check-up. I'm hoping to deal with this without medication

13 Do you have any problems taking your medication?

	Number of respondents	% of respondents
No	27	77.2
Yes – side effects	2	5.7
Yes – timing of medication	0	0.0
Yes – how I have to take it	0	0.0
Other	6	17.1
Total	35	100.0%

Other

- I'm so used to it now, but Metformin gives you terrible wind and there's the timing problem with Byetta injections
- Don't want to go on medication but might have to
- Initially had problems but now my body is used to the meds
- Metformin makes my bowel movements loose, but now I am on a slow release version it's better. And Pioglitazone gave me heart problems, which is why I don't take it now
- I find I can't take my morning Metformin as soon as I get up, so I take it to work with me. But that means I sometimes forget to take it, and only remember it when I start to feel ill
- Remembering it!

14 Do you take your medication as prescribed by the doctor?

	Number of respondents	% of respondents
Yes, always	29	82.9
No	0	0.0
Most of the time	6	17.1
Total	35	100.0%

15 If you DO take your medication as directed, why is this? (tick all that apply)

	Number of responses	% of responses	% of respondents
I have been told to take it	16	34.7	55.1
My medication keeps me well/makes me better	8	17.4	27.6
I know I will feel worse if I don't	9	19.6	31.0
Other	13	28.2	44.8
Total	46	100.0%	

Number of respondents answering this question: 29

Other

- When I was first diagnosed, nobody told me how to take them (about taking them around mealtimes, intervals and things like that). When the nurse realised my GP hadn't given me any advice she sent me on the course, and that was very helpful
- I want to stop my problems getting worse. I trust the doctors
- Not on medication yet but would take it as directed
- It's just easier to stick to a routine, so I don't forget. And it's easier when I'm in the work routine and doing things regularly, than it is when I am on leave
- I'm just into the routine so I don't think about it
- It's habit now, and it seems to work
- I am a machine operator, and sometimes I get a bit unsteady. I did stop taking the medication because they made me feel a bit dizzy but that didn't make me any better, so I have started taking them again
- I take it at the times stated on the box
- The doctors know best
- I take a lot of tablets for a lot of things, so I just set them all out together and take them when I need to. I trust the doctor
- Because it's on my list. And I take all my medication that is on this list
- I'm that kind of person - I do what I'm told. You can't afford not to
- Not answered x 1

16 If you DON'T always take your medication as directed, why is this? (tick all that apply)

	Number of responses	% of responses	% of respondents
Side effects	0	0	0
I forget	4	50.0	66.6
Inconvenient/complicated	0	0	0
I don't like taking medication	0	0	0
I don't think it helps me	0	0	0
I prefer to manage my symptoms in other ways	0	0	0
Other	4	50.0	66.6
Total	8	100.0%	

Number of respondents answering this question: 6

Other

- If I'm busy and don't take it at the usual time
- If I haven't got it with me
- If I haven't eaten I don't take it. It has to be taken with food, and if I skip breakfast because I'm busy, I don't take my medication in the morning
- It's just occasional, I take it as directed most of the time

17 Have you ever spoken to your GP or nurse about any concerns you have with your medication?

	Number of respondents	% of respondents
Yes	22	62.9
No	13	37.1
Total	35	100.0%

What happened?

- I was having hypos about 10 minutes after taking Gliclazide. You're supposed to wait an hour after taking it before you eat, but now I take it closer to the time when I eat. You just have to use your common sense
- My blood sugar went haywire due to my meds for other conditions. I was put on insulin but told to still take my other diabetes meds. That's when the hypos started, and I was worried. So I was taken off the insulin but I still had hypos for a while because I still had 'residual' insulin in my body. They've always listened to my concerns
- Wait for six months review before starting Metformin
- Reassured me. If I feel something is wrong or bothering me, I will tell them.
- I was on Rosiglitazone and was having a bad reaction so Dr changed my medication to Pioglitazone
- Gliclazide made me feel hungry, so the Dr told me to reduce my dosage of it
- When I was first put on insulin, I had a four-week course to show me how to use it. It also covered adjusting the dose, diet, reading blood tests and things. I felt fully informed at the end of it
- It was the pharmacy rather than the GP. I asked them to do a meds review for

me, and discovered I was taking some of my non-diabetes medication at the wrong times. Once I sorted that out, I felt much better in general

- It was my insulin, they put it up to eight and that made me feel bad. But when I told them, they put it down to six and I've been fine ever since
- I'm on a higher dose now and it causes me to have sweats and diarrhoea. We talked about me having to change my dose if it stays like this
- I spoke to my consultant because I thought the insulin was causing me to have hypos. He was happy for me to reduce the insulin and he said I could reduce it faster than I was doing
- They aren't bad - they tell me I have to control it, but if you are busy you don't always have the time for exercise or regular meals. And you can't always take your medication at the right time
- The GP never seems to have the time to explain things, or isn't interested. The practice nurse is more helpful
- GP was happy with my decision
- Discussed and was quite happy with the explanations given. And discussed adjustments to make during Ramadan. That was helpful
- I have mentioned before that I get sick of taking medication. I find sometimes it affects my appetite but obviously I was told I needed to take it for my diabetes. Also, I was told it might affect my sex drive which it does
- I said I thought the tablets were a waste of time. They didn't agree. I told them in no uncertain terms, but I just take them now
- Doctor reassured me about my medication and I trust my doctor
- She is very good, and always helps when I have a problem or a question
- Monitor reading, I didn't get it right at first
- Not answered x 2

18 Is there anything that would make it easier for you to take your medication?

- Not realistically - the complications are all to do with work and family, and you can't change that!
- I don't like taking tablets, I prefer meds in liquid form
- No, after initial problems I am fine now.
- Quite happy
- No, I manage well
- No, it's easy. I only have to do it twice a day and the pens are really handy and easy to use
- No, it's not a problem - except for not feeling able to take it first thing in the morning, with the risk of forgetting it later
- I don't need anything
- Probably smaller tablets!
- Maybe a lower dose
- No, it's fine
- Not a problem
- No, because I've worked it out for myself and the consultant is happy with that.
- The tablets are very big, it would help if they were smaller
- No, I'm quite happy
- Not really
- No, it's not a problem

- No. I just do it
- I find it is easy to take it – in the morning I take it just after eating some toast.
- Not a problem
- It's not a problem anyway
- No. It's not hard
- No x 8
- Not answered x 6

19 Apart from your medication, is there anything that makes your symptoms better – or worse?

- I get numbness in my fingertips and toes. But I do find that exercise helps, and eating the right food. It's just finding the time for exercise, and being careful with food - especially on special occasions, when there's a family celebration or something like that
- Drinking water, so I keep hydrated. Following the Slimming World eating regime. It helps me control my weight but it feels better too. And doing more physically. I can't go to a gym because of my weight, but I do feel better if I walk more and faster, things like that
- There isn't anything, because I have lots of other problems (arthritis, thyroid and other things). I try to eat healthily and I don't drink or smoke and I never have. I don't drink tea or coffee and I've stopped eating chocolate, biscuits etc
- Eat proper food, learnt about GI indexes/making better food choices, exercise more, swimming - more energised
- Apart from watching diet, I don't eat or drink excessively and exercise by working in garden or house
- I find if I eat two small pieces of dark chocolate every night that helps.
- I don't have any symptoms
- I stopped eating chocolate, biscuits and sweets and cakes. Lose weight and eat sensibly. I'm learning all the time. I used to eat a lot of grapes but now I realise that there is a lot of sugar in fruit, so it's not really good for you
- Diet, keeping my weight down
- No
- When I have the time to exercise regularly, I do feel much better - less lethargic, and much more energy. But the problem is fitting the gym into a busy life
- Not really
- Keeping a healthy eating routine. A lot of people on the Slimming World website say they keep it under control by diet, so it's not just me. And not worrying about it helps, too
- I try to eat healthier now. I have lots of brown bread and I don't have sweet things. I don't feel as dizzy now
- I don't know because my blood is out of control right now - it's never been so high. And we can't seem to get it down
- Exercise, eating the right food, less stress in life
- Keeping busy, so I am not always thinking about food and reaching for the fruit bowl. I think being on insulin makes you think about food all the time, so being busy keeps you away from that. I get much better readings when I'm busy because it keeps my blood sugars down
- No. I don't take exercise

- Regular meals. And I've just started going to the gym, which seems to be making me feel better in general. But I have a number of other conditions so it's quite hard to work out what is affecting what
- Eating the right food - food is the best medicine for your body. I'd like to see more research on this. Porridge in the morning lasts longer. Some herbs can help to control the symptoms - bitter melon (eating and drinking), and some people find aloe vera helpful. Gram flour and pulses help, too
- Asian remedies, especially bitter melon. If I have bitter melon as part of a meal, I don't need to take Metformin. Other people find the same
- My wife cooks all the right food - plain meat or fish and plenty of veg. And I don't drink as much. I used to drink 10-15 pints a day. Now I don't drink except on Fridays when I have a full bottle of wine with a takeaway. And at Sunday dinner time we have a pub lunch so I have a pint of beer before, then a full bottle of wine with the dinner and an Irish coffee afterwards
- Eating properly and at regular intervals, and exercising regularly - as long as I don't do it on an empty stomach
- Nothing I can think of
- I have a treat once a week - trifle, or something like that - but then I go for a walk afterwards, to work it off.
- Nothing. I hate having it and my weight has gone up, but that's the steroids I take for something else.
- As long as I keep to my diet and don't go mad on treats. I eat healthy.
- Losing weight, watching what I eat and changing my medication
- A little exercise
- Avoiding stress. If I get wound up about anything, I feel worse
- I always eat something last thing at night. And I keep a carton of orange juice with me all the time. When I'm about to have a hypo I can see 'floaters' in front of my eyes. If I take juice as soon as that happens, I can usually prevent the hypo
- Sometimes, having something sweet. An energy tablet, a biscuit or a little chocolate
- No
- Not answered x 2

20 How did you find out about the things that affect your symptoms? (tick all that apply)

	Number of responses	% of responses	% of respondents
By accident/trial and error	12	24.5	37.5
Support group/other people with Type 2 Diabetes	3	6.1	9.4
GP/Consultant	7	14.3	21.9
Practice nurse	9	18.4	28.1
Leaflets/internet	2	4.1	6.3
Other	16	32.6	50.0
Total	49	100.0%	

Number of respondents answering this question: 32

Other

- From the course I went on. And when I went to Aquafit I found it really good.
- You hear about things on the telly and I've picked up leaflets in the surgery. Most of them talk about eating wholemeal foods and I try to just be sensible and do the best I can
- Try different foods
- All my family members are on insulin
- My insulin course
- You just start to notice the times you feel better, and see the connection with exercise or whatever
- I've learned over the years how to live with it
- I used to see the dietician and she was really good. Talking to her encouraged me to go to Slimming World
- I'm still trying to work it out
- You just get used to observing yourself and recognising all the signs so you manage it properly
- Experience. And I work with elderly people so I learn a lot from their experience
- The experience of family members in Pakistan - it's [bitter gourd] a well-known remedy there
- I live a bit like a goat - if I want something I eat it, and then I don't eat it again for a while
- I've discovered how important it is to control my sugar intake
- I had a dietician who wrote out everything for me in Edinburgh and sent it through for me to follow. There is one thing that I can't give up and that's butter as long as it not put on too heavy the Dr says that fine. Margarine is horrible
- My diabetes nurse at the hospital suggested I try milk, orange juice and a biscuit. The juice worked fastest, so that's what I have now

21 How easy do you find it to make changes to your lifestyle in order to manage your symptoms?

	Number of respondents	% of respondents
There isn't anything I can change	3	8.6
Easy because it keeps me well	3	8.6
Easy most of the time but sometimes I fall 'off the wagon'!	8	22.8
Difficult, but I do it anyway	3	8.6
There are things I should avoid but I enjoy them	2	5.7
I take medication to manage any problems	1	2.9
Other	15	42.8
Total	35	100.0%

Other

- It's difficult knowing what I need to do. I don't do stupid things, but I must be doing something wrong because my bloods are always so high
- I miss chocolate, biscuits and cakes the most, especially at Christmas and Easter when the shops are full of it. I feel like a second class citizen because I can't have it. I feel inferior, not the same as everyone else but I do it because I have to

- I used to cheat a bit, but never again. My sister nearly died, and that changed my approach and encouraged me to change my lifestyle. These days I find it easy to change my lifestyle because I want to stay healthy and keep off insulin
- My diet wasn't too bad anyway, and I don't need to lose weight. So there is nothing I could alter
- You just adjust, really. You see what alters things and you change what you do
- As long as you watch what you eat, it's not too hard
- I have to have meals at regular intervals, but being retired I can pretty much order my own life for that. I used to get irritated when my father-in-law insisted on having his dinner at noon every day, but I'm a bit like that now because it helps me to control my diabetes
- It's OK, but sometimes the common sense approach, cutting out what you're not supposed to eat, is a bit dull. But I am careful, when I have a hypo, to have a sugar cube rather than a Mars bar
- I try to make time to go for a walk. And eating the right food is important so I try not to eat too much processed food. The Asian diet doesn't have as much processed food as the western one
- I have always tried to keep fairly healthy
- I very rarely eat sugary food now
- I was asked to go along to an exercise class, but I don't like sitting in groups holding hands. I wouldn't mind listening to an expert talking about it, but I'm not going to go to a class
- I manage quite easily as I was never a big eater anyway
- I am very single-minded, so when I decide to do something I do it properly. But I hate it and it does get to me. Like when I'm in Asda and I can only eat about a quarter of what I can see on the shelves
- It's not hard, I just have to make sure my sugar levels are high enough before I go out anywhere, and I always have my orange juice with me

22 Is there anything that makes your symptoms worse?

- Emotions. If you are upset or worried, the diabetes gets worse. And not controlling my sweet tooth!
- I have a lot of back pain, and I think my diabetes symptoms are worse when that flares up
- No, I've given up the things that trigger my symptoms. When you live on your own you have to make sure you keep yourself well. I am the patient and the carer
- Sugar - wrong food
- Nothing really if I watch my diet and take the medication
- Having hypos - you know when you are having them - I find they are caused by lack of sugar
- The wrong food, stress and being overweight. I'm tackling the weight now - I've lost more than a stone
- Bad diet. And if I miss my medication - when I'm out longer than I expect, for instance. You have to make sure you take your meds with you
- Walking, exercise
- Forgetting my medication

- No, because I keep it under control. But I do meet people, often older diabetes patients, who don't want to take the messages on board about healthy eating, and they bury their heads rather than taking control
- I don't know
- Eating sweet things
- Eating sweet stuff, definitely
- Stress in life
- Eating the wrong things at the wrong times, and not keeping my meals balanced. It helps if I have a good breakfast, and then I don't need much lunch but I have a good evening meal - but that can't be too big
- When I am worried about something
- Doing too much physically. I don't mean actual exercise, but heavy housework or moving furniture. That sort of thing can make you feel bad
- Very big meals
- Skipping meals
- Exercise without food
- Nothing I can think of
- Sometime I just don't feel like eating or can't be bothered to make something
- Not eating the right food, and not balancing the tablets
- Eating lots of very sugary things
- Stress
- Eating too much, and eating the wrong food - especially fried or fatty food
- Too much sweet stuff, I sometimes haven't realised
- Too much sweet stuff
- Infections
- No x 4

23 How do you manage this? (tick all that apply)

	Number of responses	% of responses	% of respondents
Avoid things that make me worse	18	40	54.5
Take medication to prevent symptoms	6	13.3	18.2
I just deal with it	8	17.8	24.2
Other	13	28.9	39.4
Total	45	100.0%	

Number of respondents answering this question: 33

Other

- I try not to get down or upset, but that is very hard when so many things affect the way you feel
- Eat chocolate
- I'm being very positive and proactive at the moment, I want to deal with my diabetes and not get worse
- Keeping my meds with me all the time, and keeping an eye on my food. It's about timing and availability
- Stop what I'm doing and go home to bed
- Not a problem
- Now that I know how to keep well with diabetes, I just want to do anything that

- prolongs my life and helps me to carry on having a good quality of life
- I try to manage it, but I do get tempted, and that's why it's out of control
- In the early days, I managed purely with diet and exercise. And I still know pretty well what I can and can't do. You learn from experience
- In the mornings, I have to get to work and don't always have time for breakfast but I do try to take something. I have Metformin with my main meal
- I have carers that come in three times a day but if a hypo happens when they are not here I just go into the kitchen and sit on the stools I have in there and make a sandwich
- I'm OK most of the time, but I've got two cruises booked this year and I don't know how well I'll manage with all the food and drink!
- Not answered x 1

24 How does Diabetes affect your daily routine?

- I have to pace myself, and sometimes let things go if I haven't got the energy to do them
- In lots of ways. Pre-planning is crucial because of having to time meals and meds so carefully. And Byetta has to be kept cool, so you always have to have a coolpack for it when you're away from home
- I plan ahead in case I feel unwell and unable to leave the house. I make sure I have plenty of groceries in. Changes to my diet
- Try to live healthily although it is hard – can get caught short if I can't get food – learnt to carry a banana or snacks
- Have to watch diet when I eat out
- Not really, sometimes I feel a bit faint if I go too long without food. I have to eat immediately
- Not much – but you have to be careful with your feet
- Not much, but I have to take a nap after lunch
- Small things – like one day when there were huge traffic problems and I couldn't get home from work one night. I had to stay with a friend and I don't carry my evening Metformin with me (because I usually only take it at home). Luckily I knew someone near my friend's house who has diabetes and I was able to get some from her for that night. Otherwise, I'd have been quite ill. So you couldn't really do anything on the spur of the moment if it meant missing your medication
- It's hard to say because I have so many other problems and you don't know what causes what
- Not much, although I do still get very tired
- All my lifestyle has been changed
- It doesn't, most of the time. But I never used to eat breakfast and now I have to. I don't like eating breakfast and sometimes I forget, or try to skip it. But I know it makes me feel worse if I don't eat it
- Lack of energy, unable to do things as fast as I used to do
- It does restrict what you can and can't do, especially medication if you have to inject yourself. And the need to eat at regular intervals is a bit restricting
- I can't read very well any more, I have to go to see an eye specialist
- It doesn't (but my other health problems mean I haven't been able to work for several years)
- It does affect what I do. If I feel tired and lethargic I can't do all the things I

need to do

- Sexually, not the same any more. I have taken Viagra, but it's useless - you might as well take aspirin
- It doesn't really. The only time I have to be careful is Ramadan. But I have learnt to adapt my eating and cut down my exercise in Ramadan, and I amend my medication for that period with my doctor's support. Strangely enough, I felt better last Ramadan than usual. But I know a lot of people who can't manage their diabetes well in Ramadan
- It does not affect me in any way
- I try not to let it. When I got my diagnosis, I was told the trick is to manage it so it didn't manage me. You have to watch your diet, and be careful about getting infections
- It doesn't. I don't make any changes
- You don't really think about it, apart from the hypos
- Sometimes I get sick of taking tablets
- I never used to eat regular meals, but I do now. I even put things out in the morning, to remind me to eat them later when I wouldn't normally bother to eat. And I take two daily half-hour walks, to keep myself fit and control my weight. And I used to spend time in the pub every day. I only go once a week now, for a couple of hours on a Friday
- It doesn't really. It's just habit now – you get to know what helps and what doesn't
- Sometimes I have no energy, sometimes I feel dizzy
- Learn to live with it
- Not much x 2
- Not at all x 4

25 What symptoms do you find most difficult in terms of carrying out daily activities?

- Tiredness, painful feet and hands
- Hypos, and the timing thing about eating before I start to have one
- The slumps are awful but haven't had one for a long time
- Not the end of the world. I can manage the symptoms
- Dryness of the mouth. It makes it hard to talk sometimes and I have to drink something
- None - I'm fairly fit otherwise
- Nothing major, but I worry when I go on holiday - I daren't put my medication in my suitcase in case my luggage gets lost, so I have to carry it all in my handbag and then I worry about having them taken off me by Customs
- Glaucoma and cataracts
- The tiredness - it means I don't do as much housework as I probably should!
- Keeping away from food makes me worse
- It's hard to say really because my arthritis and other illnesses probably affect me more
- The hypos - I can't cope with the shakes. I have to pull myself out of it, but it takes a long time to feel better
- At home, I want to do more but do not have the energy. At work, lack of concentration

- I don't like injecting in restaurants, so I have to go out to the car to do it. That puts me off eating out a bit. And if I eat a big meal out that throws things out of balance. And I get tired after any kind of physical activity, even walking the dogs. I need a sleep afterwards, or at least to sit down and recharge
- My eyesight. I can't see small print
- Nothing, as long as I am sensible about what I can do
- Lack of energy - especially if I've missed a meal. I have to eat a lot to get my energy back, then I can feel bad because my sugar level goes too high
- Exercise at the end of the day if I haven't eaten. I always have to have emergency rations with me when I exercise. But it's also difficult if I eat too much and my blood sugar goes too high. If your sugar's too low, you can eat something. If it's too high, you can't just take another tablet
- Sleep. I get very tired. More exercise would probably help me a lot
- I don't really find anything difficult on a daily basis
- I have other health problems that cause me much more trouble than diabetes
- I don't like having it and I'm cross that my weight has gone up. But it doesn't change my routine
- I miss having a chocolate biscuit every now and again
- The injections sometimes
- My feet. They hurt and they wake me up at night, but I won't let them stop me doing anything
- Blurry eyes, feeling dizzy, feeling hungry, too warm, sometimes I can't stand the central heating, loss of balance
- None x 8
- Not answered x 1

26 Are there any activities that you no longer do or are unable to do as a result of having type 2 diabetes?

- I can't clean the house in one go the way I used to. I have to let it go
- I had to stop work due to ill health, and I have stopped going to church
- Drink - hangovers are much worse
- Eating chocolate etc
- I notice a lot of problems from my head, I can't stand properly and feel dizziness
- I still do everything, but they all just take longer
- Reading
- Sometimes too tired to do anything
- I had to stop work - I had a very physical job and I couldn't keep on with it
- Drink! It's affected my social life, because really that was the pub. I don't go much now because there's no point if you can't have a drink
- Can't walk or take exercise because of arthritis in my feet. Can't manage other things
- Driving - lost sight in left eye
- Can't have sex x 3

27 What is your most useful source of support to help you live with type 2 diabetes?

	Number of respondents	% of respondents
My GP / consultant	4	11.4
The Practice nurse	6	17.1
My family / friends	3	8.6
The internet	2	5.7
Other people with Type 2 Diabetes	0	0.0
Leaflets	2	5.7
Other	18	51.5
Total	35	100.0%

Other

- The lessons I learned when I went on the course
- It's actually very hard to get good information or advice. I think the GP, and the nurses, don't really look past your size. I know I need to lose weight, but it's not as easy as that. And when I did lose five stone, my bloods were still seven and above. I don't feel I really understand, even now. The dietician tells me one thing, I do it and then I have hypos. Nobody can give you a straight answer, that's the problem
- I use common sense, and I was given leaflets when I was on the insulin course. The diabetic nurses and the nurses' helpline are good
- GP has diabetes and I have a very good relationship with her. The doctor would be first port of call but I find the Diabetes Centre helpful as well
- Not just my GP, but the whole multi-disciplinary team at the surgery – the dietician's great. I used to have a really good practice nurse who knew a lot about diabetes, but the new one isn't so knowledgeable
- As well as the nurse practitioner, my husband is very supportive
- I don't really get much
- The specialist nurse at the Diabetes Centre is really switched on. She's on a crusade to get people managing their diabetes well and she's great. She can be a bit of a demon if you don't do what you're supposed to do, but I really trust her
- Friends and family
- My own experience
- Experience over the years
- I tend to be other people's source of information!
- My doctor's the very best
- The nurses at the hospital are really good. They are always very positive, and that keeps me positive
- I don't get any help or advice from anyone
- I read about it in books and magazines - if I understand about it, I can deal with it
- The hospital, especially the diabetes nurse there
- Diabetic Centre

28 Anything else you want to tell us about living with Type 2 Diabetes?

- I think surgeries should do more to make sure you have all the right information at the start, so you know how to look after yourself. And there

should be education about diabetes in schools, so children understand how important it is to look after yourself and stay well. It would be good to have access to more services to help us manage better for longer. Help to pay for opticians or home help would probably save money in the long run because we would be able to care for ourselves much longer

- Nobody will explain things. I've been monitoring my bloods, but when you show the information to the nurse or doctor, they don't explain what it means or give you any advice about your reading - so you're none the wiser. That's stupid. And there's a big difference between the way medics approach type 1 and type 2 diabetes - as if type 1 was the 'real' condition. I feel embarrassed about having type 2. I'm not a proper diabetic. In my head, I don't have 'real' diabetes, I'm just fat
- Not just because of diabetes, but with all the other illnesses my life has shrunk and I feel like a prisoner in my own home
- Hard to adjust when younger Don't keep your head in the sand - you could go blind. Stop smoking. Learn to live with it, there is a lot you can do
- You cannot let it rule your life but under no circumstances can you ignore it. I can live with it with no problems by taking the meds and watching the diet
- Father had diabetes and all my siblings have as well
- I have been told by GP to eat less sugar which I do. My father struggled with diabetes so the doctor checked me as a precaution and found I had it as well. Never had a problem with it, I just take the medication and that seems to sort it out
- It's important to find out as much as you can, and do what the doctors and nurses say. I didn't in the beginning, but my sister nearly died and that taught me a lesson. I've been told I might need insulin, but I'm determined to stay off it
- Type 2 is in my family. I find insulin easier to take than other meds, it's easy to carry the pen around with me
- It stops me making a pig of myself with chocolate. I'm living with it and it doesn't affect my life too much. I am better now I am on medication. I used to get blinding headaches and a really bad thirst, but they've all gone now I'm on medication
- I have a lot of other conditions, but I find it's the diabetes that most affects my other health problems rather than the other way round. In fact, my diabetes has stopped the surgeon from being able to do anything about one of my other health problems
- It's not a big problem if you manage it carefully. It really depends on how you control it, and how you decide to live your life. Everything in moderation works for me
- I would really like to see a dietician for advice on what to eat and how I can control it that way. But when I went to see one, she said she wasn't really supposed to work with diabetics because there's no funding for it. That made me feel bad about asking, but if I could have a dietician to help me I think it would be easier to manage. I don't want to keep going on courses, I just want advice when I need it
- I lived down south when I was diagnosed, and I used to meet with a dietician there once a month, which really helped me a lot to manage my weight and what I ate. I really miss this
- Weight management seems really important. When I was ill with pancreatitis I went down to 10 stone and I didn't need to take any diabetes meds. I really

struggle with my weight and I've finally admitted I need help with it. I'm going to Weightwatchers and I've lost a stone so I hope my diabetes symptoms will keep getting better

- It's a very bad thing to have. It wasn't so bad at first, but it affects you more and more as time goes on. You always have to be very careful. Nobody can see you have diabetes, but it makes you feel bad pains in your legs and eyesight problems. It becomes more worrying as it gets worse. It is depressing if you have worked hard all your life because now I have to be so careful about what to eat, how to work, taking tablets. And you can't always join in with your friends and family, you just want to sit down
- I hate the fact that diabetics are popped in a box and told what to do. it isn't serious, and I don't want to be on databases for students to look at. I just want to get on. I won't go to the Diabetes Centre for my foot checks, for example, I just go to an ordinary clinic. Why should I have to go to the extra expense and pain of specialist services? And the constant blood checks . . . I refuse to go in the box!
- It's a horrible disease - you can never forget you have it. Sometimes you feel OK, then you feel really bad. It's hard to get the balance right. Ramadan is very difficult because your energy levels get so low. It's OK in the morning, but by the evening I am very tired from not eating or drinking
- For the first two or three years, you can control your diabetes with exercise and eating habits. But I'm finding now that as my body wears down, I have to increase my medication to stay stable. My first hypo was a shock, because I've been spotting other people's early symptoms professionally for years. I collapsed and woke up in hospital with a diagnosis, and that made me realise how quickly a hypo can come on. You only have a finite time to do something to stop it
- At the moment I am OK, I've got it under control and it feels normal now because I know more about it and the doctor looks after me
- I find taking medication and the effects it can have on your system, e.g. my sex drive is nowhere near what it used to be and sometimes my appetite is not as good. Also if I go for a drink I struggle sometimes to drink beer but obviously it is for my own good, I know that. But it does change your lifestyle to what you used to do and not need to think of at the time
- It's OK - and I can't fault the care I've had, so manage it well and I'm happy with it
- My GP won't send me to the General for a health MOT, I think it might help me
- If you eat sensibly and have an occasional treat and stick to your medication you should be fine
- The nurse and I argue like hell - she gives me hell about my weight. But she's pleased with me now I've lost two stone. I find it hard to believe Diabetes is dangerous. It doesn't really feel it
- Sometimes when you are a diabetic and you tell people they are really put off in case you take ill. Also you have to tell banks and insurance companies you are a diabetic and when you go on holiday your insurance can be a lot more
- There's no getting away from it. I do hate it. But it's all down to you - you have to just get on and deal with it. So I do
- Watch what you eat and take your medication
- When I was first told about diabetes I was not told all the different things it

could affect. I have since been told my lost sight, quadruple bypass and stroke are all down to my diabetes

- Not answered x 3