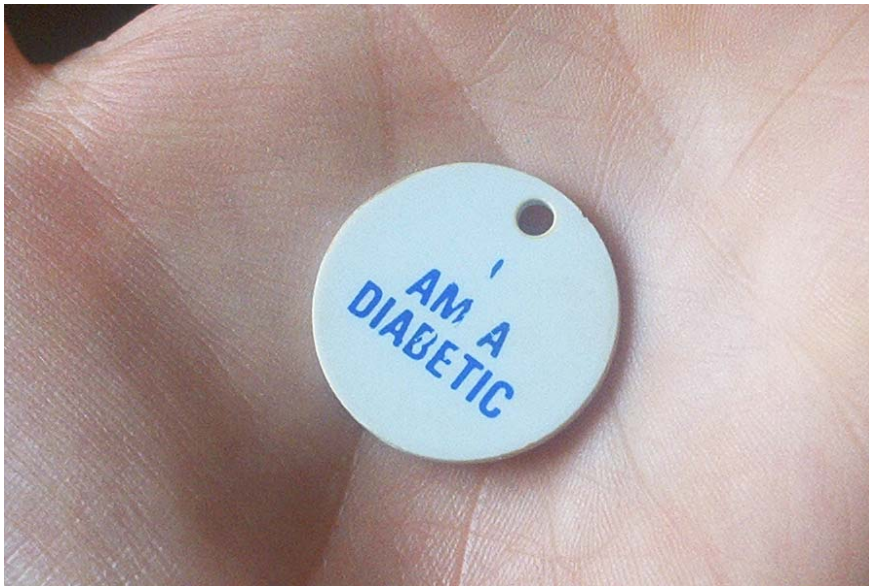


# **Attitudes to Pregnancy Risk and Conception among Women with Type 1 Diabetes**



**End of Award Report for  
Newcastle Healthcare Charities  
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# 1. Executive Summary: Key Findings

## 1.1 Key Issues relating to mental well-being

- Many women suffered from periods of poor mental well-being, including; depression, anxiety and eating disorders, often resulting in periods of poor glycaemic control.
- The need for mental health support was not confined to diagnosis, negative body image or diabetes related complaints, but was often required at times such as a relationship break-up; failed attempts to get pregnant; or a pregnancy that ended in miscarriage.
- The lack of mental health support to help regain control was a prominent emerging theme.

## 1.2 Key Issues relating to management/control

- Good glycaemic control appeared to be most influenced by: positive mental well-being; Bolus/basal injection system; dietary support; knowing your body; taking responsibility for health and pregnancy as a trigger for improved control.
- Poor glycaemic control appeared to be most influenced by: conflict over diagnosis; difficulties in daily management including: food, occupational stress, body image and depression; failure of pregnancy; failure of conception and coping post-birth.

## 1.3 Key Issues relating to health care support

- Overall there was a general consensus that the one-stop-shop provision of diabetic care at the Newcastle Diabetes Centre was highly rated.
- The greatest level of dissatisfaction about the service was in relation to the lack of continuity of care. Many disliked the fact that they would rarely see the same consultant twice resulting in a lack of any on-going relationship and repetition at each visit.
- Some women had problems understanding doctors whose first language was not English and many felt like test subjects for training doctors rather than patients.
- The diabetic specialist nurses were viewed as a constant source of support and it was felt that the nurses understood a bit more about the reality of living with diabetes.

#### **1.4 Key Issues for knowledge about Pregnancy Planning and risks involved**

- Few women had ever received information about how sexual activity could impact on diabetes. Most believed this information should be available and repeated.
- The majority had been asked if they were planning a pregnancy. Most felt this was a 'closed' question, offering little opportunity to discuss the implications of pregnancy, especially amongst those who were sexually active but not planning a pregnancy.
- Overall there was a relatively high level of knowledge with regards to how to approach the planning of a diabetic pregnancy. Awareness of the potential complications was generally limited to the risk of a 'bigger baby'.
- Less than 50% of the sample was aware that a pre-conception clinic existed in Newcastle. More women who had experienced pregnancy than not were aware of this service.
- Only 10 of 24 pregnancies experienced between 14 women in this sample were diabetically planned. Two were planned pregnancies, but not diabetically. The remaining 12 became pregnant accidentally despite contraceptive use.
- For those whose pregnancies were accidental, most had a good knowledge about how and why to plan a pregnancy. They knew what to do but they had not been planning to become pregnant, raising the potential importance that contraceptive advice and education may play in reducing the level of diabetically unplanned pregnancies.

#### **1.5 Key Issues relating to pregnancy support, birth and post-birth experiences**

- Mothers were overwhelmingly positive about the care that they received within the pre-pregnancy stage and during their pregnancy, especially the regular phone contact with diabetic specialist nurses.
- However some mothers felt that because their anti-natal care was provided by the RVI, they missed out on general midwifery care and signposting to anti-natal activities for all mothers.
- Most had acknowledged the higher chance of a C-section, but when it came to the point of birth, some felt unprepared and cheated by the experience.
- Most mothers had been unable to breast-feed at all or for any length of time. Most said the issue had not been raised with them, either in terms of encouragement to breast-feed or information about how it may affect their diabetes.



## 2. Introduction

The pregnancies of women with Type 1 diabetes have high rates of poor outcome in comparison to the general population. This is despite the St Vincent Declaration that called for the elimination of such differences. Epidemiological data show a continuing high rate of serious foetal abnormality among women with insulin dependent diabetes. The damage is caused to the foetus very early in pregnancy due to high levels of blood sugar. The way to improve outcomes for babies of women with diabetes is to assist them to prepare for pregnancy and control their blood sugar before they become pregnant. This emphasises the importance of preconception care. The first stage in this process of improving pre-pregnancy care to these women is to understand their perspective on pregnancy, diabetic control and accessing currently available services. This research, therefore, sought to facilitate the development of preconception care by examining how a group of women with Type 1 diabetes understand and approach the risks associated with their condition. This research will directly feed into the care strategies that will be implemented in the preconception service being developed by the Diabetic Centre at Newcastle PCT.

### 2.1 Background and Aims of the Research

The St Vincent Declaration, adopted by the UK and ratified by the World Health Organisation Regional Committee for Europe in 1991, calls for near normal outcomes of diabetic pregnancy. This has been achieved in leading centres in the UK and Scandinavia and in clinical centre trials (Casson *et al.* 1997). However, population based studies in the UK indicate that perinatal mortality and congenital malformation rates continue to be significantly higher (up to 5 times the rate of the general population in the case of perinatal mortality) (Hawthorne *et al.* 1997; Penny, Mair & Pearson 2003; Taylor *et al.* 2002). Other negative outcomes include excessive foetal growth and hypoglycaemia in the baby after the birth.

The St Vincent Declaration has been renewed in the NHS National Service Framework for Diabetes: Standards (DOH 2001), which states that:

“The NHS will develop, implement and monitor policies that seek to empower and support women with pre-existing diabetes and those who

develop diabetes during pregnancy to optimise the outcomes of their pregnancy.” (ibid: 5)

The studies where the outcomes for mother and child have improved emphasise the importance of optimal glycaemic control both before and after conception, throughout pregnancy and during labour (Siddiqui & James 2003; Väärasmäki *et al.* 2000). The implication, as the National Service Framework stresses, is that: ‘self-management is the cornerstone of effective diabetes care’ (ibid: 4). The Framework calls for local NHS management to closely monitor and audit ‘advice to women on the importance of optimal glycaemic control before and during pregnancy’ and the provision of pre-conception care (ibid: 37). As part of this Newcastle Diabetes Centre has set up a pre-conception clinic.

The research had the following **aim**:

To study the attitudes to risk management and reproductive choice of a sample of women with Type 1 diabetes using qualitative social sciences methodologies in order to capture their social contexts.

## **2.2 Key research objectives**

- 1) Explore how women with Type 1 diabetes understand their condition, the risks that come with it and the implications of pregnancy and their reproductive choices.
- 2) Identify the social contexts that influence how women with diabetes identify and manage health and pregnancy risk.
- 3) Contribute to the development of preconception care for women with diabetes in Newcastle
- 4) Facilitate the development of a large study focused on developing and testing models of intervention based on the findings here.

## **2.3 Methods**

The project established access to a detailed database of women with Type 1 diabetes receiving treatment from the Newcastle Diabetic Centre. From the database 140 women aged between 20 and 37 were randomly selected. They were sent a letter and information sheet from the Newcastle Diabetes Centre asking for their consent to take part in the study. Only once the women had returned a consent form to the Newcastle Diabetes Centre agreeing to take part, were their details passed on to the research associate.

A total of 63 women responded to their letter, providing a 45% response rate. A purposive sample of 32 women was then selected for a first interview<sup>1</sup> (including 2 pilot interviews). Those women received a follow up phone call with the researcher before being asked for final consent to participate in the study. The researcher stressed their right to anonymity and their right to withdraw at any time without having to give a reason. Most interviews lasted between 30 minutes to an hour and with agreement all were tape-recorded. All interviews took place either in the interviewees' own home or work place.

Ten of the interviewees were approached by letter to ask for their consent to be contacted for a second interview<sup>2</sup>; all ten gave their consent. Second round interviewees were chosen on the basis of the information they provided in the first round that warranted further exploration in a second interview. This included issues such as: their experiences of pregnancy and motherhood, difficulty in conceiving; prior experiences of pregnancy that had resulted in negative outcomes; or their experiences of depression.

The decision was also taken to undertake a focus group with some of the remaining first round interviewees. The main impetus for this focus group was the decision by Newcastle PCT to focus on the education of women with diabetes about pregnancy as one of their NSF priorities for 2005-6 (DoH 2004). A decision was taken by the project's advisory group (all members of whom are in the NSF working group for this priority) that it would be useful for the findings of this research to feed into the NSF priority and vice versa. A letter was sent to a further ten of the first round interviewees and three women who attend a Newcastle GP clinic but do not make use of the services at the Newcastle Diabetes Centre, asking for their consent to participate. Five women took part in the focus group<sup>3</sup>, four from the first round interviewees and one from a Newcastle GP clinic. The session was audio-taped with permission and later transcribed.

All quotes made within this report are followed by a pseudonym chosen by the interviewees and their current age.

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<sup>1</sup> See Appendix i for the first interview schedule.

<sup>2</sup> See Appendix ii for the second interview schedule.

<sup>3</sup> See Appendix iii for details of the focus group schedule.

## 2.4 Sample profile

### 2.4.1 Demographics

The age range of women interviewed<sup>4</sup> was 20 to 35, averaging at 28 years. Age at diagnosis ranged from 2 to 28 with a modal age of 9, and a mean age of 14. Seventy-five per cent of women were diagnosed by age 20, with 25 per cent being diagnosed in their 20s. Nine of the sample were mothers (including one who was pregnant); two were pregnant at the time of interview and 21 were neither pregnant, nor mothers. Three of the latter category had experienced a pregnancy but not motherhood. Ten of the women in the sample were married, ten had a steady partner (nine lived together), three were separated and nine were single. None of the single interviewees were pregnant or mothers, although one had experienced a pregnancy and terminated. More than half of the interviewees had some history of diabetes in their family, with 34 percent having a history of Type 1 diabetes. All but one interviewee were of British origin and all but one interviewee were of white ethnicity<sup>5</sup>.

Just over half of the sample had undertaken a university level education and a further third had undertaken either 6<sup>th</sup> form or college. The remainder of the sample had finished their high school education. In relation to current employment, one of the sample was currently unemployed; two were full-time students (one of whom had a part time job); two worked part-time only; eight women were on maternity leave (six intending to return post-birth) and 19 women worked full-time.

### 2.4.2 History of Diabetic Complaints

All women were asked to read a list of diabetic complaints and highlight which, if any, they had ever suffered from and how severely. This revealed that the majority of women suffered some degree of low and high blood sugar problems. Between 16 and 25 per cent of all women also suffered from at least one further complaint of high blood pressure, retinopathy, neuropathy, nephropathy, although none of the sample suffered from heart disease.

Just over two-fifths of the sample also suffered from differing levels of depression, often instigated by struggles with diabetic diagnosis; multiple

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<sup>4</sup> All but one member of the focus group are contained within this data. Additional biographical data on the 5<sup>th</sup> member of the focus group was not obtained, as she had not been interviewed in the first round of interviewees.

<sup>5</sup> For the purpose of confidentiality the nationality and ethnicity of these two interviewees has not been stated.

diabetic complaints; issues of body image; failure to conceive; failure of pregnancy; fear for pregnancy outcome; a breakdown of a relationship, occupational stress or other people's lack of understanding about living with diabetes. Further indications of a lack of mental well-being were also evident where participants talked about eating disorders, anxiety attacks, stress and self-destructive behaviour.

### **2.43 Contraceptive use**

Fifty-nine percent of the sample were using some method of contraception at the point of interview, the most commonly used method was the combined pill (26%), with a further 6% using both the combined pill and condoms. Smaller proportions used the mini-pill (6%); condoms (9%); depo injection (6%) and the coil (6%). Thirteen (41%) of the overall sample were not using any contraceptive method at the point of interview, three who were pregnant, four who were actively trying to get pregnant and six who were not (none of whom were in a relationship).

## **2.5 Key Issues relating to Mental Well-Being**

- A large proportion of the sample suffered from occasional or continuous periods of poor mental well-being, including; depression, anxiety and eating disorders. This often resulted in periods of poor glycaemic control. The lack of mental health support to help regain control was a prominent emerging theme.
- The need for mental health support was not confined to diagnosis, negative body image or diabetes related complaints, but was often required at times such as a relationship break-up; failed attempts to get pregnant; or a pregnancy that ended in miscarriage.

### 3. Management and control of diabetes

#### 3.1 Health locus of control

All interviewees were asked to examine 18 statements<sup>6</sup> from Wallston *et al.* (1994) Multidimensional Health Locus of Control Scales (HLoC) and to state to what degree they agreed or disagreed with those statements (on a scale of 1-6 with 1 being strongly disagree and 6 strongly agree). The overall scores were then calculated for the four subscales of Internal control, Chance, Reliance on Doctors and Reliance on Other people. Table 1<sup>7</sup> below, highlights the range of and average scores for each category.

**Table 1: Health Locus of Control**

	<b>N</b>	<b>Possible Range</b>	<b>Minimum</b>	<b>Maximum</b>	<b>Mean</b>
<b>HLoC Internal</b>	32	6-36	18	36	29
<b>HLoC Chance</b>	32	6-36	6	24	12
<b>HLoC Doctors</b>	32	3-18	5	18	13
<b>HLoC Others</b>	32	3-18	3	15	9

The results showed that in general the women in this sample had an overall high sense of internal control and relatively low level of belief in chance or fate controlling their disease. For many women, whilst there was a strong sense that they were the main factor that affected their diabetes, there was also recognition that there were times where they did not feel entirely in control of their diabetes, for example, as a result of illness.

When discussing this issue many talked about apportioning blame for poor control that they knew had resulted from their own behaviour as well as it not being fair to blame themselves when it was out of their control. This sense of feeling guilty (internal factors affecting control) or unfair criticism (external factors affecting control) was a common theme in the daily lives of many of the interviewees.

<sup>6</sup> See Appendix iv for a copy of the HLoC questions.

<sup>7</sup> The possible range being 6-36 for the subscales of Internal control (questions: 1, 6, 8, 12, 13, 17), Chance (questions: 2, 4, 9, 11, 15, 16) and 3-18 for reliance on Doctors (questions: 3, 5, 14) and reliance on Other people (questions: 7, 10, 18).

In relation to the other two scores, there was also in general more reliance on or belief in medical professionals than other people. However all of these results varied by a number of factors explained below.

Correlations were conducted between the various HLoCs and each other as well as other factors including biographical data, daily management, control levels and so on. This analysis showed that

1. Women with an above average Internal HLoC were more likely to be married or live with their partner ( $p$  is less or equal to 0.05), as were women with an above average Others HLoC ( $p$  is less or equal to 0.01).
2. Women who had a below average Internal HLoC were more likely to have stated that they had suffered from depression ( $p$  is less or equal to 0.025).
3. Women who had a lower level of knowledge about how to plan a diabetic pregnancy were more likely to have an above average Chance HLoC ( $p$  is less or equal to 0.01).
4. Women who had a history of diabetes in the family (Type 1, Type 2 or both) were more likely to have an above average Doctors HLoC ( $p$  is less or equal to 0.01) and an above average Others HLoC ( $p$  is less or equal to 0.05).
5. Women who found the information they received from their consultant confusing, not detailed or practical enough were more likely to have a below average Doctors HLoC ( $p$  is less or equal to 0.025) and a below average Others HLoC ( $p$  is less or equal to 0.025).
6. Finally, if a woman was a mother, pregnant or had a desire to become a mother in the future, she was more likely to have an above average Doctors HLoC ( $p$  is less or equal to 0.01).

Other relationships would have been interesting to explore, in particular, the different HLoCs of women who had 'diabetically planned' their pregnancy rather than the pregnancy occurring by accident or not being planned in diabetic terms. However, with this sample the numbers were simply too small to draw any statistical conclusions. Further research with a larger sample size would enable some of these relationships to be further explored.

## 3.2 Issues around diagnosis

### 3.21 Coping with the diagnosis

A large proportion (72%) of those interviewed found their diagnosis difficult to accept using language such as *devastated, overwhelmed, life changing, in denial, resentful, shock and fear* to describe how they felt. Of those whose initial response was accepting of their diagnosis, the common reason for acceptance was having been so ill it was good to finally know what was wrong so that it could be treated. Only 3 (9%) of the women completely accepted their diagnosis and they all came from families who had a history of Type 1 or Type 1 and 2 diabetes and had almost perceived their eventual diagnosis as inevitable.

Most women felt that they had some level of support (93%) early in their diagnosis; the majority stated the main support came from family. Where medical professionals were referred to (much less common), the most frequently named support came either from paediatric teams or diabetic specialist nurses.

As the women began to comprehend what being diabetic meant and began to come to terms with their diagnosis, their acceptance of being diabetic also changed. In comparison to the 72 percent who were initially un-accepting, this figure was now 31 percent.

Current literature accepts that women diagnosed as teenagers often struggle more with diagnosis, as was found to be the case here. However, it was equally common for women diagnosed early or later in life to initially accept their diagnosis only to suffer a delayed reaction some time on from the actual diagnosis:

*I've been very adept at putting my head in the sand and I just did that for so long and when I eventually pulled it out I didn't like what I saw and I just fell apart so, but by that stage the complications had gone on for at least 2-3 years by then. So yes, you either don't acknowledge it, often you just don't put the 2 and 2 together to start with. It's not really... I suppose it's different if you've had diabetes itself for a few years and you've thought well why should I all of a sudden be affected by it now, why should it be an issue now? Maggie, 33.*



In some cases women talked about the need for specific counselling often a year on from diagnosis when the reality of being diabetic actually sank in:

*Last week I went to register with the GP up the street and we were sorting out my prescriptions and he asked me do you feel angry at all that you've got diabetes? And I said no-one's ever asked me that before and that was interesting. I think it's something they don't deal with the psychological effects of being diagnosed and the fact that it might not hit you straight away. Catherine, 22.*

### **3.22 Medical support at diagnosis**

As noted above, medical professionals were not deemed as a main source of emotional support at diagnosis. How certain professionals acted, however, did impact on some women's ability to come to terms with their diagnosis. The majority of the sample had been diagnosed by the GP. A small but notable proportion, however, were diagnosed in hospital often as a result of a misdiagnosis or a failure to diagnose by their GP. Some noted how their GP had thought that they or their parent/s (if a child at the point of diagnosis) were hypochondriacs and had been sent away, only to be diagnosed later at crisis-point:

*I got very sick and the doctor thought being a student nurse that I was a hypochondriac... I'd gone to the GP and he'd told me to come back in two weeks if I wasn't feeling any better, and in those two weeks I was blacking out I was in DKA I was vomiting, I had all the classic symptoms of DKA, so the two girls that I lived with called the doctor out to do a house call because I was really unwell and they were very concerned about me... I was really sick and he wouldn't come out and then my flat mates at the time insisted and eventually he did a house call and I was rushed straight to hospital and I ended up in a coma. Alice, 35.*

In total, a third of the women described their experience at diagnosis, in terms of how their GP (or hospital doctor) broke the news to them, as a negative one. A further third were too young to remember how the news of the diagnosis was broken to them, leaving only one third stating that this experience had been a positive one.

### 3.23 Information sources at diagnosis

The women were asked about the information sources that they sought out at the point of diagnosis or when they were old enough to search for information themselves, and also about the types of information sources they would recommend to women with new diagnoses of diabetes. The most used and recommend sources were the Diabetes Clinic staff (especially the diabetic specialist nurse), leaflets, Diabetes UK and family.

## 3.3 Sources of Poor Control

### 3.31 Conflict over diagnosis

Whilst a large proportion of the interviewees felt that in general they coped well on a daily basis with managing their routine and control, a fifth of the sample described their routine as either ill managed or very poor, self-describing as *bad diabetics*. Most of these women had never come to terms with their diagnosis:

*I'm not good at taking my insulin, diabetes is like my enemy, it's the worst thing and I fight it constantly and I'd love to come to terms with it and be at peace with it one day but I don't, so I can go up to 4-5 days without taking any sort of insulin at all. Maureen, 27.*

Other women talked openly about the distress that the diagnosis had caused them resulting in self-destructive behaviour. One woman in particular noted that it was only the threat of becoming blind that made the reality of her behaviour sink in and resulted in her seeking out professional help. She noted, however, that had this help been available at the time of diagnosis, it may have prevented her from going down the destructive route that she had in terms of her own diabetic care:

*I went to see someone about having a better mental attitude and she gave me some exercises to do and it's completely changed the way I thought about it. Because before I was completely down in the dumps, so, the way I thought then was I was just going to die, and then after I saw the psychotherapist, the way I think now is totally different and my eyes got better... But I think it took my eyes for this to be effective. Maybe if I'd had that [psychotherapist] when I was younger, maybes I would have thought different when I was older, so the doctors need to be aware that this might help people if they are going off the rails. But I just really*

*really think that having a positive mental attitude is key to how you feel, how you think determines how you feel. Sarah 22.*

### **3.32 Difficulties in daily management**

#### *3.321 Food*

For many people one of the most common difficulties faced on a daily basis that impacted on their control was problems with food. Women talked about the difficulties of carbohydrate counting and resulting insulin intake; having to eat 'the right things'; having to eat so much; and *the love of chocolate*. The carbohydrate counting appeared to be a more common problem, the longer someone had been diabetic. This may be as a result of the longer standing diabetics having been educated one way about food and then having to re-learn daily food management as a result of the new long and short acting injection system, where-as most new diabetics went straight on to the dual system and carbohydrate counting from the start.

#### *3.322 Crisis points*

For some women a poor routine and resulting poor control had arisen through a crisis in their personal life. This was often a temporary period of poor management and control, but often took months to overcome, as one woman noted:

*It was January when I split up with Dave and that was like his choice like and that was when I sort of fell off me pedestal I suppose and stopped eating. I was very very low after that for a while, 3 months, still. I didn't eat for 3 months, all I had for 3 months was lucozade and milk, I got low, I got really low. And this year I'm just sort of getting back on track now. Kat, 35.*

#### *3.323 Occupational stress*

*A small proportion of women talked about the difficulties they faced as a result of other peoples' lack of understanding about living with Type 1 diabetes. The example below describes one woman's employer's lack of understanding or empathy with her situation. The impact of this employer's behaviour resulted in increased stress levels and for a period of six months uncharacteristic poor control:*

I should have been at the hospital on Wednesday and I cancelled it... they arranged it for 11.30 in the day and my boss said you're not going... if I've got an early appointment I'm there by 9.15 and my bloods are already being done and I'm out by 9.45 at the latest and back at work by 10. She said if it's 11.30 you'll need time to get there and back and be there and you're not having that much time off... and she's not happy with it. And you just can't explain things like this to them. They just don't understand at all. And if I've been to the hospital, I'm stopped from having my lunch hour, she lets me go [to the clinic] and then she penalises me the rest of the week by having to work my lunch hour. It's against the law, but if I say that to her, it will be me that gets sacked. I know I could do something about it, but I've been there and I've done it and I have been sacked because of it. *Sam, 29.*

### *3.324 Body image*

Just over two thirds of the sample stated that diabetes made them feel in some way differently about themselves and their body. The issue of body weight was a noted concern for half of the participants, one that had been there from the initial diagnosis and introduction of diabetes and its treatment into their lives. It was also the most devastating to the women, because unlike other issues, for example injection scaring, weight could not be hidden. There was clear distress about the weight gain most experienced after beginning their insulin regime and many admitted to deliberately not taking their insulin in order to lose weight:

*That's why I had depression a few years ago. I used to hate myself, I hated being diabetic, I wouldn't follow the regime, I would miss out insulin on purpose. I put on weight and if I didn't take insulin I'd lose it so I used to do it on purpose. From when I was 16 until a couple of years ago I was miserable. Emma, 24.*

One participant who had a history of eating disorders argued that the experiences around her diagnosis had been detrimental to her mental-well

being. She also felt strongly that the impact of that diagnosis was the main reason she would never come to terms with being diabetic:

*I've always suffered from eating disorders and I thought well now I've got something where I have got to concentrate on what I eat and it kind of made it worse to be honest, so it was pretty devastating... I got a shock cause short term I put on about 4 stone in 6 months, I went from an 8 to an 18 which was really hard and they didn't really explain that to me and that was the most devastating part of becoming a diabetic, because it happened so quickly in months I was so stretched it was awful. I hate my body with diabetes, because I used to be very thin and I had come down to a size 14, but sometimes to do it I had to stop taking my insulin to bring my weight down. It's a constant battle, so diabetes makes me hate my body. And I think in modern society when there's so much emphasis on how you look it's devastating to you and I think when you're not told about it and it's just part and parcel of being on your insulin, it's not good enough, you need more help with that. Maureen, 27.*

The interviews with women highlighted various ways in which the information and support provided around diagnosis did not prepare them for what lay ahead, and that subsequently the difficulties of mentally dealing with and managing having diabetes were heightened. For example, a number of women said they had never been warned about the various effects diabetes could have on their body, in particular that they would be likely to suffer from recurrent thrush (these comments are not just attributable to women who had been diagnosed either at an early age or many years before).

Therefore, for this group of women, having diabetes in many cases changed the relationship they had with their own bodies in ways which could be a trigger point to different levels of mental health problem and subsequent issues of daily management; problems that the discussions they had with medical professionals around the diagnosis of their condition did not prepare them for.

### *3.325 Depression*

When directly questioned about suffering from depression as a result of their diabetes just over 40 percent of the participants stated that they periodically or continually suffered from depression. Due to the feelings of social stigma still associated with mental health problems and depression, people are not always

comfortable either admitting such problems, or seeking advice and a definitive diagnosis. Therefore, over and above the respondents who acknowledged a formal diagnosis of depression, other respondents talked about eating disorders, anxiety attacks, stress and self-destructive behaviour, without framing them as an issue linked to depression or having a mental health problem. For many how they felt about themselves and their body was a key explanatory factor, especially in relation to eating disorders and depression.

An individual's mental well-being particularly when living with a chronic illness should be at the forefront of discussion for every review or follow-up. How someone feels in themselves will often have an impact on how much they control their diabetes, or how much they feel their behaviour can impact on their condition. The majority of participants valued the care that they received. However, they also felt that amongst the different providers they came in contact with there was rarely time to explore the mental health issues they experienced and they were unable to build up (in most cases) relationships with care professionals that allowed them to open up and discuss how they felt beyond their physical health. Without any instigation from the medical professionals to open that discussion, most participants did not feel that they could or had the right to do so:

*The difficult things have been coping with what has happened to me as a result of the diabetes and the symptoms can be a bit unpredictable. And that affects the depression where I feel like I'm sinking into a black hole and I don't know if that triggers the symptoms or the other way round, I'm not sure if the depression follows the diabetes going to pot or the diabetes going to pot causes the depression. But whatever happens when I'm in the black hole, I don't look after myself properly and that is responsible to some extent for the problems... I don't mean that they are scared to ask me how I'm coping or feeling but, I think they have to think crumbs have I got time to open that can of worms, especially when they maybe feel that they're not able to help. And a lot of people say it's quite useful to talk, but it still makes you kind of think oh crumbs I've vocalised all that and I still feel that the balls almost in my court to do something about it. Maggie, 33.*

Although in recent years diabetes professionals have acknowledged the potential importance of supporting the mental well-being of their patients, the

findings of this research show that at present, the mental health support needs of this sample of patients were not being met.

### **3.33 Failure to conceive**

Women who are diabetic have an extra layer of planning to consider pre-pregnancy and they have to have optimal glycaemic control, ideally for a couple of months prior to conception. Therefore, if actual conception takes more than a few months this can put additional pressure on a woman who may have to have optimal glycaemic control for a lot longer than 2 months prior to pregnancy and the 9 months of pregnancy, if after all this effort the pregnancy does not occur, this acts as another trigger point to extreme anxiety and distress, with knock on implications for diabetes management. A small number of participants spoke of how failed attempts at pregnancy were another reason for deterioration in management and control. For some the stress of not being able to conceive and perform what they saw as the role of a 'normal' woman, made daily management difficult:

*We're still trying but still no success yet... it's just that all me friends have children and I always used to say that I wanted loads of children but now I'd be happy if I just had one, just so I could prove that I could have one.*  
Susie, 33.

### **3.34 Failed pregnancy**

The failure of a pregnancy was another matter that raised the issue of mental well-being and a source of poor control. A number of the participants including mothers, currently pregnant women and women who were not mothers, had experienced the failure of a pregnancy. Two women had also terminated an accidental pregnancy, one because of the information they had received post-conception about the impact their poor control could have had on their baby. A further woman had also made the decision to terminate for these reasons but then miscarried before the abortion was set to take place. Had they known this information before, they both felt that they would have made more of an effort to make sure their contraception was more effective.

Although some had been offered generic counselling after the loss of a pregnancy, most said it was offered but not really encouraged and none had been offered specialised counselling. This lack of post-loss support had a marked impact on some of the participants:

*I would have done [liked counselling] after the 2<sup>nd</sup> miscarriage, not the first necessarily, the first was maybe just one of those things and I could accept that, but the 2<sup>nd</sup> I struggled because, and professor [X] was quite good I spoke to him quite a lot, but nobody offered me anything then when I really could have done with it. Because by then I was really struggling to think you know is there something the matter, is there a problem and we're not going to be able to carry a baby, you know, or is there something wrong with these foetuses is that why it keeps happening. So I did struggle after the second one and it would have been useful but nobody offered me anything. Alice, 35.*

### **3.35 Post-birth**

For some women, pregnancy acted as a catalyst for improved daily management and glycaemic control with an expressed a desire to maintain that good control post-birth. For others, however, who had said they felt the same during pregnancy then lapsed back to previous behaviour after birth:

*Everything was perfectly controlled until I had her. Basically you don't have the incentive now do you? She's not inside you. It was never that well controlled before I decided to get pregnant and I was never that bothered about it, but when I decided to have her it was about 8 and good through the pregnancy and now it's not so good. Claire, 26.*

All of those who felt the most difficult thing for them was when their routine got disrupted were mothers, who had had a fairly settled routine pre-pregnancy. The impact of caring for someone else did mean that they couldn't always follow their routine, which occasionally led to problems:

*And after the pregnancy both times actually, your diabetes just has to go out the window for a little while. These two (twins) are 3 and a half months now and I'm only now starting to feel like I can take charge of it again. But for the first 3 months, you've got no chance because they're up and down during the night and so you are and your diabetes is completely different if you are up through the night, and you just can't test cause you don't physically have the energy, you haven't got the time especially with two of them, it's a nightmare. So it's just I'll do the best I can and test when I can but it's definitely taken a back seat for a while*



*until I get a bit of respite and get back into the routine of testing 5-6 times day like I used to. Alice, 35.*

### **3.4 Sources of good control**

#### **3.41 Positive mental attitude**

The single biggest influence on the sample's ability to maintain a good control over their blood sugar was their attitude to being diabetic. Many had rationalised their condition by comparing it with things that affect other people such as cancer and had concluded that there could be worse things than having diabetes. For these women the acceptance of their condition had been the main hurdle and once accepted, they generally controlled their condition. In total just over 40 per cent of those interviewed stated that they felt very little restriction in their current life and that most had made a conscious effort that they controlled their diabetes not the other way around:

*I don't think of it that way, it's just part of my life, it's just something I do, that's it. Janette, 31.*

#### **3.42 Bolus/Basal Medication Regime**

By far the majority of interviewees were on a bolus/basal system of insulin, most commonly injecting 3+1 times per day. Only five interviewees remained on a twice a day, morning and night insulin regime. Although a small number of women didn't notice any difference when they moved from a two a day to the bolus/basal system, the majority did state that it was a revelation in diabetes care and self-management. As the quotes below reveal, *freedom* and *flexibility* were seen as the main benefits of this regime:

*And oh god, what a huge difference moving from that. Much better, much more flexible... It's totally, totally different, I mean for years and years even until a couple of years ago I was stuck in the mental rut that I had to eat every 2 hours and I had to have snacks and I hated having snacks and when you're trying to lose weight it doesn't help when you have to eat all the time... There's so much more flexibility, it's brilliant. And it's like not really having diabetes except for the injections and blood testing. Julie, 30.*

*It just gives you that much more independence if you're thinking of having a late dinner or whatever it's easier more freedom. Chloe, 20.*

### 3.42 Dieticians

Dieticians appeared, to varying degrees of success, to play a key role in promoting good control amongst women who were newly diagnosed or who were in the process of changing their regime:

*The dietician was very good, very helpful, because at the start I wasn't very good at the counting carbs. Catherine, 22.*

However, the extent to which the women valued the dieticians was directly related to the degree to which the women felt that these individuals lived in the real world when it came to their nutritional advice:

*And the dieticians are better [at Newcastle Diabetes Centre], more useful than any I had at [other clinic in North East England] they just made you write everything you ate and they would just sit there and say, ooh you shouldn't have that and you shouldn't have that, now go away. And they couldn't never understand when you said you didn't eat the same thing or at the same time every day. And you would end up lying and saying yes I had brown rice and I had... you know there was no point to it. Ruby, 28.*

### 3.43 Pregnancy as a trigger

For a number of our interviewees pregnancy was the trigger for improved levels of blood testing and control. This change was three-fold; for most of those who diabetically planned their pregnancy, optimal glycaemic control was achieved prior to pregnancy. Unfortunately for a small number of pregnancies, although they had set out to diabetically plan their pregnancy, they had underestimated the length of time it would take to become pregnant and had stopped taking precautions before reaching optimal glycaemic control before conception. Thirdly, for those pregnancies that had been accidental this change in behaviour did not happen until pregnancy had already occurred. Pregnancy seemed to act as a trigger for improvement in all areas of diabetic self-management:

*But as soon as I knew that I was pregnant that's when I really knuckled down and said right... and check my blood sugars about 20 times a day and whatever. Lucy, 28.*

### 3.5 Key Issues relating to management/control

- Poor glycaemic control appeared to be most influenced by: conflict over diagnosis; difficulties in daily management including food, occupational stress, body image and depression; failure of pregnancy; failure of conception and coping post-birth.
- Good glycaemic control appeared to be most influenced by: positive mental well-being; Bolus/basal injection system; dietary support; knowing your body; taking responsibility for health and pregnancy as a trigger for improved control.

## 4. Health care support

Since diagnosis the majority of women have attended the Diabetes Centre in Newcastle (or another clinic prior to the Newcastle Diabetes Centre's existence) on an annual basis. The majority of women have at least one follow-up appointment (30/32) each year, with 18 having 2-3 appointments in addition to their annual. A number of challenging issues were raised in relation to how the annual clinic and follow-ups ran, however, before discussing these points it is important to highlight that despite these issues the majority of interviewees appreciated the overall system of annual reviewing at the Newcastle Diabetes Centre:

*I mean they are very nice people and they sound like they're about to come in for a lot of criticism but I guess we're trying to provide constructive advice, it sounds awful that we're complaining but we're not really because we do appreciate it. Rachel, 35.*

The fact that all services were in one place and that blood work results could be given on the same day were highly valued aspects of the service. Eleven of the interviewees had experienced care for their diabetes somewhere other than Newcastle and were therefore able to compare their different experiences. All talked favourably about Newcastle and quotes like the one below were common descriptions of how Newcastle compared to other centres:

*I moved to the general this year after I started at my new doctors here, they sent me to the general clinic... When I went there the person checked your eyes, I spoke to 2 dieticians, I spoke to one proper doctor, diabetic specialist nurse, the feet person, just loads of people, there's that many I've forgotten. It's a hell of a lot better cause I felt like it was a specialised place, I mean I know the people in [area X] do, do diabetes but here you get everything done at once, eyes, feet, chats, doctors, nurses everything and it's much better. In [area X] I went to the optician for my eyes and for my feet I went to the doctors so it's better here cause it's all done at once. And it's good because if there was something wrong then they're the best people to be with you know? And to tell you about it. Christine, 23.*

## 4.1 Continuity of care

By far the greatest level of dissatisfaction expressed by the women about the service they received at the Newcastle Diabetes Centre was in relation to the lack of continuity of care. Whilst most talked positively about the centre as a whole, there was a common dislike of the fact that they would rarely see the same consultant or doctor twice. Most of the professors were held in high regard but the majority of women stated that they rarely saw them and that it was potluck who they saw on the day of their annual review. In total more than half the sample had negative views about the doctors that they saw at the clinic and only 19 per cent stated that they saw the same consultant or doctor most of the time:

*You very rarely see the same people mind, and it's quite annoying cause you rarely see the same doctors twice... you see different doctors all the time and half the time you just want to get out of there. Emma, 24.*

The key reasons for complaints of this nature were: the lack of any on-going relationship; the fact that each time a woman went for an appointment she had to explain her entire history to someone new; many felt like a number and not a person; many felt that they were given confusing or conflicting advice from one appointment to the next and therefore often felt less inclined to trust what their doctor was telling them:

*The doctors don't know you from Adam and they don't remember what they said to you last time if you see the same one, which is fine, it's their job but you do feel like you're in a big machine and they're just pumping out the sausages and they get through you as quickly as possible and whether they actually offer any useful advise to anybody I don't know. Rachel, 35.*

A further complaint in relation to consultants was the level of incomprehensibility of some doctors whose first language was not English. This was problematic for one quarter of the sample:

*The doctor I saw today, I don't know how to say this, I couldn't understand him and he couldn't understand me, there was a language barrier, do you know what I am talking about? Kat, 35.*

Other women noted that whilst they appreciated all doctors had to train somewhere; they felt that overseas doctors were using them for their education and were not actually interested in them as patients:

*Doctor wise I didn't have a very nice experience with one doctor, to be one doctor to be truthful I don't like the fact that there's so many foreign doctors because not because they're foreign from here that's fine like I'm foreign from here you'd say that's fine it's just they come from abroad and they're only here for like six months or a year and they don't really I feel that they don't really care. You know they're just here to do their one year then they're gonna go back and at the same time you have your six months and doctors here, they're just here for six months but at the same time they're learning and then they're gonna move to another hospital here they're not gonna go back abroad elsewhere and I don't like that and also I've had a couple of narky experiences with doctors from abroad so and I just think it's like you know they think that you're the patient and you don't count and you're just here for my education... Aaliya 31 (Focus Group).*

Six women stated that they did get to see the same consultant most of the time. Two believed that they got to see the same person because of their insistence and being willing to wait hours in order to see the same consultant:

*I do ask if I can see her and usually they say that's fine as long as I'm able to wait. And I would rather wait and see the same person, and that sounds really snotty and it's not that I have a problem with other doctors I think it's just nice to have one doctor who knows you and what's going on. And I know she's got loads and loads of people to see, but you feel like she remembers you. I feel I've got a decent level of rapport and conversation with her and she doesn't give me orders, I've never felt that orders have been given other than in a couple of specific circumstances, it's more perhaps we should try this or that rather than you must ...I respond better to that. Maggie, 33.*

In contrast to how the women viewed their consultants, only four women held negative views about the dieticians they saw and none of the sample held any negative views about the diabetic specialist nurses. The diabetic nurses were viewed as a constant source of support and their expertise and 'down-to-earth'

approach were highly valued by the women and it was felt by most that the nurses understood a bit more about the reality of living with diabetes:

*I think where I've had good advice, that hasn't come from the doctors, it's come from the diabetic specialist nurse or the dietician. I find that they are more clued up about the reality of living with it, I think it works in the order that the doctors are the least clued up about the reality of living with diabetes, then there's the diabetic specialist nurses who are very clued up but are quite uncompromising they still maintain the line of this is what we want you to do. But I think as the years go on they are becoming less regimented and they realise that it's not practical you can't be weighing your cereal every morning and that you can't weigh your slice of bread to see if it's the same as it says on the packet. Especially eating out, that's not practical. So the nurses they are clued up they are more practically aware but they still toe the party line in terms of what they expect you to do. And if you go outside of that it's your own responsibility. Louise, 24.*

#### **4.2 Key issues relating to health care support**

- Overall there was a general consensus that the one-stop-shop provision of diabetic care at the Newcastle Diabetes Centre was highly rated.
- The greatest level of dissatisfaction about the service was in relation to the lack of continuity of care. Many disliked the fact that they would rarely see the same consultant twice resulting in a lack of any on-going relationship and repetition at each visit.
- Some women had problems understanding doctors whose first language was not English and many felt like test subjects for training doctors rather than patients.
- The diabetic specialist nurses were viewed as a constant source of support and it was felt that the nurses understood a bit more about the reality of living with diabetes.

## 5. Pregnancy and risk

### 5.1 Sexual activity and diabetes

All women were asked about their knowledge of the impact that sexual activity could have on their diabetes and all but two women were aware that because sexual activity was a physical activity, it could cause hypoglycaemia. For the majority (78%), however, this knowledge had been gained from personal experience rather than from a medical professional (13%) or literature (9%). Although classed as common sense information, the majority stated that it would have been useful information for them to have, especially as a teenager and if old enough, at first diagnosis:

*No-one ever spoke to me about it but, well I think it's an important thing to cover cause I mean I credit myself with having you know a reasonably good level of intelligence and I was able to make the connection between sport and sex, but perhaps there are people who don't understand the condition in the same way and need it explained. And I think it would take an awful lot of confidence to come out and ask and I doubt many women would. Roxanne, 25.*

In addition other issues not discussed that were felt to be important were in relation to alcohol intake, sexual health problems such as recurring thrush and handling a hypo if drinking or clubbing.

When asked about how that kind of information should be imparted views were mixed. Just under a third thought a leaflet would be the answer, whilst others said they would not read leaflets. Just over a third stated that a sensitive one-2-one with a diabetic specialist nurse would be their preference, whereas others stated that people might find that too embarrassing. Finally the remaining third thought that talking through a leaflet during a one-2-one with someone was the best idea. Discussion from the focus group also highlighted a lack of consensus over which method was best. What these opinions highlighted was that no one method would capture all audiences. Different people react to different styles of information presentation and therefore if messages about sex and pregnancy are to reach all women with diabetes, then a number of methods should be employed:



*Different people are different, some people read, some don't. I feel better when I'm told something, I do read magazines but usually I only read the headlines. So I suppose they just need to say it, tell people or have written stuff as well. Just be explicit in the same way you say condoms protect against STDs. You should have glucose tablets by your bed you know. But I guess it might be difficult to talk about, if they ask if your in a relationship and then decide to tell you, that's no good because not all people have steady relationships, just because you're diabetic doesn't stop you having one-night-stands you know everyone's different in how they view sex. But it needs to be brought up. Kate, 31.*

There was also recognition that this type of information needs to be repeated at various stages, as people who do not yet need that information do not tend to internalise the messages to the same degree as those who do need it. Also at first diagnosis if women are of an age where they may be sexually active it is crucial to impart this knowledge at an appropriate time. At the point of diagnosis each individual has to adjust to the fact that they are diabetic, life may be more hectic than normal and it is likely that glycaemic control will not be at an ideal point for pregnancy and therefore it is important that every woman with diabetes is aware that an untimely pregnancy is not a good idea. However, at the point of diagnosis, a lot of information is imparted and it will be crucial for medical professionals to make sure that they are not giving too much information that the woman is likely to switch off:

*That's a difficult one isn't it, because you don't want to throw too much information to people all at once, you know how do you impart that information and when's the best time because it's different for every individual.... But I don't know when is the best time, cause it's like a lot of information for people who are newly diagnosed with Type 1 diabetes. And I don't think it's necessarily something that needs to be covered in the first week or even the first month of diagnosis but it needs mentioned within the first few months... You want to be able to leave people a month or so just to get their head round the fact that they have diabetes... but on the other hand you want to get across to women that it is not advisable for them to get pregnant within the first few months of diagnosis as well. Alice, 35.*

## 5.2 Knowledge of risk and how to manage risk

All women were asked to discuss a range of topics about: their knowledge of how and why women with diabetes should plan their pregnancies, their awareness of pregnancy or pre-conception services for women with diabetes, as well as any experience they may have had of a planned or unplanned pregnancy.

In this context it is important to be explicit about the terminology of 'planning'. Where women had sought advice pre-pregnancy and controlled their blood sugars pre-pregnancy this was classed as a diabetically planned pregnancy. Where the pregnancy was planned only so far as an active decision was made to become pregnant with no other diabetic planning, this will be referred to as a planned (not diabetically) pregnancy. Finally where an accident (failed contraception or failed use of contraception) had occurred, and the pregnancy was not planned in any way, this will be referred to as an unplanned or accidental pregnancy.

### 5.21 How and why to plan a diabetic pregnancy

Overall there was a relatively high level of knowledge amongst the sample with regards to the diabetic planning of a pregnancy, although more understood how you plan rather than why you need to plan.

Statistical tests highlighted some significant relationships in relation to pregnancy planning as described below. Women were more likely to have a good-excellent knowledge of 'how' and 'why' to plan a diabetic pregnancy:

#### The older their current age

How - ( $p$  is less or equal to 0.05) Why - ( $p$  is less or equal to 0.025)

#### The higher the level of employment status

How - ( $p$  is less or equal to 0.05) Why - ( $p$  is less or equal to 0.05)

#### The longer an interviewee had been diagnosed diabetic

How - ( $p$  is less or equal to 0.05) Why - ( $p$  is less or equal to 0.025)

For the most part, the women knew that they had to plan, they were aware that that involved telling the nurse or doctor that they want to start trying, that they would have to have optimal glycaemic control during pregnancy (less aware

pre-pregnancy) and that they would have to be tightly monitored during their pregnancy.

In relation to why they should plan and their awareness of potential complications, the most common response was that they might have 'bigger babies'.

*They told us about the size of the baby an' all that, but it didn't really matter in the end cause he was 10lbs anyway! Helen, 30.*

*All I remember them saying was that diabetics could have bigger babies, that's all they really said. Gemma, 24.*

A few women were aware of the increased risks of miscarriage, congenital malformations and the potential that their child (especially if father is diabetic) could be diabetic. However, overall there was little comprehension of what could go wrong or how optimal glycaemic control could possibly prevent negative outcomes.

Unfortunately the sample size of those who had experienced pregnancy (diabetically planned or not) was too small to draw any firm statistical conclusions in relation knowledge of planning. However, it is worth noting some of the relationships, which indicated that with a larger sample size may be worth further consideration and exploration.

All women who had diabetically planned their pregnancy were aware of how to plan in comparison to less than half of those who had a pregnancy that was not diabetically planned or was an accident. In relation to why women with diabetes needed to plan their pregnancy, half of those who had diabetically planned their own pregnancy had a good understanding in comparison to a third of those who had not planned or who had had an accidental pregnancy. All women who had planned their pregnancy were aware of the pregnancy specific service in Newcastle, less than half of those who did not plan knew of this service.

The data also seemed to suggest that with a larger sample there may well be an association between higher levels of education and greater knowledge of how and why to plan as has been noted in other research (Holding *et. al.* 1998).

### 5.3 Reality of pregnancy planning activity

The two tables below show the planning nature of the pregnancies within this sample as well as some background information and knowledge levels of how and why to plan a diabetic pregnancy.

To summarise in total there were 24 pregnancies experienced between 14 women in this sample. Ten out of the twenty pregnancies were diabetically planned, the outcomes of which were:

- 2 = still pregnant (2 x good control pre pregnancy)
- 7 = healthy outcomes (incl. 1 set of twins) (5 x good control pre-pregnancy; 1 x average)
- 2 = miscarriages (2 x good control pre pregnancy)

Of the 13 unplanned pregnancies, two were not accidents and hence planned but not in a diabetic sense. The other eleven pregnancies were not planned in any way and all occurred due to mis-use or failure of contraception. Of these pregnancies the outcomes were:

- 1 = terminated due to diabetic concerns (1 x poor control pre-pregnancy);
- 1 = terminated due to non-diabetic concerns (1 x poor control pre-pregnancy);
- 4 = miscarriages (4 x poor control pre-pregnancy);
- 5 = healthy babies- (3 x good control pre-pregnancy; 1 x average control; 1 x poor control pre-pregnancy);
- 1 = healthy baby who now has incontinence problems due to possible mild spina bifida (1 x good control pre-pregnancy)
- 1 still pregnant = (1 x average control pre pregnancy);

The planning nature of 1 of the pregnancies is unknown, as the other 3 pregnancies to this woman were not diabetically planned, it may be assumed that this one was also not diabetic planned. The outcome was:

- 1 = ectopic pregnancy (control level unknown)

**Table 2a: The Planning Nature of the Sample's Pregnancies**

Pseudonym	Val	Kathryn	Emma	Helen	Gemma	Sarah	Maureen	Catherine
Age	32	29	24	30	24	22	27	22
Marital status	Married	Married	Married	Married	Married	Boyfriend	Live-in partner	Single
Knowledge - why to plan	Good	Limited	Limited	Limited	Limited	Limited	Good	Limited
Knowledge - how to plan	Good	Limited	Good	Good	Limited	Limited	Good	Limited
Issue raised by clinic	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No
1 <sup>st</sup> pregnancy (control level pre-preg*)	Diabetic Planned (GC)	Planned (not diabetically) (GC)	Diabetic Planned (GC)	Diabetic Planned (GC)	Unplanned accident (PC)	Unplanned accident (PC)	Unplanned accident (PC)	Unplanned accident (PC)
Contraceptive use during accidents	----	Lax use of combined pill	----	----	On combined pill	On combined pill	On mini pill	On combined pill (dianette)
Outcome	On-going	Healthy baby	Healthy baby	Healthy baby	Healthy baby	Miscarried	Miscarried	Terminated

\* Control level pre pregnancy GC = good control; AC = average control; PC = poor control

**Table 2b: The Planning Nature of the Sample's Pregnancies continued...**

Pseudonym	Claire	Lucy	Madeline	Kate	Alice	Jules
Age	26	28	31	31	35	24
Marital status	Separated	Separated	Married	Married	Married	Live-in partner
Knowledge - why to plan	Limited	Limited	Good	Good	Good	Limited
Knowledge - how to plan	Limited	Limited	Good	Good	Good	Limited
Issue raised by clinic	Yes	Yes	Yes	Yes	Yes	No
1 <sup>st</sup> pregnancy (control level pre-pregnancy *)	Unplanned accident (GC)	Diabetic Planned (GC)	Unplanned accident (PC)	Unplanned accident (GC)	Unplanned accident (PC)	Unplanned accident (PC)
Contraceptive use during accidents	On Combined pill	----	On combined pill	Forgot to take combined pill	On combined pill	On mini pill
Outcome	Healthy baby	Healthy baby	Terminated	Healthy baby (possible prob as 2yr old)	Miscarried	Miscarried
2 <sup>nd</sup> pregnancy (control level pre-pregnancy *)		Unplanned accident (GC)	Diabetic Planned (AC)	Diabetic Planned (GC)	Diabetic Planned (GC)	Unknown
Outcome		Healthy baby	On-going	Miscarried	Miscarried	Ectopic
3 <sup>rd</sup> pregnancy (control level pre-pregnancy *)		On Combined pill	-----	Diabetic Planned (GC)	Diabetic Planned (GC)	Planned (not diabetically) (AC)
Outcome				Healthy baby	Healthy baby	Healthy baby
4 <sup>th</sup> pregnancy (control level pre-pregnancy *)					Diabetic Planned (GC)	Unplanned accident (AC)
Contraceptive use during accidents					-----	Coitus interruptus
Outcome					Healthy twins	Pregnant

\* Control level pre pregnancy GC = good control; AC = average control; PC = poor control

Holding *et. al.* noted that 'poor pregnancy planning was related to poverty, poor education, unresolved desires to become pregnant, lack of marital support, poor relationships with health care providers and a perception of discouraging advice from health care professionals' (1998: 893). What this research appears to indicate is that while there may be educational, support, affluence and health care relationship associations between those who know how and why to plan a pregnancy and those who don't, these do not appear to be the factors related to unplanned (accidental) pregnancy for the most part in this particular sample. All women except two who wanted to have a child had diabetically planned their pregnancy. None of the remaining 14 pregnancies were planned. All 14 considered themselves as using contraception (including one using coitus interruptus).

This raises a particularly tricky dilemma: how to educate women about pregnancy who have no interest at that time in becoming pregnant? It was not found to be the case that women were not accessing pre-conception care due to a lack of knowledge or because they thought their consultant would not approve of their decision to become pregnant (although such cases will exist), they simply were not planning to become pregnant.

For some of these women, their knowledge about how and why to plan a pregnancy was very good and so they were good examples of the fact that accidents do happen. It was simply a failure of contraception or contraceptive use coupled often with a hectic point in life that led to these pregnancies. It is worth noting that large life events such as getting married often meant that the last thing on a woman's mind was remembering her contraceptive pill or having the best blood sugar control:

*I suppose I was thinking, how did this happen? I'd taken the pill for years and years and I found out on my honeymoon that I was pregnant and I thought I've avoided it all these years, how did it happen? But I think it was with all that was going on before you get married. And then the second thought I had was oh my god, my diabetes has probably been the worst it's ever been for the last month or so before the wedding and then the last two weeks you know like anyone on holiday when I was on my honeymoon it just went out the window... I know for a fact that they were not good and I just thought, my god, this baby's got no chance. There must be something wrong with it because I've had nightmare control for at*

*least the last month. It's just not the best time to find out that you are pregnant; god knows what will be the matter with it. So it was horrible really thinking oh my god, it couldn't have happened at a worse time. And then of course you panic and when you panic it's harder to get your blood sugars under control... But I just kept thinking this is the worst time, probably the worst time for the development of a baby as well, and I just kept wondering what would be wrong with the baby and things. But then I lost that pregnancy... In fact by the time I found out I think I'd already lost that pregnancy anyway. Alice, 35.*

Just under half of the sample was aware that a pre-conception clinic existed in Newcastle, and as expected, more women who had experienced pregnancy than not were aware of this service. The majority of women (88%) also stated that if they found themselves unexpectedly pregnant, their first thoughts would be about diabetes and that they would need to contact the clinic at the Newcastle Diabetes Centre immediately.

Some although they knew to contact the clinic, said that their initial thoughts would be much more about the fact that they were pregnant before considering how the diabetes may affect these pregnancies. These women were all single and were therefore envisaging the pregnancy occurring in un-known relationships.

*It would all depend on what type of relationship I was in at the time. There would be 2 scenarios really, if I was in a steady relationship and we were talking about having children, and we were actually trying for me to get pregnant, I would obviously have contacted the diabetic place well before we started trying. And if I found myself pregnant in that situation obviously I would contact the hospital. If I found myself pregnant at this time (no steady relationship) I would have major concerns about whether or not to keep it and what to do, I wouldn't know. And that would be nothing to do with the diabetes, it would nothing at all to do with the diabetes, it would be to do with the fact that I don't know if I can cope with a child, you know, can I afford to financially and emotionally support this child? Janette 31.*

*But it also depends on personal circumstances, I mean one morning when I had to take the morning after pill, I was more, you know it didn't even*

*occur to me about being pregnant and diabetes it was 'Am I pregnant? Or am I not?' and then I think it seems to be a decision past that, not a decision before, first you've got to deal with am I pregnant when I didn't plan to get pregnant you know, and I'm not in a relationship or not in a decent relationship anyway, and then once you've got an answer to that you then move on to the other stuff. It wasn't my main priority if you know what I mean when I have been in that situation. Gillian, 32.*

The stories these women have to tell are very important in understanding the nature of the unplanned pregnancies in this sample. Janette shows that she is aware of what to do if she wanted to plan a pregnancy, but she was also aware that unplanned pregnancies can happen and this was common in the overall sample.

### **5.31 Are you planning a pregnancy?**

Almost all women had been asked at their last annual review or follow-up about whether or not they were planning a pregnancy or not. However, most felt that this question was a 'closed' question and did not offer sufficient impetus to start a discussion about pregnancy.

*I mean I remember a couple of years ago at the annual review, I was asked the closed box question are you thinking of getting pregnant and I just said, no but I'm not un-planning one either but that's because of my single situation, and I know I'm not knocking that question, but it doesn't necessarily mean anything – are you planning a pregnancy? You know I could say anything to that and that was right we'll tick that box and then we'll move on. Maggie, 33.*

*Well at the review it's a closed ended question, are you thinking about pregnancy? No. Move on. It doesn't give you a door to open to just start planting the seed, excuse the pun it wasn't meant that way! But you know what I mean? If it is a close-ended question it stops you dead. It could have given the doctor the opportunity to start to chat about it, whether they were interested or not. Sam, 29.*

For some of those who were asked that question and had been planning and gave a positive response to the question, the reply was no more satisfactory than for those above who had not been planning:



*At the annual review, they have a single A4 sheet of paper double sided and it says something like, do you smoke?, do you drink?, how much do you drink?, pregnancy advice and it would be along the lines of are you planning to have a baby, well then get your control levels right, full stop, let's move on to something else. And that was their advice for the whole year so, I would say that that wasn't particularly useful, at all, really. Rachel, 35.*

Further to that, when one interviewee showed interest in knowing more now, despite the fact that she was not actively planning a pregnancy, she was told not to bother herself with those types of questions until she was planning:

*...because the doctors say, you've no need to know at this stage, mmm because I have had that comment passed, I've asked a question and they've skimmed the surface but because I'm not even thinking about getting pregnant why bother to worry yourself about it now. My argument would be well would it not be better for me to know now before I need to worry about it? Do you know what I mean? Sam, 29.*

Despite these criticisms, the majority of women did feel that the annual review was a good time to start a conversation about these issues. However, who should provide this information; where to provide it; its timing; and the manner of the question and information provided were seen to be key to the successful transference of knowledge.

#### *5.311 Who should provide the information?*

Opinions on who should provide this type of information were very mixed. Many women felt that this type of discussion should occur with whichever professional had the better relationship with them, or whoever they felt comfortable talking to:

*I think it depends, if I remember rightly, and again this was due to me asking, the first official questions I asked about pregnancy I think was with the doctor at first and then I'm assuming that that was passed on because the next time I went I had to see the nurse and it was brought up in conversation with the nurse... you can't just say it shouldn't be the doctor who speaks to you about pregnancy it should be the nurse, cause it*

*depends on every individual and if you're an open person like I am you can talk to anybody about absolutely anything. Whereas if you're the type of person who is quite shy and wouldn't mention the word sex to anybody let alone to a male doctor and you're a young female, then do you know what I mean? I think it is purely, on a one to one, the doctor working out for themselves you know what type of person have I got in front of me here, is it better for me to discuss it or is it better for the nurse to discuss it. We can only really talk about the people who are going to be more difficult because as far as I am concerned I'm easy. But it's got to be done sooner rather than later, because I'm lucky it hasn't happened by mistake. Sam, 29.*

Others felt that if it was left up to the discretion of each professional to decide if the individual in front of them would talk to them and that no one person had the designated job of raising this topic, then it may not get raised at all. With that point in mind, many women believed that a diabetes specialist nurse who was family planning trained would be the best individual to approach this subject:

*A diabetes nurse who's a family planning nurse would be useful, that would definitely be useful. And there's always the embarrassment factor as well, talking about these things. So talking to someone who is specifically trained for that would be great. Roxanne, 25.*

#### 5.312 Where should the information be provided?

A number of women also expressed a desire for a contraceptive service within the women's health clinic that they could attend at the Newcastle Diabetes Centre (which could be signposted from the annual review). Most felt that the style of clinic that is currently provided for pre-conception, if available for all women about sexual health issues, may help to impart the knowledge about contraceptive efficacy and the prevention of accidental pregnancies (and the importance of this because of diabetes) much more effectively than would be possible at the average GP clinic:

*If there was a connection between family planning and the diabetic clinic then perhaps it would encourage people to get off their backsides and use it, if it was available. If there was someone, I know it wouldn't make it a one-stop shop, but it would make it, at least you would have a designated*

*person that you know you could discuss this with. I mean you see lots of people when you go but you're not going to mention pregnancy to a podiatrist and when you finally get to see the person you might talk to about this, there's either too many other things to talk about or it's other priorities that come up. But at least if there was a designated service within the clinic, you might not need to go but it would raise awareness. That would be a good idea. Maggie, 33.*

#### *5.313 When should the information be provided?*

The issue of timing to raise this issue was acknowledged by most women to be the most difficult issue to clarify. This was particularly the case when considering women who were not thinking about pregnancy but were sexually active and therefore at risk of pregnancy, as many women could relate to this situation. However, equally there was recognition that having reached their mid-late 20s before receiving this information for the first time, this was too late:

*I mean I'm not saying that within 3 months of being diagnosed you're going to have all the rest thrown at you but I mean I've been diabetic 23 years and only within the last 5 years is when I found out about it. I would say after 23 years of being diabetic it's too late to have left as long as that. Sam, 29.*

The general consensus therefore appeared to be that this information needed to be provided repeatedly, in a number of different ways, including: annual review conversations; leaflets/publications in the waiting area; and most favoured, through a women's health clinic available at the Newcastle Diabetes Centre where women could go for sexual health, contraceptive as well as pregnancy advice.

#### *5.314 How should the information be presented?*

When asked about how much women would want to know however, views were very mixed. Some women were quite happy in their selected ignorance. It was not that they were not aware that there were things to know, but rather they had made the decision not to ask about them, or that they had so much contact with the hospital that they felt if anything was wrong they were in good hands:

*I know about the babies getting really big, complications and that's all I was really told. I think I knew enough because I was at the hospital so much I felt comfortable and I knew things were going all right. Claire, 26.*

*Yeah I probably did, I think if they'd given us too much information I would have been in a state of panic so it was enough. Kathryn, 29.*

Others stated that they thought that the information should be more available so that anyone who was sexually active would be aware of why they needed to be careful with contraceptive use. Some felt that they wanted to know everything in order that they could make an informed decision about whether or not to become pregnant, and on what to do if they did accidentally become pregnant:

*Obviously you can get pregnant by mistake, every option needs to be told and then it's your choice isn't it. I would want as much information as possible whether it is good or bad. Kat, 35*

Of the twenty who were not pregnant or mothers at the time of interview, seven stated that they did not want to have children in the future, all for diabetic reasons. In particular the thought of their child being diabetic or exacerbating their own condition was the deciding factor. For these reasons, some women felt that it was only fair that people were fully aware of the consequences of pregnancy, so that they could make an informed decision as to whether they wished to become pregnant:

*I am aware that what's already gone wrong with me could get possibly get a lot worse by becoming pregnant. You know if you're body's already a bit of a wreck before you get pregnant then what will you be like afterwards? And you've got to think would you be fit to look after that child and that goes part and parcel with things like depression. I've spoken to people with post-natal depression who didn't really feel clued up for a couple of years and that would be another fear for me, I'm not as bad now but I just think that I would be a candidate for post-natal depression. Maggie, 33.*

The most common response however was a need for a balanced presentation of information:

*I think I would like to know the risks I mean I wouldn't want to go into it and not know what the risks are, I mean that would be irresponsible. But at the same time I would want to know what I could do about it, so put it in some kind of proportion as well, I mean how much of a risk is that, you know whether it's statistically or not, you need to know so you realise is this something that is likely to happen to me or my family, or is it something that's a very small risk, I think I'd like to know about it in that way... And I imagine it's going to be very emotional process anyway you know, quite stressful in some ways, and the last thing you'll need is stress. And if it's something you want and it hasn't happened yet, then to find out that if it does happen that there will be terrible consequences, you know I think you need that balance. Roxanne, 25.*

### **5.32 Use of the pre-conception clinic**

As the pre-conception clinic was a relatively new service at the time of interview, very few women had in fact utilised this service for their pregnancy. All of those interviewed, however, considered that this was or would be a useful service for those women with diabetes considering pregnancy. Within the sample three women were at the point of actively planning a pregnancy and two had connected with the pre-conception clinic. These women highlighted the supportive nature of the consultations and the usefulness of the information (including general daily management advice) that they had so far received, often contrasting these experiences with those of their annual reviews and follow-ups:

*It's amazingly different from the other end of the hospital. I've learnt so much about needle lengths, injection sites, blood testing, you know when you were going at the other end of the hospital and you went and your blood glucose level was fine, they couldn't tell you anything useful, it was a different person every time with a different theory. Going to the women's health you get three people interested in you, who've got practical advice, have you thought about doing this... and then you've got the dieticians as well... amazing, amazing difference, so completely positive attitude amongst them. It's much better practical advice, absolutely, 100%... You see the same people. And you can go as often as every fortnight if you want to until you are organised and set up with a good routine, you're getting the readings that you want. They're at the end of the phone line, they ring you at work, just to see how it's all going*

*and if you've got any problems and that sort of thing so it's great! Rachel, 35.*

## **5.4 Pressures and fears associated with pregnancy**

Many women talked about the pressures and fears they associated with pregnancy. As noted in section 3.326, many women found the pressure of having to maintain optimal glycaemic control for extended periods of time whilst trying to conceive hard to cope with. Almost a quarter of the women interviewed stated that they felt one of the biggest restrictions that diabetes placed on their lives was in relation to pregnancy and motherhood. For the majority the key matter was related to spontaneity and planning, in that women with diabetes could not afford to *just get pregnant*:

*A big part of the restriction with me was to do with getting pregnant, because it's not as easy just getting pregnant, you have to think about what the consequences are and how you're going to cope with the diabetes a lot more. Kat, 35.*

For a smaller proportion, the restriction went further than planning. For some it was also about a restriction on enjoying the process of pregnancy, and not feeling able to share things with other people in fear that if things went wrong, the blame would be placed on the fact that they were diabetic:

*Well with this pregnancy knowing things that could impact on this pregnancy that you feel that other people involved don't necessarily know and you don't necessarily want to tell them. It's hard. You know I don't yet know what's going to happen with this pregnancy and I mean, if something went wrong, I don't know if I'd want my husband's family knowing that that could have been down to me really. I would rather they just thought that it was an awful accident, because I would feel responsible and I think that they would feel that I was responsible. Val, 32.*

## 5.5 Key Issues for knowledge about Pregnancy Planning and risks involved

- Few women had ever received information about how sexual activity could impact on diabetes. Most believed this information should be available and repeated regularly in different formats (1-2-1 sessions and leaflets suited to different age groups).
- The majority had been asked if they were planning a pregnancy. Many felt this was a 'closed' question that offered little opportunity to discuss the implications of pregnancy, especially amongst those who were sexually active (often sporadically) but not planning a pregnancy.
- Overall there was a relatively high level of knowledge with regards to how to approach the planning of a diabetic pregnancy. Awareness of potential complications was generally limited to the risk of a 'bigger baby'.
- Only 10 of 24 pregnancies experienced between 14 women in this sample were diabetically planned. Two were planned pregnancies, but not diabetically. The remaining 12 became pregnant accidentally despite contraceptive use.
- For those whose pregnancies were accidental, most had a good knowledge about how and why to plan a pregnancy. They knew what to do but they had not been planning to become pregnant, raising the potential importance that contraceptive advice and education may play in reducing the level of diabetically unplanned pregnancies.

## 5.6 Support through Pregnancy

For those women who had experienced pregnancy, discussion centred on the type of support that they had had or felt they would have liked but were not offered. For the most part these women were overwhelmingly positive about the care that they received within the pre-pregnancy stage and during their pregnancy. The most common response during both stages was of the constant contact particularly with the diabetic specialist nurses:

*They were brilliant during the pregnancy, there was mainly [diabetic specialist nurse] and one called [diabetic specialist nurse] and they would ring us every week between appointments just to see how things were going. I had a lot of contact and it was a bit more friendly because sometimes the doctors can be quite standoffish and so seeing lots of the nurses was good. Emma, 24.*

*Everyone else at the general was fantastic, the nurses told me what I needed to do and really supported me and were really helpful. If I had problems I could call them up. The diabetic nurses they were absolutely brilliant. They were just there is you just needed to talk as well. Gemma, 24.*

The constant support on the phone was one of the most valued services by these women, and for those women who were not pregnant or mothers, when asked what services they thought they would want the most common response was phone access to the diabetic specialist nurses:

*I guess just to have someone available all the time to answer any questions you had like one of the nurses. Catherine, 22.*

Many of the mothers commented on the level of increased care as a positive aspect of their pregnancy. Most did note that it was hard work having to attend the RVI so frequently but there was also a recognition that it was worth it:

*I think it was every month I was at the hospital at the RVI maternity bit and I can't really remember but I think it was every day or so the diabetic specialist nurse would ring to see if things were alright, so that was good. It was a lot but when you're pregnant that's good it's a lot better. Claire, 26.*

Some mothers did find the process however was quite medicalised and wished that more time were spent on them as women becoming mothers, rather than being diabetics who were pregnant:

*Well when I went to the clinic I saw the diabetic nurse there and everything was about him (baby) really and I didn't feel they focused on me as much. I would have preferred just a bit more time spent with me finding out I was ok as well. I mean I had scans, blood tests, urine tests and for me it was just a couple of minutes with the diabetic nurse or the diabetic doctor and as I say it would just have been nice to have 5 more minutes on me. Helen, 30.*



On the other hand, however, a number of women noted that the additional care they received although time consuming was very comforting and was perceived as a positive to be diabetic during pregnancy:

*I mean I suppose the only thing you notice with pregnancy is that you're going much more frequently to the hospital, you do feel as if you spend your life in the RVI but on the positive side you do get a lot more scans and things which in terms of pregnancy I actually think I had an advantage by having diabetes because I had early access to the RVI, early access to scans and lots of thorough scans, because I know someone whose little girl died of a heart defect and they had no idea anything was wrong and I just feel so reassured that we have so many thorough scans so you know you're not hopefully going to have any surprises when the baby is born, if you've made it through the pregnancy then chances are things are going to be ok, that they are normal and healthy... Where general people walk around and think oh I'm pregnant and everything's going to be fine. I mean it must be lovely, I've got friends who get pregnant and then just assume that they're going to have a baby and I could never think like that. I would get pregnant and then hope that I had a baby at the end of it... So actually having diabetes in pregnancy was actually an advantage to a degree. Alice, 35.*

One further interesting point that was noted by a number of mothers was the fact that during pregnancy unlike their usual experience at the Newcastle Diabetes Centre, they got some consistency with their consultant. This was noted as a very positive experience:

*Well I got to see the same doctor more often which was good for being pregnant because I definitely think you need to be able to see the people so you get comfortable asking them questions and things like that. I think it felt a bit more personal. Kathryn, 29.*

The only really negative criticism about the professional care during pregnancy was related to non-diabetic anti-natal services and midwifery support. Some mothers felt that because their anti-natal care was provided by the RVI, they missed out on general midwifery care and signposting to anti-natal activities for all mothers.

*But I felt a bit like I was a diabetic who was pregnant rather than a woman who was pregnant if you know what I mean, medicalised... But eh, well I had a lot of contact I think. There was always somebody I could get hold of at some point, the only thing was, it was just the non-diabetic things... There was [good support] from a diabetes point of view yes, but I felt like I missed out on a lot of things because I saw the doctors all the time... and like other people knew when there were workshops and things like for breastfeeding an' that, you know the classes, breathing classes, and when you go round the hospital and all that sort of thing, and I had to say can I go and see, because they didn't ask me. So I feel I missed out on quite a bit. Kathryn, 29.*

*That's probably one of the things that I would say from the anti-natal at the RVI is a bit lacking. I never really had a great deal of time with the midwife, I never saw the midwife from me own practice like most pregnant women would do without diabetes, you know, all my pregnancy care was at the RVI... It doesn't seem to be part of the system that you spend a lot of time with the midwives... I did miss the midwife, definitely and there was issues like breast-feeding and things that were never discussed. And things like the section might have been discussed in a bit more detail if I'd actually seen a midwife... I think a lot of people assumed that I would see a midwife at the surgery but that was never the case. Alice, 35.*

## **5.7 Support at Birth**

One issue of discontent that was raised by most mothers was the fact that they had been unable to have a natural birth. For the most part the mothers had acknowledged that there was a higher chance for them than a woman without diabetes that they would need to have a C-section, but when it came to the point of birth they felt unprepared and cheated by the experience. The level of dissatisfaction was highest amongst those who did not feel that they had been given enough information about what would happen before they went in to labour and after the operation:

*I would have liked to have had a natural birth and I would like more information on how to maybe make that happen next time. I don't... really really desperately don't want to have another caesarean, it was awful, nobody prepared me for what it would be like afterwards. And they chucked you out far too early, I wasn't ready to go home at all, I was*

*immobile I was in so much pain and me husband works nights and when he wasn't around it was just so hard. It puts you off having another one. I really wanted the whole experience and felt a bit cheated. Helen, 30.*

*6 weeks before my due date and had to go in and have a caesarean, well try... that was the worst thing about it that you couldn't go full term and you had to go in at 38 weeks and my body just was not ready, it didn't want to know, and that's the worst thing. I don't know if it runs in my family but my mum included, were a good two weeks over, before they gave birth. So that was the worst thing, I couldn't do it normally. I had the waters broken and it just wasn't like I planned it you know. Kate, 31.*

It was apparent that most mothers given the chance would have preferred a normal birth and it is important that mothers-to-be are provided with more information about the realities of a caesarean before going into labour.

## **5.8 Breast-feeding**

A final issue of discontent that was raised by most mothers was related to the issue of breast-feeding. Few of the mothers interviewed had been able to breast-feed at all or at least beyond a few weeks and many felt that they had missed out on this important bonding process with their child:

*And I wanted to breast feed but I didn't get to try straight away and then they said it was too late to start because she'd had a drip down her nose they said she would have to have a bottle and I wasn't very happy about that, I wanted to try, but... Gemma, 24.*

One mother felt that there was a lack of knowledge amongst regular midwives as to the needs of the baby with regards to food after birth. That because the mother was diabetic there would be an automatic need to feed the child and not allow time to attempt breastfeeding:

*Oh but the thing that really annoyed me and I don't know if it's to do with diabetes or not but the breastfeeding, I didn't get to do it with either and I really wanted to... I wanted to do it and I kept asking the sisters and I went to the classes and everything like that... With the first one I had no choice they fed him the bottle they thought it was more important to get food into him and I felt like the midwives who were fabulous people, didn't*

*understand enough about the diabetes... Different people do it in different ways but it did feel like everyone had been there and then the baby was born and ... yet although they didn't need special care, because they'd come from me and I was diabetic they were treated differently, even though you'd worked so hard for them to be normal and they'd come out perfectly normally, blood sugar normal, absolutely super, and even though you'd done all that, they were still treated differently and that was annoying. Kate, 31.*

Many also commented that this was not an issue that been raised with them, either in terms of encouragement to breast feed or information about how it may affect their diabetes. This included one mother-to-be who was due days after this interview:

*And I was thinking as well that breast feeding is going to have an impact on my diabetes, I don't know how yet and I don't feel like I've been given any information on that, that could mean that it's just that that isn't necessary yet, but as I say I have a meeting on Thursday and it's on my list of questions to ask. Madeline, 31.*

Most women commentated on the issue of breast-feeding from an emotional and bonding point of view. However, in addition to these factors is that recent clinical research indicates that breast-feeding may lower the chances of passing on diabetes. Babies who were breastfed for at least three months had a lower incidence of Type 1 diabetes and there is evidence to suggest that they are less likely to be obese and at risk of Type 2 in later life (Davis 2001; Kimpimaki *et. al.* 2001; Martorell *et. al.* 2001). Further research has also shown a link between the development of Type 1 diabetes and a child's exposure to cow's milk and cow's milk-based formula (Vaarala *et. al.* 1999; Paronen *et. al.* 2000; Monetini *et. al.* 2001). It is therefore crucial that the issue of breast-feeding is discussed in more detail, much earlier in the pregnancy.

## 5.9 Key Issues on Pregnancy and post-birth support

- Mothers were overwhelmingly positive about the care that they received within the pre-pregnancy stage and during their pregnancy, especially the regular phone contact with diabetic specialist nurses.
- However some mothers felt that because their anti-natal care was provided by the RVI, they missed out on general midwifery care and signposting to anti-natal activities for all mothers.
- Most had acknowledged the higher chance of a C-section, but when it came to the point of birth, they felt unprepared and cheated by the experience.
- Most mothers had been unable to breast-feed and said the issue had not been raised with them, either in terms of encouragement to breast-feed or information about how it may affect their diabetes.

## **6. Policy and provision recommendations**

### **6.1 Provision of information and advice about general sexual health**

The findings of this research show that few women felt that there was enough information available from any source (GP, Annual reviews, literature etc.) about sexual health, (including pregnancy awareness) and diabetes. This was seen to be important particularly for young people and newly-diagnosed individuals. Opinions about how to provide this information were varied and highlighted that no one method would capture all audiences.

Different people react to different styles of information presentation and therefore if messages about sex and pregnancy are to reach all women with diabetes, then a number of methods should be employed. This includes more literature of different styles and with different target audiences; sensitive one-to-one sessions with a diabetes specialist nurse; a combination of the two, where a diabetes specialist nurse could go through literature with an individual rather than providing literature and stating to get back to them with any questions. Many women thought the idea of having a diabetes specialist nurse who had family planning training would be the most useful resource for this information (see section 6.3).

### **6.2 Provision of information and advice about pregnancy**

The findings of this research show that in general the level of knowledge about how to plan a diabetic pregnancy was high, although specific knowledge was less comprehensive as to why extra planning was required. Most women believed that more information should be provided about why to plan a diabetic pregnancy, but that this must be done in a positive fashion and not simply attempt to scare women into compliance, which few believed was an effective methodology in any case.

Most women felt that the annual review question of whether they were planning a pregnancy or not was a 'closed' question and did not offer sufficient impetus to start a discussion about pregnancy. Due to the fact that more than 50 per cent of the pregnancies within this sample of women were completely accidental, the issue of increasing contraceptive awareness and competency must be considered important factors in decreasing the proportion of diabetically

unplanned pregnancies. Whilst most women perceived the annual review as a useful opportunity to signpost women to a specific service on sexual health, as noted above, many women perceived having a specific clinic run by a diabetes specialist nurse who had family planning training would be best placed to provide this information (see section 6.3).

### **6.3 Link to family planning**

Many of the women suggested that a more effective way of getting the pregnancy planning message across, especially to those women who are sexually active but not actually planning a pregnancy, was through a link with family planning to the diabetes centre. One of the most favoured aspects of the Newcastle Diabetes Centre is the one-stop-shop nature of the service. Many therefore felt that if contraceptive advice and sexual health information was also available on-site, this would encourage more women to consider the implications of their sexual and contraceptive behaviour on their diabetes. A diabetic specialist nurse with family planning training was seen as the best person to head such a provision.

### **6.4 Mental health awareness**

The findings of this study have revealed that in addition to those areas already highlighted within current literature, depression, anxiety and eating disorders were also related to: negative body image caused by diabetes; failure to conceive; failure of pregnancy; fear for pregnancy outcome; and also from events such as a breakdown of a relationship, occupational stress or other people's lack of understanding about living with diabetes. Further to this, the inability to cope with a diabetic diagnosis was not confined to young people, but was also common amongst women who were diagnosed later in life (and often had a delayed reaction to the diagnosis).

The aim of all professionals working in the field of diabetes is to promote good self-management and optimal glycaemic control at all times, and particularly for women with Type 1 diabetes at the point of pregnancy planning and conception. It is therefore crucial that all aspects of a women's daily regime are explored including her mental well-being, rather than confining exploration to dietary habits, blood testing and insulin regime. This is especially important when it may be the routine medical and dietary management that becomes stressful, creating problems with mental health.

An individual's mental well-being particularly when living with a chronic illness should be at the forefront of discussion for every review or follow-up. How someone feels in themselves will often have an impact on how well they control their diabetes, or how much they feel their behaviour can impact on their condition. The majority of participants valued the care that they received within the diabetes centre, especially the fact that all aspects of their annual review were dealt with in one place at one time. However, the conveyer belt system and lack of time available per patient did leave many feeling that those providing their care did not have time for them to open up and discuss how they felt beyond their physical health. Without any instigation from the medical professionals to open that discussion, most participants did not feel that they could or had the right to do so.

Of note, however, when women did talk about the kind of help that they would like to deal with mental health issues, they did not want help from consultants or diabetic specialist nurses. There was a call for specific counselling or group self-help with other diabetics, with the Newcastle Diabetes Centre staff acting as a signposting service for these add-on groups.



## 7. Issue for further study

Although in recent years diabetes professionals have acknowledged the potential importance of supporting the mental well-being of their patients (Bradley & Gamsu 1994; Shillitoe 1994; Krans *et al.* 1995; Snoek & Skinner 2002), the findings of this research show that at present, the mental health support needs of this sample of patients were not being met. This research as an exploratory piece has raised awareness on the issue of mental well-being and the lack of available support, as viewed by the participants. However, it is limited by the fact that its original focus was not on how to improve mental health services for these participants and its generalisability is limited by the small numbers of participants involved.

There remains little evidence to support whether psychological interventions have the desired impact on improving clinical outcomes (Snoek & Skinner 2002). Therefore, further research must focus on how best to support the mental well-being of patients with diabetes, especially with issues requiring specialised help, such as coping with a delayed reaction to diagnosis, and issues relating to pregnancy. As such, any research which aims to support women with Type 1 diabetes to be healthy in the holistic sense, must take on board the views of these patients, if services are to be developed that are appropriate to and accepted by the patient group concerned.

Whilst this research was able to undertake some small scale statistical correlations, this aspect of the study was limited by sample size. One purpose of this study had always been to explore issues around attitudes towards risk and pregnancy, with a view to this study forming the pilot basis of a much larger study. The initial findings of this study highlight a number of important themes that would benefit from an extended study involving at least 150 women. Involving more women who have experienced pregnancy (for some motherhood) would allow for greater exploration of suggested relationships concerning the planned nature of pregnancy for women with Type 1 diabetes.

In particular, a larger study would allow for an examination of whether the finding within this study that more than 50 per cent of all pregnancies were as a result of contraceptive mis-use or failure, rather than planned (but not diabetically) pregnancies, was representative of the wider population of women



with Type 1 diabetes. Understanding why women become pregnant and the level of truly accidental pregnancy is crucial to improving the outcomes for the pregnancies of women with Type 1 diabetes, through more effective contraceptive efficacy for those who are not planning as well as pre-pregnancy planning for those who are.

Finally, many women suggested that a more effective way of imparting knowledge about pregnancy and sexual health (and contraceptive efficacy) to all women with diabetes and especially to those who are not planning a pregnancy would be through a specific clinic. The general preference was for this clinic to be on-site at the diabetes centre, and manned by a diabetes specialist nurse who has family planning training. The introduction of such a service would therefore benefit from a thorough evaluation for user satisfaction as well as changes in contraceptive efficiency and unplanned pregnancy rates amongst women with Type 1 diabetes.



## **Appendix i: 1<sup>st</sup> Round Interview schedule**

### **Background Information**

What is your age?

Do you have any educational qualifications:

Do you undertake any paid work?/ Do you undertake any unpaid work?

DO you have a partner, married, single?

Is there any history of diabetes in your family?

How would you describe your nationality and ethnicity.

### **Diabetic complaints**

Can you have a look at this list of diabetic complaints and then tell me briefly if you have suffered from any of the things on the list and how severe the complaint was.

Low blood sugar: 'hypo' (Hypoglycaemia); High blood sugar: (Hyperglycaemia); High blood pressure (Hypertension), Nerve damage (neuropathy); Eye problems (retinopathy); Kidney disease (nephropathy); Heart disease; Depression.

### **Contraceptive History**

Can you look tell me what if any contraceptive method you would most commonly use/ before you became pregnant. And how long before you became pregnant did you stop using your method of contraception.

### **Health locus of control**

(see Appendix iii)

### **The personal history of the diagnosis and condition**

How long have you been diagnosed as having Type 1 diabetes?

Did you suspect something was wrong – did you have a hypo and not know what it s was – how did you find out you were diabetic?

If you were teenage or older at diagnosis: How do you remember feeling when you received the diagnosis?

What were your immediate thoughts about how this would affect your life?

Who helped you cope with the news?

Was there anyone particularly supportive or unsupportive at that time – in what ways?

Did you have a partner then? How/ what did you tell them?

If you were young at diagnosis: Do you remember how you felt at the time when you received the diagnosis?

Did you understand what was being said – if not when did you begin to understand?

Did you have any thoughts then about how this would affect your life? Or later on - when did it start to impact on you?



Who helped you cope with the news? – or if realisation came later – who supported you then?

Was there anyone particularly supportive or unsupportive at that time – in what ways? – again or later on?

What was explained to you about what having the condition meant?

Was anything explained to you at the time? – if not when do you remember having diabetes explained to you?

In the short term; In the longer term; For diet; For health; For having children; For life expectancy

What kinds of places and people did you seek advice from to help you understand their condition at that time? (and if younger – did someone else do the searching – and when did you start to look yourself?)

How useful were the different sources of information?

Have you impacted on how you feel now/ know now about your condition?

If someone you know was diagnosed now – where would you advise them to go for information, or what information would you give them – on what topics?

### **Daily treatment, regime and management**

Can you take me through a typical day in your life from when you get up until you go to bed. You can choose a day recently if that's easier to remember. Tell me everything about

The regime that you follow; The medication you take and what that involves:

The things you have to remember to do; The diet that you are meant to follow

What other things you do to manage your condition.

Can you reflect on how easy it is to follow that regime;

What the easiest and hardest things are about the maintenance of your condition;

Is there anything in life that you feel is made harder for you due to having diabetes;

Do you feel having diabetes puts any restriction on your life?

What level of restriction do you believe it presents for you

How do you feel when you know you've had a good day or a bad day in terms of diabetes management?

### **Health care services and advice**

Who diagnosed your condition?

How did they deal with breaking the news to you?

How helpful/ supportive were they?

What health care providers have you come into contact with since then? (If pregnant/mother – pre pregnancy first)

Annual checkups?; Educational support?; Specialist clinics?; GPs?; Nurses?



How often you are in contact with these different individuals?

What kind of advice you receive from the various providers?

How easy that information is to understand?

How do you feel about the usefulness and practicality of the information you've received in relation the reality of your daily life?

What other sources of information do you use now?

Internet?; Self-help?; Support groups?; Family/friends?

How do these sources differ from 'medical' sources?

Are there sources you would like to have that are not available to you – or you don't know how to access – or know if they are available?

(if no access to) what do you think about self-help groups (esp in relation to pregnancy?)

### **Personal relationships, sex and pregnancy**

How does having Type 1 diabetes makes you feel about yourself and your body?  
(if young when diagnosed – ask in relation to becoming sexually active)

Do you have any concerns about whether being diabetic will affect you sexually?

Does it impact on how you feel about yourself sexually?

Does it impact on your personal relationships?

If partner – how much is your partner aware of your condition and what it means;  
how soon did you tell them? How did they react? How supportive were they?  
How did their reaction make you feel?

If not in a relationship – how comfortable are you explaining your condition to a  
new partner – when would you explain and why?

In terms of sexual relations: how much do you know and how do you feel about  
the potential risk of hypoglycaemia as a result of this physical activity?

Does that impact on your feelings about sex in general?

Do you feel that health care providers give enough information about how having  
sex can affect their condition?

If you were going to try to plan to have a child (or be reflexive if you are  
pregnant or have had a child) what would be the important sources of advice and  
support you would want to approach;

Are (were) you aware of any services in your area for diabetic women who want  
to become pregnant?

How would (did) you go about finding out?

What did you do to plan your pregnancy?

What would you do to plan your pregnancy?

If you found yourselves pregnant (especially if unplanned) who would you first  
seek advice from?



## Appendix ii: 2<sup>nd</sup> round interviews

Each interview will be tailored to the specific information provided in the first round of interviews.

**Background Information** – review previous details for any changes

**Diabetic complaints** – review previous details for any changes

Specific questions probing about depression and mental health support.

**Contraceptive History** – review previous details for any changes

**Health locus of control** – provide feedback on HLoC and the significant findings for whole sample, then offer opportunity to discuss what it implied about how each interviewee views themselves in relation to their diabetes.

**Daily treatment, regime and management** - review previous details for any changes

**Health care services and advice** – discuss any further follow-up or annual check up experiences since last interview

**Personal relationships, sex and pregnancy**

Awareness of pre-conception clinic since last interview. If used, feelings on experience and usefulness.

Discussion about findings in relation to knowledge of how and why to plan a diabetic pregnancy – should there be more information? If so presented when and by whom? Further discussion about the lack of knowledge around why to plan and potential complications – how much information should be provided without scaring people. How can the message be relayed to women who are not yet planning – given the 50% 'unplanned' pregnancies in our sample.

Should discussion focus on whether people are sexually active or using contraceptive rather than considering pregnancy to facilitate more discussion about why to plan?

How do they feel about the level of planning and adherence to good glycaemic control and healthy diet/ exercise pre and during pregnancy required for women with Type 1 diabetes?

How does that make them feel about pregnancy?

What factors & circumstances promote or discourage effective pregnancy planning?

Topics to cover – general women vs diabetic 'topics' – 1<sup>st</sup> interview didn't ask specifics – how many of the below were covered

- diet/weight
- exercise



- obesity
- smoking
- alcohol
- illicit drugs
- screening – such as rubella or HIV
- genetic counselling – such as Down’s syndrome
- Travel – avoid high-risk malaria zones.

How many had medical tests pre-pregnancy including urinalysis for kidney complaints, cholesterol & Triglyceride blood tests, eye exam to screen for glaucoma, cataracts and retinopathy?

What targets were set?

Did they feel that targets were realistic?

What difficulties if any have they had in reaching or sustaining those targets?

What is their perceived ability to effect a change in outcome by their actions?

Personal control Vs fate? (This could be general as well)

How much do they feel in terms of positive reinforcement to the notions that control matters, that good control is achievable and worthwhile in improved health outcomes and that it is possible within the person’s lifestyle?

Type of birth – did they have a choice? Feeling on this? reasons for choice? – extra planning required? – how well explained?

Breastfeeding link – lower chance of child becoming diabetic – what are women told about breastfeeding?

Coronation Street plot line: Katy Harris who has diabetes type 1 tells Martin that what she really wants is to settle down with him and have a baby. Martin is not keen having had a family already, Katy wants to change his mind. What kind of plot line should follow?

### Appendix iii: Focus group

- Introduction (5 minutes) : Opening Discussion (10 minutes) : Talking about sexual activity (40 minutes) : Format of information and advice (20 minutes)
- Summing Up the Session (10 minutes) AH/JMcL
  - Objectives of the session
    - Informing provision
    - Why sexual matters are important
    - Using data from research project interviewing women with type 1 diabetes about some of these issues
  - Format of the session
    - Order of discussion/issues
    - Interactive
    - Participatory
    - No right or wrong answers
  - Confidentiality
  - Tape recording, if you can say your name to help transcribing
  - Discussion style
- Would like everyone to say their name and tell the group about something that made them smile today, and which services, people they are involved with in relation to supporting their health needs.
- In the research we have been doing we have heard a range of perspectives about different issues in relation to working with professionals and support services and we want to discuss these different perspectives with you.
- Some women felt quite distant from the services they use, that they don't have much of a relationship with consultants and others, do you feel the same, does this matter?
- The distance women felt in regard to the professionals involved depended on the type of professional, do you agree, who do you tend to build a relationship with?
- Diabetes affects various aspects of your life as well as sexual matters; do you feel you can talk to service providers about some of the constraints, restrictions women have talked to us about in the research?
- What enables you to have a good relationship with a professional that might allow you to discuss questions about personal issues such as sexual activity and pregnancy?
- Do you think providers are comfortable talking about sexual matters, for example hypoglycaemia during sexual activity?
- What perhaps makes it difficult to discuss these kinds of things?
- What are the kinds of questions you would like to ask providers?
- What do you want to know about?
- Women talked about a range of sources of info they use, lets look at some of the different ways you find out info and what is good and bad about each, we can then think about how they can be used to raise sexual matters.
- Have you read any material or received info geared towards young women, did it work, what did and didn't?
- What are the different kinds of ways you can present information about sexual activity?
- What kinds of ways of talking about and presenting the issues stay in your mind?
- When do they stay in your mind?
- Coronation Street plot line:
  - Next week Katy Harris who has diabetes type 1 tells Martin that she doesn't really care if she's failed her mock exams because what she really wants is to settle down with him and have a baby. Martin is not keen having had a family already, Katy wants to change his mind. What kind of plot line should follow?



## Appendix iv: Health locus of control statements

		1=STRONGLY DISAGREE (SD)		4=SLIGHTLY AGREE (A)		2=MODERATELY DISAGREE (MD)		5=MODERATELY AGREE (MA)		3=SLIGHTLY DISAGREE (D)		6=STRONGLY AGREE (SA)	
		SD	MD	D	A	MA	SA						
1	If my diabetes worsens, it is my own behaviour which determines how soon I will feel better again.	1	2	3	4	5	6						
2	As far as my diabetes goes, what will be will be.	1	2	3	4	5	6						
3	If I see my doctor regularly, I am less likely to have problems with my diabetes.	1	2	3	4	5	6						
4	Most things that affect my diabetes happen to me by chance.	1	2	3	4	5	6						
5	Whenever my diabetes worsens, I should consult a medically trained professional.	1	2	3	4	5	6						
6	I am directly responsible for my diabetes getting better or worse.	1	2	3	4	5	6						
7	Other people play a big role in whether my diabetes improves, stays the same, or gets worse.	1	2	3	4	5	6						
8	Whatever goes wrong with my diabetes is my own fault.	1	2	3	4	5	6						
9	Luck plays a big part in determining how my diabetes improves.	1	2	3	4	5	6						
10	In order for my diabetes to improve, it is up to other people to see that the right things happen.	1	2	3	4	5	6						
11	Whatever improvement occurs with my diabetes is largely a matter of good fortune.	1	2	3	4	5	6						
12	The main thing which affects my diabetes is what I myself do.	1	2	3	4	5	6						
13	I deserve the credit when my diabetes improves and the blame when it gets worse.	1	2	3	4	5	6						
14	Following doctor's orders to the letter is the best way to keep my diabetes from getting any worse.	1	2	3	4	5	6						
15	If my diabetes worsens, it's a matter of fate.	1	2	3	4	5	6						
16	If I am lucky, my diabetes will get better.	1	2	3	4	5	6						
17	If my diabetes takes a turn for the worse, it is because I have not been taking proper care of myself.	1	2	3	4	5	6						
18	The type of help I receive from other people determines how soon my diabetes improves.	1	2	3	4	5	6						



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