And I Will Leave a Trail: Learning to Live with Type 2 Diabetes: A Narrative Curriculum

by

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ABSTRACT

> *I will not follow where the path may lead, but I will go where there is no path and I will leave a trail. (Anonymous, 1998)*

This thesis chronicles my journey of learning to live with type 2 diabetes. The thesis is the trail I am leaving as I explore my own experiences, the experiences of other people with diabetes, and the literature about diabetes as I try to understand what it means for me to be diabetic. The thesis functions as a curriculum of my own process of understanding my diabetes and may also be used as a model for others to reflect upon their experiences with diabetes.

The journey begins with a description of my motivation for the thesis and the research methodology including a description of how others may use the thesis as an inspiration for their own reflections about diabetes. It continues with narratives of seven participants with type 2 diabetes and creates a broad overview of the experiences and feelings of people with type 2 diabetes. A literature review of diabetes follows which allowed me to increase my understanding of the pathophysiology of diabetes and its treatment. This literature chapter is written for the lay reader so as to facilitate an understanding of the complexity of diabetes. The thesis concludes with personal narratives, poems and journal writing which describe my experiences as a diabetic.

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Acknowledgments

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A Note to the Reader

Throughout the thesis you will see the phrase "a person with diabetes" and the term "diabetic" used interchangeably. I believe it is important to briefly explain my rationale for this decision.

Many health care professionals object to the term diabetic, feeling that it objectifies and stigmatizes the person who lives with diabetes. Often, in discussing this issue, it will be pointed out that the person is more than "just" a diabetic. While I respect this position, I choose to view it differently. While I would certainly agree that I am not just a diabetic, I am a diabetic and this permeates my sense of self. Diabetes is an extremely invasive disease, affecting virtually every aspect of one's life (Callaghan & Williams, 1994). It also requires ongoing adaptation as diabetes is a progressive disease which often causes long term complications (Nhylin, Lithner, & Norberg, 1987). Thus, those with diabetes often focus a significant amount of attention on their disease in order to maintain glycemic control.

As you read the narratives of my participants and my own narrative, you will see our struggle to live with diabetes. It is my feeling that in this struggle I embraced being diabetic as I attempted to integrate this chronic illness into my sense of self. In addition, although several of my participants discussed issues related to being labelled, every participant readily used the term diabetic in telling me their stories. Therefore, although I am aware of the controversy, I have chosen to honour my own experience and the words of my participants by using the term diabetic in the thesis.

CHAPTER ONE: FEARING THE JOURNEY:

INTRODUCTION

> *The most difficult decisions are often not the ones in which we cannot determine the correct course, rather the ones in which we are certain of the path but fear the journey. (Evans, 1998, p. 162)*

In the summer of 1995 I stumbled upon a thesis topic. I had been pondering many possible topics but nothing really struck me as "the" topic. I had already realized that working from a purely academic standpoint -- without connecting my work to myself -- would not be satisfying for me. I wanted to find a topic that was relevant to my life.

In March of 1995 I had been diagnosed with type 2 diabetes. The diagnosis was completely unexpected and I was distressed to have been diagnosed with a chronic disease. I knew type 2 diabetes was a common disease, however, I did not personally know anyone with diabetes. As a nurse, I was familiar with treatment modalities for diabetes but I had never really thought about what it was like to have diabetes. Yet suddenly, I had diabetes. How did other people feel when they were diagnosed with diabetes? I knew the basics of the diabetic diet, I was familiar with medications used to treat diabetes, both oral agents and insulin, and I had seen the multitude of complications that can arise from uncontrolled diabetes. I even understood that "patient self management day to day and year to year constitutes 90% or more of the overall program" (Hiss & Greenfield, 1996, p. 180). But as a person suddenly diagnosed with diabetes, all I understood was that my life was forever changed. And I quickly realized that while my nursing knowledge was useful, there was so much more to be learned.

Since I was a young child I have always used the library as a source of information. I particularly appreciate reading stories of other people's experiences. I have always loved the narrative form because it creates the possibility of my connecting an/other's story to myself. A story is a representation of a life and when I read the narrative I can imagine the actual life. This imagination allows me to then reflect upon my own life. I can extrapolate how I might react in the situation. I can compare and contrast the narrators reactions with my own imagined reactions. I may see new perspectives for viewing the world. I may even see possibilities when I had previously seen only impossibility. This is the power that narrative has for me. Egan (1986) says it well, "the story form is a cultural universal; everyone everywhere enjoys stories. The story then, is not just some casual entertainment; it reflects a basic and powerful form in which we make sense of the world and experience" (p. 2). Therefore, I use narratives to help me to contextualize my experiences within the world.

Consequently, I searched the library for stories about people with type 2 diabetes. I was shocked to discover that I could find no autobiographies by people with type 2 diabetes. I did locate several autobiographies by people with type 1 diabetes, but they did not satisfy my need to read about others with type 2 diabetes.

At the same time, I began to search for other information about type 2 diabetes. As a nurse, I was familiar with the disease, but my nursing knowledge was not particularly helpful in assisting me to understand what it is like to live with diabetes. In addition, I wanted to be certain my knowledge was current.

As I began to research the topic I quickly discovered there is a commonly held misconception that type 2 diabetes is mild and easily treated (Henry, 1996). This misconception is encouraged by the current classification system which differentiates two different types of diabetes called type 1 and type 2. Both conditions are likely to result in long term complications (Harris, 1996). However, doctors often use the terms "borderline diabetes" or a "touch of sugar" when informing patients of their type 2 diabetes diagnosis (Hiss & Greenfield, 1996). These terms, the mild symptoms, and the treatment modalities of diet/exercise and oral antidiabetes agents, rather than insulin, implies, to many people, that type 2 diabetes is not a serious illness. As one of the participants in a study related to diabetes said, "It never crossed my mind it was such a serious illness. The doctor gave me pills and I was okay. It didn't affect me that much" (Maclean & Oram, 1988, p. 44). Many patients, including myself in the period immediately following my diagnosis, are unaware of the serious nature of type 2 diabetes (Hiss & Greenfield, 1996). "One of the biggest challenges with type 2 diabetes is the development of a sense of seriousness about the disease given the fact that the onset is so unintrusive. Diabetes is a very insidious disease" (Nelson, 1992, p. 81-82).

However, the reality is that diabetes, of any type, is a serious disease:

> Diabetes is a leading cause of death by disease. If left untreated or improperly managed, the high levels of blood sugar associated with diabetes can slowly damage both the small and large blood vessels in the body, resulting in a variety of complications:
>
> - heart disease is three to six times more common in people with diabetes than without;
> - diabetes is a leading cause of adult blindness;
> - in Canada, people with diabetes account for 25 percent of all new cases of serious kidney disease; [and]
> - worldwide, half or more of all nontraumatic leg amputations are due to diabetes. (Canadian Diabetes Association [CDA], 1997b, p. 1)

In addition, our health-care system spends five to six billion dollars annually to treat people with diabetes (CDA, 1997a).

However, the more I understood about the clinical aspects of diabetes, the more I desired to see how other people with diabetes handle their disease. It seemed so complex.

How was I going to learn to cope with this? Hinnen (1993) describes the multiple tasks facing a person with diabetes:

> Diabetes self-care requires cognitive functioning, problem solving, agile psychomotor skills and vigilant continuous performance of behavioral goals. There are multiple steps one must perform in adhering to the diabetes regime. The life-sustaining skills of taking insulin injections [for some people] and eating required meals and snacks require many steps and interrelated decision-making. Blood glucose monitoring four to six times a day, record keeping, hypoglycemia treatment, exercise adjustments, and wellness and illness management are all complex tasks that are multifaceted in nature and require synthesis of information and often immediate action. (p. 118)

As my awareness of the complexity increased, so did my desire to connect with other people with type 2 diabetes. Although I had spent months reading about diabetes I wasn't able to see myself in the literature. As Kiesinger says, "the stories offered by the 'experts' in these publications were not my story" (1998, p. 73). During my research I discovered that there were an estimated 1.5 million Canadians with diabetes, 90 percent of them having type 2 diabetes (CDA, 1995). Where were their stories? I could not be the only one who would appreciate reading stories of people with type 2 diabetes. This seemed to be a significant gap in the literature. So there it was. I needed to hear stories about people with type 2 diabetes. Since they didn't exist, I needed to search [research] them out. I could research diabetes for my thesis and satisfy my own need for stories, all at once. I would ask other people with type 2 diabetes to tell me their stories. I would write about my own experiences with diabetes. Together, these would provide the stories for my thesis. In addition, my knowledge/expertise as a nurse and my understanding of the clinical literature about diabetes would provide additional depth to my understanding of the stories. Therefore, as Laurel Richardson (1990) said, "I wrote this book [thesis] because I needed to read it" (p. 7). And so, my thesis journey began.

The thesis uses the metaphor of a journey because I have a basic belief that, as individuals, we are all on a life journey and we use stories to tell about our journey:

> Stories allow people to draw from their own personal beliefs and values to interpret and apply new information to their own lives. A good story takes listeners on a collective journey with many paths; each path is uniquely suited to the needs of the individual, with wisdom gained that is uniquely suited to their own life. (Carter, Perez & Gilliland, 1999, p. 189)

I wanted to hear stories about life with diabetes so that I could travel on these multiple paths and continue to move on my own life journey. Therefore, I have used the journey metaphor to create a structural framework for the thesis. The metaphor resonates for me. The thesis articulates my own journey of learning to live with type 2 diabetes and also my journey of writing the thesis. To demonstrate this more actively I have used quotations related to journeys as chapter titles. These quotations were not chosen randomly. Each of them have resonated through different periods of my life. Their use in the thesis helps me to connect my entire life journey with my diabetes journey and my thesis journey. In addition, each quotation is relevant to the particular chapter in which it is used.

I have always told stories and listened to the stories of other people in an attempt to understand my own and their experiences. While I realized that my thesis could provide stories of people living with type 2 diabetes, I wanted to choose a methodology which would highlight the stories. For me, it was the stories that were important. Therefore, the choice of methodology became obvious. A narrative methodology would focus on the stories of my participants and myself. "Narrative analysis takes as its object of investigation the story itself" (Reissman, 1993, p. 1). Furthermore, the method is relevant for me as I tend to view the world through a narrative lens. I think in narrative and relate to the world by telling stories. Therefore, using narrative as my method seemed particularly appropriate. As Connelly & Clandinin (1990) say, "narrative and life go together and so the principal attraction of narrative as method is its capacity to render life experiences, both personal and social, in relevant and meaningful ways" (p. 10). In addition, "by making intricate details of one's life accessible to others in public discourse, personal narratives bridge the dominions of public and private life. Telling a personal story becomes a social process for making lived experience understandable and meaningful" (Ellis & Bochner, 1992, p. 79-80). Thus, stories have a power to look beyond the obvious plot and engage the reader. Stories have different meanings for different readers. Stories create a site for the reader to engage with the text in whatever way is meaningful to him/her. As Metzger (1979) so eloquently says:

> Stories go in circles. They don't go in straight lines. So it helps if you listen in circles because there are stories inside stories and stories between stories and finding your way through them is as easy and as hard as finding your way home. And part of the finding is the getting lost. If you are getting lost, you really start to look around and to listen. (p. 104)

The thesis describes my getting lost, my looking around, and, I hope, my finding my way home.

As well as containing my narrative and the narratives of my participants, the thesis also includes a chapter containing basic information on the pathophysiology and treatment of diabetes. This chapter was added to increase the comprehensibility of the narratives for the lay reader. However, the writing of this chapter became an integral part of my own reflective process. Thus, while the thesis began as a way to provide stories of people living with diabetes, it became a site for the development of and reflection upon my own personal story. My story is central to the thesis because the whole of the thesis became a curriculum of my own learning to live with type 2 diabetes. Through writing the thesis I began to integrate my diabetes into my sense of self. Throughout the process of researching and writing the thesis, I was continuously reflecting on my own experiences, the narratives of my participants and my understanding of diabetes as a disease. As this reflection continued, I found that I was de/constructing, constructing, and re/constructing my sense of self:

> As chroniclers of our own stories, we write to create ourselves, to give voice to our experiences, to learn who we are and who we have been. Our diaries become the stories of our journeys through life, stories that are both instructive and transforming in the telling and the listening. The stories, these myriad voices, then serve to instruct and transform society, to add to the collective voice we call culture. (Cooper, 1991, p. 111)

This narrative curriculum can also be used as a framework for how others may reflect on their experiences with diabetes. Narratives of others' experiences readily create a site for understanding one's own experiences (Richardson, 1990). Furthermore, "when we share stories from our lives, we begin to open ourselves to others, and perhaps nowhere are others more willing to come close enough to hear than when they are being told a story" (Shabatay, 1991, p. 150). I invite my readers to read the narratives and reflect on their own experiences.

Finally, it is important to understand that I have structured the thesis in the order which was most relevant for me: the participant narratives, the medical narrative, and finally, my own narrative. This order made sense to me because both the participant narratives and the medical narratives informed and changed my own narrative. However, some readers may prefer to vary the order of the reading. I invite, in fact I encourage, the reader to read the thesis in whatever order is most meaningful to him/her. The teacher, "if he [sic] is indeed wise, does not bid you enter the house of his [sic] wisdom, but rather leads you to the threshold of your own mind" (Gibran, 1923, p. 56).

CHAPTER TWO: THE ROAD LESS TRAVELLED:

METHODOLOGY

> *"Two roads diverged in a wood, and I --*
> *I took the road less traveled by,*
> *And that has made all the difference" (Frost, 1995, p. 103).*

This chapter describes the research methodology of narrative used in this thesis. It includes a literature review of narrative as method and an explanation of how the research for the thesis was conducted. In addition, it will discuss how reading, writing and listening to stories may result in a re/constitution of one's sense of self. Paying attention to my own evolving story and the stories of my participants has made all the difference.

I began this research with three basic beliefs: One, that stories of other people's lived experiences can provide a rich source for personal reflection. As a story is read, one reflects on the connections and disconnections with one's personal experiences. By providing a concrete starting point, the narratives create a site for personal reflection. Two, that shared stories can have an influence on the actions of those who live them and those who hear/read them. Thus, stories can also create a site for change and growth. Three, that stories can assist in the construction of knowledge. Thus, the stories in this thesis provide an opportunity for increased understanding of the experience of living with diabetes.

Narrative as Method

The attraction of narrative as a research method is "because we all live out narratives in our lives and because we understand our own lives in terms of the narratives that we live out that the form of narrative is appropriate for understanding the actions of others" (MacIntyre as cited in Ellis & Bochner, 1992, p 97). In addition, the focus of narrative is the story itself, something I have long felt is important. However, there is significant disagreement about the actual definition of narrative research. Narrative is inherently interdisciplinary and may include such diverse forms as films, novels, essays, biographies, autobiographies, life histories, case studies, case reports, poems, letters and journals (Riessman, 1993).

To begin understanding narrative research, it is necessary for the reader to understand the use of the terms story and narrative. I have followed Carr, Taylor & Ricouer (1990) in using the term story for those events which are lived or told. Stories become narratives only after they are written during the analysis process. Therefore, a narrative requires a story which changes into a narrative as the narrativist chooses what to include/exclude.

Narrative research is an art which does not have an established set of directions. Therefore, "when we follow a narrative, we must be able to follow its construction as well as its content, for content is produced through narrative strategy" (Pagano, 1991, p. 198). The creation of the narrative functions as the analysis of the research because "how we arrange and rearrange the text in light of our discoveries is a process of testing, clarifying and deepening our understanding of what is happening in the discourse" (Mishler, 1991, p. 277). In addition, "every narrative, however seemingly 'full' is constructed on the basis of a set of events which might have been included but were left out" (White, 1981, p. 1). Thus, the narratives written from my participants' stories were constructed twice. Once when they told me their stories and again when I wrote the narratives.

In this thesis I refer to three different forms of narratives. The first is the narratives which were constructed from the stories told to me in the interviews of my participants. These narratives are structured through my analysis to create a sense of order which allows the reader to make meaning of the text (Schulz, 1997). A full description of the process of narrative construction is provided later in the chapter.

The second form of narrative is the medical narrative related to diabetes. This form of narrative is substantially different from the other narratives because it is written in the standard medical discourse. However, the medical narrative does tell a story. It tells the story of how the healthcare profession views diabetes.

The third form of narrative is what Richardson (1994) calls "the narrative of the self.... A highly personalized, revealing text in which an author tells stories about his or her own lived experience" (p. 521). This narrative of the self focuses on my experiences as a diabetic and includes what I call "incident narratives," stories about a specific incident in my life written in a narrative form. These incident narratives have a clear plot, raison d'etre and a resolution (Paget, 1982). This narrative of the self also includes journal writing and poems. The narrative of self differs from the participant narratives in that my narratives were collected over a much longer period of time, approximately five years, and therefore show much more evidence of temporality and evolution. Therefore, the entire narrative of the self is a multilayered reflection on my own experiences with diabetes.

My own narrative was written and rewritten as I struggled with how to best describe my own experiences with diabetes. I wanted to demonstrate the entire range of my actions, thoughts, and emotions related to my diabetes. However, at times, I found myself concerned about issues of privacy and the ethics of including other people in my narratives. Therefore, I sometimes chose to exclude some elements of my experiences. It is difficult to know how including these elements would change my narrative. But while it was important for me to describe my experiences as fully as possible, it was even more important that I follow my intuition. Some elements were just too personal to be included and some stories might have harmed other people. Therefore, I constantly wrote, rewrote, reviewed, and wrote again in order to describe my experiences fully while minimizing the risk of harm for myself and others.

. However, neither the participant narratives or my narrative of the self does justice to the actual experiences of my participants or myself. No narrative could. Any narrative, no matter how full or rich, is only a simulacrum of the life which it describes. The narrative "is not the actual event but rather a story about the event. The narrative is subsequent to what it tells. The paradox of narrative understanding is that we begin telling the story at the end of a lived experience" (Schulz, 1997, p. 115). But narratives are as close as we can come to the actual experience due to the limitations of language to describe experiences (Clandinin & Connelly, 1994). It is also important to understand that although the narratives, once written, become static, in life we tell stories, then we modify the stories and create new, richer stories (Miller, 1996). Thus, we are all, "at once, engaged in living, telling, re-telling and re-living stories" (Connelly & Clandinin, 1990, p. 4).

In addition, the meaning that I, or anyone, may draw from the narrative is only one of the possible meanings (Clandinin & Connelly, 1991). As Schulz (1997) says, "no story can be told in its entirety, a text always leaves gaps in the telling of the story which readers must fill, and which individual readers fill in different ways" (p. 133). Consequently, "people make sense of text in relation to their own past experiences, their beliefs and expectations, and their present needs and aspirations" (Clark, 1990, p. 338). Thus, the meaning of any narrative is transformed as the reader moves through his/her life journey (Rosenthal & Bar-On, 1992). The meaning that a particular narrative has for me today may no longer be relevant in the future.

Beginning the Research

When I initially decided to write narratives about type 2 diabetes I realized that it was necessary to improve my own knowledge of the topic. I began by reading popular literature about diabetes. This reading set the stage for my own initial writing about diabetes. I frequently wrote in my journal about issues related to my diabetes. I also began to write my first incident narratives. Generally, these narratives described incidents related to my diabetes which were noteworthy because of the emotional response I had experienced. Occasionally, I wrote poems about my diabetes. Poems allowed me to explore my experiences as a diabetic at a deeper and more symbolic level.

As I worked on these initial writings I began to see areas of connection with the popular literature. For example, it was commonly acknowledged that most diabetics have difficulty maintaining their diet (Nathan, 1997). In addition, I began to be aware of areas of conflict in my own life. This allowed me to begin to identify potential questions for my participants. Once this stage of initial writing was complete I was ready to begin interviewing participants.

As the purpose of the narratives was to create a site for personal reflection, I hoped that my participants would provide me with diverse experiences which might demonstrate some of the range of experiences with type 2 diabetes. I was not attempting to present a "typical" experience, instead only some of the possibilities. Thus, diversity among the narratives might allow a variety of readers to connect in some way with the writing. Therefore, I kept my criteria for inclusion into the study quite broad, limiting it only to adults with type 2 diabetes using diet and/or oral antidiabetic agents. My hope was that my participants would describe patterns and perspectives that I had never envisioned (Davis, 1991). The purpose of the research was to describe my own and my participants' experiences. But it was also to give the readers the possibility of connecting with the story:

> Readers are put in the position of experiencing an experience that can reveal to them not only how it was for us but how it could be or once was for them. They are made aware of similarities and differences between their world and ours. It becomes possible for them to see the other in themselves or themselves in the other among other possibilities. (Ellis & Bochner, 1992, p. 100)

Data Collection

After having my research plan approved by the Human Research Ethics Committee, I advertised in the local paper for participants. [A copy of the advertisement is included in appendix A.] The advertisement ran for seven days, and over that time I received twelve responses. Several people were excluded from the study because they did not meet the research criteria. For example, one individual called and wanted to tell me her father's story. Another claimed to have been "cured" by a radical diet. Neither of these individuals were appropriate for inclusion into the study.

During the initial telephone conversation I informed each respondent of the purpose of the study and the expected research plan. I also provided some information about my interest in the topic. In particular, I mentioned that I have a background in nursing and that I am a type 2 diabetic. I collected telephone contact numbers after informing each individual that once I had received all the responses I would contact them to arrange an interview time. As I expected to interview only seven participants, I told the last three respondents that I had already received sufficient responses, but that I would contact them if I required further participants.

I eventually interviewed seven individuals with type 2 diabetes, including five women and two men. My participants represented a broad range of age and experience with diabetes. Their ages at the time of interview ranged from 40 - 87 years of age. One had been diagnosed with diabetes only four months prior to the interview, another had been diabetic for more than 30 years.

Prior to the interview all participants were briefed on the purpose of the study and had the research methodology explained. Each of them then signed an informed consent. [A copy of the informed consent can be seen in appendix B -- please note that the title of the study has since changed to reflect a shift in the research focus.] I particularly advised them they were free to refuse to answer any questions, or to withdraw from the study at any time, for any reason. In addition, each would be given the opportunity to review the narrative I would write of their experience and could make changes or request that it be deleted from the thesis.

At this time, I also gave each participant the choice of using a pseudonym or their own first name in the eventual narrative. I wanted to offer the participants the option because I believe the use of a pseudonym, if not desired by the participant, is a disempowering experience. Several participants chose to use their own name and therefore, I discussed the possible impact of this choice with them. I was particularly concerned that they understand using their own first name meant anonymity could not be guaranteed. However, after thinking about the implications, each of these participants confirmed their choice to use their own name. Several individuals did prefer to use a pseudonym -- these individuals were give the option of choosing their own pseudonym or allowing me to choose one for them.

Data collection occurred through a semistructured interview process regarding the individual's life with diabetes. I used the active interview structure described by Holstein & Gubrium (1995). I chose this method because "narrative complexity requires an interview format that accommodates contextual shifts and reflexivity" (Holstein & Gubrium, 1995, p. 55). Using the method of active interviewing meant that while I had a purpose for the interview -- to hear the participants' stories of living with type 2 diabetes -- I did not have set questions which were asked of each participant. I encouraged participants to describe specific experiences within their lives which would explicate how they lived with diabetes. When necessary, I prompted the participants with questions, although I preferred to allow them to describe their experiences in a way which was most satisfactory to them. I did, however, have a list of questions which I used to assist in the interviewing process if a participant was having difficulty thinking of things to talk about. Generally, the active interview format allowed me to be flexible in allowing the participant's responses to guide how the interview should proceed. I was particularly concerned I not force the participants to reveal things they preferred to keep private. I believe the participants had the right to choose what they wanted to disclose without pressure from me. Therefore, my purpose was to "encourage subjects [sic] to tell stories and assist them in developing and clarifying their stories" (Kvale, 1996, p. 274). While the focus was on type 2 diabetes, each participant chose to discuss his/her diabetes in a way which was meaningful for him/her. Therefore, there is an "improvisational, yet focused, quality to the interview" (Holstein & Gubrium, 1995, p.77). The interviews lasted one to two hours, until the participants indicated that they felt they had adequately described their experiences with diabetes.

I feel it is important for me to acknowledge that my presence undoubtedly had an effect on the participants. Although I used open-ended questions and encouraged them to discuss anything they felt was relevant, it is possible my responses may have directed participants in some, as yet unrecognized, way. It is important to understand that I did respond to my participants stories. It would have been virtually impossible for me to have sat silently and only listened to their stories. The stories engaged me, as stories always do. At times, in response to a story, I disclosed some of my own experiences with diabetes. I believe this encouraged the participants to feel I was a partner in the interview. Although I cannot ignore the possibility my disclosures may have affected the content of the data, it may actually have contributed to the depth of the interview and the quality of the data I received (Sword, 1999). In addition, my nonverbal responses may have had an impact of which I am unaware. Furthermore, my position as a type 2 diabetic, rather than strictly as a researcher, almost certainly had an impact on the stories my participants told. Several indicated they would not have participated in the study had I not been diabetic. All the participants specifically addressed the issue of my diabetes. Several asked questions about my management of my diabetes, for example, did I use medications or just diet/exercise? A number of participants, during the telling of their stories, made reference to the fact that, "I understood," "I know what it is like to live with this disease." In addition, my position as a nurse also affected the stories my participants told. Several were pleased to know of my nursing background, expressing their hope that the thesis might assist health care professionals to better understand how difficult it can be to be diabetic. However, while it is not possible to know the effect my presence had on my participants, this subjectivity is not unexpected in narrative research. It must be understood that:

> Each interview is a product of the mutual interaction between speaker and listener. Narrators do not simply reproduce pre-fabricated stories regardless of the interactional situation, but rather create their stories within the social process of mutual orientation according to their definition of the interview situation. (Rosenthal, 1993, p. 64)

Immediately following each interview I made notes about the interview and journal entries to assist in my reflective process and the eventual construction of the narratives. (Kiesinger, 1998).

Narrative Construction

Each interview was audiotaped and then transcribed verbatim. Generally, audiotapes or videotapes are necessary because of the difficulty of reproducing, from memory, the content of the interview (Millett as cited in Riessman, 1993). These transcriptions provided a basis for the narrative which would be created of each participant's story. During the transcription process I also focused on the particular tone of voice and any pauses in the conversation and made notes to myself which would assist in my later conversion of transcripts to narratives.

Once the transcription process was complete I began by reading, rereading, and re-rereading a particular transcript. In each reading I was not focusing specifically on the content, instead I was aiming for an overall feeling for the transcript. When I felt I had absorbed the transcript to the point of saturation, I again reread the transcript and highlighted specific passages I felt particularly described that individual's experience with diabetes. These highlighted passages were then removed from the transcript in order to begin to structure the narratives. I physically organized the passages in a variety of ways in an attempt to create a coherent narrative. Once I had a basic framework for the narrative, I then returned to the transcript, searching for other passages which might add further depth to the narrative. Next, I physically created a written narrative. Generally, the specific words of the participant were used, although I often had to add connecting words which were not present in the transcript. In addition, the narratives were organized in a manner which I found coherent, not in the way they were originally organized in the transcript. Frequently, a number of statements, which were spread throughout the transcript, were combined to create one paragraph about a specific topic. This technique is called narrative smoothing and is used to help increase the coherence of the narrative (Connelly & Clandinin, 1990). However, narrative smoothing must be used cautiously so as not to obscure the voice of the narrator. "The problem, therefore, is a judicial one in which the smoothing contained in the plot is properly balanced with what is obscured in the smoothing for narrative purposes" (Connelly & Clandinin, 1990, p. 10). In an attempt to maintain the voice of the participant, I used their words wherever possible. I also particularly focused on maintaining their phraseology and grammatical articulation. However, it is impossible to know exactly what the effect of my narrative smoothing was on the participants' stories. This is a complex issue within narrative research, one which can never be completely resolved (Richardson, 1990). Narrative smoothing is necessary if the narrative is to be accessible for the average reader. Therefore, it is important to acknowledge the use of narrative smoothing, in an attempt to make the process of narrative construction more visible. "To acknowledge narrative smoothing is to open another door for the reader" (Connelly & Clandinin, 1990, p. 10). But it is important to remember I am the one who created the final narrative. As Apter (1996) says, "I am the one who selects their quotes. I tease out revelations. I put together things that were not given to me already packaged" (p. 42).

When a narrative was complete, I put it aside for at least a week. This allowed my own saturation level with the transcript to decrease. I then returned to the narrative and reread for coherence and fullness of story. Then I reviewed the transcript to determine whether the narrative seemed to provide an accurate characterization of the participant. The criteria of verisimilitude and plausibility are identified by Connelly & Clandinin (1990) as important in determining the “goodness” of a narrative. Does the narrative ring true? Could I [or any reader] imagine the story actually occurring? Does the account remind me of the actual participant? In assessing the characteristic of verisimilitude I also reviewed my field notes from the interviews and from the transcription process as well as the transcript of the interview. In some cases, after reviewing the narratives, I made decisions to include elements of the interview which were not directly related to diabetes because they seemed to provide an increased understanding of the particular individual. For example, in Elsie's narrative I included her discussion of World War II because that experience in her life seems to have been extremely relevant to her current coping mechanisms. In addition, I felt it improved the narrative by adding depth and making it more rounded. After this process of review, if changes, other than minor grammatical changes, were undertaken, then I repeated the process of setting narrative and transcript aside and returning to it some time later.

Because narrative research does not have established guidelines, there are also no clearly established criteria for determining the value of a particular narrative. It is generally accepted that the standards of reliability and validity used in quantitative research are not appropriate for narrative research (Connelly & Clandinin, 1990). However, criteria to be used in replacement of reliability and validity, are not so clear. I have already discussed the concepts of verisimilitude and plausibility. Another possible criterion is that of transferability (Guba & Lincoln as cited in Connelly & Clandinin, 1990). This refers to the question of whether the meaning made in the narrative can be transferred to another situation. I would suggest that any meaning-making is transferable. Each reader makes sense, or meaning, from a narrative in a way which is relevant to his or her present situation.

Other criteria suggested include balance, fairness, completeness, and sensitivity (Wolcott, 1990). However, Wolcott acknowledges that these criteria are elusive and each researcher must satisfy him/herself in regards to whether these criteria have been met.

Kiesinger (1998) states that a narrative should be evocative, having the power to "move; inspire; and evoke feelings, memories and most important, connection" (p. 91). I have wondered whether the fact a narrative is evocative for me is sufficient to judge the value of the narrative? Determining the effectiveness of any narrative is one of the primary challenges of narrative research. I believe the only possibility is to continue to recognize the difficulty and to reflect repeatedly on this concern. By doing this, one can hope that conflicts related to the goodness of a narrative may be addressed as they arise.

In addition, as described later, I asked each participant to review her/his own narrative. I believe this has assisted in determining the narratives were balanced and fair. Finally, by clearly demonstrating the process of narrative construction, I allow the reader to judge for him/herself.

It is difficult for me to explain exactly how I determined a narrative was complete. It seemed based primarily on intuition rather than any objective criteria. May (1994) says it well:

> Expert qualitative analysts can always explain their analytic processes and can recount the sequence of cognitive operations they carried out that preceded discovery.... Technique and rigor, however, cannot entirely explain what moved the analyst from confusion to insight, from chaos to order, and from simple description to understanding. The product is shaped *but not completely defined* by the process through which it was created. (1994, p. 14)

One of the most difficult decisions I have made in writing the narratives was the choice to write in the first person. Narrative research, although based on personal narratives, is more typically written in the third person. I am uncomfortable with the use of the third person because I feel it tends to depersonalize stories, taking the "voice" away from the participants and assigning it to a somewhat anonymous third person. However, I was also concerned with using the first person because I worried I was coopting the participants stories. What right did I have to write narratives of their stories in the first person?

During my research of the literature related to narrative inquiry, I discovered that one form of narrative research, often called "life story," "oral history," or "life history" typically uses the first person. Life history is, "an extensive record of a person's life told to and recorded by another, who then edits and writes the life as though it were autobiography" (Langness as cited in Geiger, 1986, p 336). Silvera, in defending her choice to use the first person says, "they speak in their own words.... This is an act of empowerment" (1989, p. viii). Bar-On (1996) also discusses this issue, stating, "they were so powerful in their own discourse" (p. 14). As both of these statements resonated with me I made the decision to use the first person for my participant narratives. However, because the narratives used in this thesis focus primarily on one aspect of life, namely type 2 diabetes, I have chosen to use the term narrative rather than life history.

One advantage of using the first person for the narratives is that the participants become both characters in and narrators of the narrative (Kiesinger, 1998). The narrative is told from his/her point of view rather than from that of an omniscient third person (Tirrell, 1990).

Throughout the process of writing the narratives, I tried to keep the following quote in mind:

> The wisest know that the best they can do... is not good enough. The not so wise, in their accustomed manner, choose to believe there is no problem and that they have solved it. (Malcolm as cited in Josselson, 1996, p. 71)

This helped me to remember that in writing someone else's story it is very easy to become not so wise. I wanted to remember that the narratives, being static pieces of writing, are not the same as the actual life they describe. The narrative, once written, "appears to stand still, the narrative appears finished. It has been written, characters' lives constructed, social histories recorded, meaning expressed for all to see" (Connelly & Clandinin, 1990, p. 9) when in fact, the life is continuing and only the narrative stands still. In addition, because I am writing the narrative of an/other, it can never be good enough. We are limited by the ability of language to describe any life. But at the same time, I must keep struggling to achieve the good enough narrative. As well, at the same time, for the purpose of the research, at some point I must accept the narrative as being good enough. But it is the ongoing struggle to achieve the good enough narrative while knowing it cannot be achieved that assists in keeping the research strong and ethically sound.

In addition, although the narratives describe the participants stories, once narrativized the text becomes mine as much as it is theirs (Bar-On, 1996). I am the one who has formulated the narrative in a specific way. This becomes a difficult issue of ethics because it is not clear who "owns" the written narrative (Apter, 1996).Therefore, once a narrative was finally complete, seeming to be full, coherent, and understandable I contacted the participants to have them review the narratives. At this time, the participant was given a copy of his/her narrative. They were encouraged to read the narrative and inform me of any errors that might be present in content/context, desired changes, or any possible concerns. I particularly asked whether they were comfortable with the use of the first person in the narrative. I also asked whether they felt their own voice had emerged. In response, many participants stated they could "hear/see my own words" in the narratives. Several participants did request minor changes to either content or context and these requests were accommodated. Finally, for those who had chosen, at the time of interview, to use their own names, I confirmed they were still comfortable with that decision. I felt it was important to allow the participant the opportunity to review the narrative prior to its publication in the thesis. As Chase says, "it acknowledges that my research depends on your story and that you have good reason to be particularly interested in what I have to say about your story" (1996, p. 49-50). In addition, asking participants about the narrative is useful in addressing the quality of the research analysis. Do the narratives accurately describe their experiences? Have I, as the researcher, understood what they meant? Did I get it right? (Chase, 1996).

One participant was no longer available for contact. After careful consideration of the ethics of the situation, I decided to leave this narrative in the thesis. In coming to this decision, I thoroughly reviewed the interview transcript and I was reminded that this participant had eloquently described the personal value of participating in the research. In addition, the participant had clearly indicated an interest in being included in the final document. Therefore, I decided it was more appropriate to include rather then exclude this particular narrative. However, because the narrative could not be approved by the participant, I decided to carefully review the written narrative looking for passages which I would have asked specific permission to include in the final narrative. There was one paragraph which I felt was particularly sensitive and should not be included without specific permission from the participant. Therefore, I chose to remove that paragraph from the final narrative.

Prior to giving the participants the narratives to review, I was extremely worried about the potential responses to the narratives. I kept recalling a quote by Josselson:

> I worry intensely about how people will feel about what I write about them. I worry about the intrusiveness of the experience of being 'writ down,' fixed in print, formulated, summed up, encapsulated in language, reduced in some way to what the words contain. Language can never contain a whole person, so every act of writing a person's life is inevitably a violation. (Josselson, 1996, p. 62)

Although I was reassured by my participants apparent pleasure with the narratives I still find this issue worrisome. I feel that the participants gave me a great gift when they opened up their lives to me. And I feel a sense of responsibility about the effect my narratives of their story may have had:

> In personal experience methods the ethical dimensions of researcher-participant relationships are highlighted. When we enter into a research relationship with participants and ask them to share their stories with us, there is the potential to shape their lived, told, re-lived, and retold stories as well as our own. (Clandinin & Connelly, 1994, p. 422)

There is no way to be certain that the participants have experienced no harm from participating in this research. However, several expressed that they were amazed and delighted to see their story written for others to read. Therefore, I am hopeful that the research has had a positive, rather than a negative, effect.

The Emerging Narrative of the Self

Once the participants' narratives were complete I became aware of a potential problem with the thesis. The narratives were filled with technical information about diabetes. This is probably because diabetics, in order to control their disease, must become knowledgeable about diabetes. "You have to become your own health care provider ...diabetes is a self-managed, self-treated disease" (Nathan, 1997, p. 4). Therefore, the narratives were relatively incomprehensible for the lay reader or the newly diagnosed diabetic. Consequently, if the thesis was to be used as a curriculum for understanding diabetes by those who read it, it became necessary to provide information about the history, epidemiology, pathophysiology, treatment, and complications of type 2 diabetes so that the narratives would be more understandable.

Therefore, I began an indepth review of the medical and nursing literature related to diabetes. I initially envisioned a brief section that would describe the basics of diabetes. I quickly realized that diabetes is too complex a disease entity for this to be possible. Therefore, I wrote chapter 4 -- The Road Goes Ever On An On -- to provide a comprehensive source of information on type 2 diabetes. However, writing chapter 4 was a very complex endeavor. There is an astounding amount of information available about diabetes. Throughout the writing I struggled with finding a balance between complexity, redundancy, and providing enough information to facilitate understanding. Although this writing was more academic and less reflective, it was just as difficult for me to write. As I read and then wrote about the clinical aspects of diabetes I was forced to face the myriad of risks to which diabetes exposes me. Consequently, during the researching/writing of chapter 4 I realized that my own thinking about diabetes in general and my own diabetes in particular was undergoing a radical shift. I realize now that this reading/writing was essential in my process of learning to live with my diabetes. It was only as I integrated my understanding of diabetes as a disease entity that I could begin to understand my own experience of being diabetic. As I began researching and writing chapter 4, I was continuing to writing in my journal and I began to see a shift in my thinking about my diabetes. When I began the thesis, although I intended to include personal narratives, I expected that this section would be fairly limited -- similar in length to one of the participant narratives. However, as my work progressed, I began to explore my own experiences much more deeply. This occurred as a result of two interconnecting influences. First, as I was involved in hearing the participants stories and writing their narratives I began to see new possibilities for how I might perceive the world. For example, when I was first diagnosed with diabetes, I viewed it as a personal affront. However, I quickly saw that several of my participants viewed it differently. As Pat said, "so you do have to change your lifestyle but it doesn't have to be as radical as they used to say." As I worked with the transcripts from the interviews I began to see new possibilities for alternate perceptions. This resulted in a shift in how I looked at my diabetes. When I perceived it as an affront, I focused my energy on struggling to deny that changes were necessary. However, when I began to feel a sense of connection with others who have diabetes -- with my participants -- I no longer felt that I was alone. Consequently, I could begin to acknowledge the reality of my diabetes and to make necessary changes in my life. Secondly, as I read a multitude of research and information on diabetes, I continued a process of persistent reflexivity. I read the information and reflected on how it was relevant for me. As I connected with what I was reading, I felt the need to move deeper into the clinical literature. As I continued to review the literature, I came to an even deeper understanding of my own body and my experiences related to my diabetes. Thus, I gradually developed a combination of intuitive understanding, rational and cognitive knowing, and bodily experiencing of myself as a diabetic. This multilayered understanding was a process of realizing, possibly denying the realization, realizing again, and adding new realizations to old realizations as I deeply focused on learning to live with my diabetes. In a sense, I believe that my work for this thesis has had the effect of writing me into being a diabetic. Hearing the stories of my participants, writing their narratives, reading/writing the clinical literature about diabetes, and writing my narrative of the self have all functioned in concert to assist me to re/construct my sense of Self. As Brody, Witherell, Donald & Lundblad (1991) say, I could "continually locate and relocate [my] own voice within a social and cultural context" (1991, p. 263).

There is one final issue related to the goodness of a narrative which may be particularly relevant to personal narratives -- that of solipsism (Connelly & Clandinin, 1990). Solipsism is raised as a concern in narrative research when there is an assumption that the research is focused solely on the experience of the individual who tells the story. In these instances, narrative research is seen to be "naval gazing," useful only for personal reflection. However, narrative research also has a general relevancy. Through describing the particular experiences of the individual, narrative research speaks to the human condition. "The narrative contributes to knowledge... by increasing our collective knowledge of human experience" (Bakan, 1996, p. 5). Thus, what is described in narrative is not "merely subjective, that is pertinent only to a single reader" (Personal Narratives Group, 1989, p. 263), but potentially relevant to multiple readers in a multiplicity of ways. The author of narrative research makes meaning from the stories which are written into narratives. Readers will make their own meanings. Narrative offers a site for others to reflect on their own experiences (Helle, 1991). As Rosen (1988) says, the narrative is "left for possessive metamorphosis within the consciousness of each individual receiver" (p. 71).

I began this research hoping to write the stories of people with type 2 diabetes. I also hoped that other people with diabetes might read the thesis and reflect on their own diabetes. And finally, I hoped the lay people and health care professionals might be able to begin to imagine what it is like to be diabetic. Thus the narratives have the potential to create a place where:

> Doctors can imagine what it is to be their patients. Those who have no pain can imagine those who suffer. Those at the center can imagine what it is to be outside. The strong can imagine what it is to be weak. Illuminated lives can imagine the dark. Poets in their twilight can imagine the borders of stellar fire. We strangers can imagine the familiar hearts of strangers. (Ozick, 1986, p. 68)

CHAPTER THREE: AND THERE ARE MANY PATHS TO TREAD:

THE PARTICIPANT NARRATIVES

Home is behind, the world ahead,
And there are many paths to tread. (Tolkien, 1966a, p. 87)

There are over 100 million people with diabetes in the world (International Diabetes Federation [IDF], 1994) and, undoubtedly, there are over 100 millions paths. This chapter is comprised of seven of those paths, narratives of seven participants who describe their experience of living with type 2 diabetes. Reading of other people's journeys may be helpful in encouraging a reflective turn on one's own experiences.

Elsie: Dancing Through Life

My mother's mother died of diabetes when she was only 32. They didn't know what it was in those days. They called it the "drinking sickness" then. My mother told me she remembered her mother going to the sink and filling a jug with water and just drinking. And she died when she was only 32. But I never really thought anything about it. I know that it's in my family -- I guess I should have thought about it -- but I didn't. So I was surprised when I got diabetes. I was having bloodwork done for something else and my doctor saw the results and sent me for some more tests and it turned out I was diabetic. This was when I was in my 60's. I'm 87 now. I tell my family now to watch out. I tell my daughter, she's a nurse, "Now you watch it. You be checked." Because I know it's in the family.

I know I have to be careful. I don't want to go on the needle [insulin]. I have a friend who was diagnosed when he was quite young and he's on the needle. He read the riot act to me when I was diagnosed. And my doctor spelled it all out for me. The diet and what I should avoid. So I decided to do what I was told.

I don't have too much trouble with the diet. There were major changes to make in my diet because I liked the things I shouldn't have. The doctor and the diabetes education centre gave me a diet sheet and they taught me substitutes. But it didn't worry me too much because I adjusted to it. There are lots of things I like that I can have. Honeydew melons and oranges -- I love oranges. And I can have ice cream occasionally. But not every day -- perhaps once a week I'll have an ice cream cone. And nuts -- I can have nuts and I love that. So I don't really feel deprived. Except -- I do love chocolate. At Christmas I had a big Toblerone® bar. That's my favorite chocolate. I like the honey and nuts in it. But I didn't eat it all at once. It was a bit difficult because we had so much snow and I couldn't get out and the chocolate was there. But I tried to just have one triangle a day.

Sometimes I do cheat. I can't drink tea or coffee without sweetening. My doctor told me about Equal® [a sugar substitute] and usually I use it. And I also sprinkle it on my cereal. But once in a while I'll have a small spoonful of sugar. But if I do I cut something else out. So I compensate. I mean, at my age, what's the difference. My doctor said, "Don't deny yourself. It's not going to kill you to have an occasional indulgence." And when my doctor sent me for diabetes education -- I've been twice -- they said, "Don't let it spoil your life. Now and again you can indulge, if you compensate later on for it." And I've found that works. Sometimes when I cheat my friends will say, "You shouldn't be doing that Elsie!" And I just say, "Well, this is one time I can allow myself." Mostly I don't. I've been in stores and they offer me a taste of something and I just say, "I'm sorry, I'm a diabetic." I don't mind saying I'm a diabetic. It's a very good excuse sometimes. I don't need to hide behind anything. I think diabetes is one of the lesser evils. On the other hand, I don't think people realize how serious diabetes is. I have a friend whose husband had diabetes and he just did what he wanted and he ended up going on the needle. That was a warning to me. And a couple of weeks ago at a group I go to somebody spoke up and said it was something they weren't bothered about. I said, "You should be bothered about it!"

I'm lucky because I don't have any of the complications. I still have good feeling in my feet. I feel every little pebble. And usually I have very good healing, although I have had this problem with the skin on my arm. I don't have any problems with my eyes. I told my doctor I want to keep my eyes. Because I'm a big reader. There are over 3000 books in my house and I've read every one of them. But my eye doctor -- he's a proper eye doctor, too -- knows about my diabetes and he watches them. I'm going deaf but that's not from diabetes -- it's just my old age. But I know about the complications. I keep myself up to date. I was very interested in forensics when I was young so I can understand. I just plan to live till I die. But I don't want to live to see the new millennium, I really truly don't. I lived through the best of times because I lived through two world wars in England. It was war but even though it was a terrible time, everybody pulled together. It was fun in a way. It was a quieter time, in a way -- more gentle. I think it's been enough for me and I'm not at all afraid of death.

I don't do my own blood glucose testing. I object to paying thirty something dollars for those strips. So I just go down to the corner lab and have it done and it doesn't cost me anything. And they do a proper job. But I have occasionally had problems. I can tell when my blood sugar is low because sweat just pours out of me. One time I was having physical therapy for my arm and afterwards I walked to the hospital to visit my husband. Perspiration was pouring out of me. The diabetes education centre had told me to carry candy but I hadn't any with me. Then my daughter saw me and she said, "Oh golly Mom, your blood sugar is low. You're going to go into coma." And she got me a packet of sugar and I had that and it quieted down. But it's a peculiar sensation. So I know I've got to watch and be careful.

Actually, I'm really lucky to be alive. Because I did a very foolish thing. I went off my medication. You see, at one time I weighed too much for my size. I weighed 151 pounds and my doctor asked me to get my weight down. I knew I could do it. Until my feet gave out I'd always been active. I was a ballet dancer but now I have arthritis in my feet and it makes it hard to walk. But I knew I could lose the weight. I mean, I used to smoke 60 cigarettes a day and then I quit. So now I stay right around 125 pounds. I have for the last six years. So I thought that I had been so clever that I would see if I could go off the pills. Normally I take two glyburide and one metformin a day. So I went off for a month. After a while I felt so terrible. I was dizzy and then I'd go have a drink of orange juice. That made me think and so I decided to go have my blood sugar checked. And it was so high that when my doctor read it out he said, "You should be dead or at least in the hospital in a coma." And it's taken me three months to get back in control. So now I know I really do need the pills. It was a very foolish thing to do.

You know, dogs can get diabetes. A friend of mine had a little Lhasa Apso and he had to put it to sleep because it went into a coma from diabetes. That makes you think, doesn't it?

Pat: You've Got To Look After Yourself

I probably should have expected to get diabetes. It's in my family but it still shocked me. You know, it's my dad, my mom, my grandfather, my grandmother. It just keeps going down the road. My grandmother was insulin dependent. My mom and dad are both type 2. My grandfather was insulin dependent. And I have aunts and uncles with diabetes. None of my brothers and sisters have it. I'm the only one, so far. But I'm the oldest.

Interestingly enough, my sisters and I were saying just last year that there's nine of us and none of our kids are diabetics. It has missed the whole group of them. So it has missed all these kids but I keep thinking all my grandchildren are going to be diabetic. But my kids keep telling me they're not going to have any kids, so there you go. I guess I don't have that to worry about, right?

I had a hard time accepting it. I was saying, "Not me! Not me! Can't be me!" I went back and forth with it. I'd do what I was supposed to and then it'd be, "Oh, to hell with this. I've got to have whatever it was." And then I'd do that for two or three days. And then get on track again. I probably did that three or four or five times and then I thought, "This really isn't worth it. Who's going to get hurt in the end?" But it's hard when you've been a relatively healthy person and someone is saying to you, "You're sick." But you don't really feel sick. But I think since I decided to make the best of it, it's been easier. But it didn't happen overnight. I'd wiffle-waffle. I'd say, "I don't want this to be me." But then, it is me. And it's part of my life -- but it doesn't have to be all my life.

I felt I should know more about it. There isn't a book or a place where you can go and say, "I'm type 2. What do I do?" There's lots about type 1. You could learn everything about it. But you get a whole bunch of pamphlets and it's got all these things about type 1 and a little thing about type 2. It would be really nice to see a book or pamphlets or something that's just type 2. There's just not much out there that's easy reading, that's easily accessible and that's very easy to understand. Because people need to know how to look after themselves.

You need a good support system, too. Especially if you've been fairly healthy and all of a sudden someone's telling you you're sick. Well, you're not really sick but if you don't do something you will be. So that's a hard one to accept. It really is changing your lifestyle. You're thinking, "I don't want to do this. I'm happy the way I am. I like to do the things I do." But then, after you've done it and you start feeling better it's okay. But I wish there was some place to get support -- just support. Where you could talk about things. A place where you could just, kind of, drop in. Like when you're a parent and you go to a parents' group. You're thinking you're alone and then all of a sudden there's three people in the group whose kids did the same thing. It's such a help. It would be good to have that kind of unregimented support.

At the diabetes education centre, I didn't feel very supported. I think they scared a lot of people. They were pushing some really drastic changes. Like this one was saying you **had** to use skim milk. I'm sorry, but I would rather go without than have skim milk. Two percent or even one percent, I can handle that. Skim milk I can't handle. But it was like, this is what you **have** to do. And it's not realistic. To say you can't have coffee with cream and sugar -- at all. You might have to go to only one cup a day with a little less sugar and a little less cream in it. Or how about coffee with whitener and one of the sugar substitutes. Or milk instead of cream. And they were like, if you didn't do these things right bang on then you were really going to be in trouble. I don't think that's supportive.

When I went to the education centre, I got two different messages. The first lady was just, sort of, laid back. She said, "Well, you have this and if you just lose some weight and do some exercise you'll be fine." Then the next visit it was a different lady and she said, "Well, if you're a diabetic, you're a diabetic and it doesn't matter whether you're type 1 or type 2. If you don't look after yourself you're going to get really sick." Excuse me?? What's going on here? On the one hand you're getting treated like it's just a cold and then on the other hand it's, "Well, you're a diabetic now so you better take care of yourself or you're going to die!" So I was very confused.

When I first found out, I was diet controlled and then that just wasn't working any more. So I take glyburide twice a day and I take metformin three times a day. That seems to have it in control again. My blood sugars run around 7.0 mmol/l. If I get down to 4.0 or 4.5 or 4.7 mmol/l, like some people want -- I can't function. I'm a basket case with my blood sugar there. So my doctor said, "If 7 [mmol/l] is fine with you then 7 [mmol/l] is fine. You're a young person. Your blood pressure is fine. You're exercising. Your pulse is okay. You're a healthy person." So 7 [mmol/l] is fine with me.

My doctor told me that the most important thing -- it doesn't matter what day it is -- is that I eat breakfast. No matter what I'm going to do. Whether I'm going to do a five hour scrub [assisting during an operation] or a one hour scrub. I need to eat breakfast. He said, "You need a basis for your day and that's breakfast." Now that I've done it for a while, if I ever miss having breakfast, I really notice it. Even though I might only have a half a bowl of cereal, a piece of toast, some juice and a cup of coffee. It just starts my day now. Occasionally on the weekend we'll have pancakes and stuff. It's amazing what you can do with egg substitute. But there are some days when it's better to sleep for five more minutes than it is to make breakfast. So, you know, you go running out. So occasionally I will have something I shouldn't have because I need to have **something** to eat. But it kind of all works out in the end.

Some people ask, "Don't you get tired of the diabetic diet? You have to weigh everything." Well, I don't. They're more into eat healthy, now. You know, have your six fruits and vegetables a day. Don't eat too much fat. Things like that. In 1989, when I first found out, they were still into weighing things. They wanted me to have 1200 calories a day and it just wasn't enough food for me. I was hungry all the time. I was working and doing things and driving my kids around and I had to have some more to eat. But now they just say to eat within reason. So I very seldom have French Fries, I just about always have salad. And lots of the time I have the dressing brought separate so I know what it is. But every once in a while I want a Caesar salad. So I have a Caesar salad. I don't have a big one. I just have the regular Caesar salad and then I'm happy again for a few months. So you do have to change your lifestyle but it doesn't have to be as radical as they used to say. You just have to decide that you're going to cook a little bit differently.

In fact, my doctor told me that when you really, really, really want to have something, then have some of it. Just don't have all of it. If it's really going to drive you crazy then have a mouthful. So we went to a wedding a few weeks ago and this lady had made this lemon dessert. It was to die for. You could just tell it was good. So I had just a tiny sliver --and it was just so good. I was happy with that. I just needed to taste it. And then I was fine. But I do save my tiny little piece of pie -- unless I've made a diabetic pie -- for my birthday or a special occasion. And it doesn't hurt me to do that. I used to make cheesecakes and stuff for dessert. But I make desserts less now. And when I do I substitute. You can get two percent and no fat cream cheese and use that. The consistency is a little bit different and they have to stay in the fridge a little bit longer, but they taste the same. It's amazing, I make some desserts and stuff now out of the diabetic cookbook. My family doesn't even know the difference -- that I've used yogurt or that replacement cream, the stuff you just whip up. They don't even know the difference. My jam doesn't even have sugar in it anymore. I just boil it until it's the right consistency and then I throw it in the freezer. It works great. My kids say, "Oh gee mom, is this ever good jam. Is it different than last year?" I say, "No, same thing." So in the process they have been eating better, too. More fruits and vegetables and not as much meat and chicken and fish. But once in a while they've got to have their chips and gravy and ketchup. But it's not every day. It's not every week. It's every now and then.

It wasn't hard to stop drinking alcohol. I didn't drink that much wine anyway. It was really easy to give that up. Cause there's lots of sugar in wine. Very occasionally I'll have a glass of dry cider. And that does me for a long time.

Sometimes I've had some really strange questions or comments. Like, sometimes at work they order pizza. I don't have any because I've brought my dinner. I'll say, "Well, I've never really been a pizza freak anyway but I am a diabetic and I really shouldn't have this today. It's too fatty and it's too late at night and I really don't need it. My dinner is just fine." And they say, "Oh, I didn't know you're a diabetic. You don't look like you are." Well, what am I supposed to look like? Or someone will say, "You're too active to be a diabetic." Well, that's how I stay well -- by staying active. Sometimes at a tea at work people will say to me, "Oh, try one of those." And I'll say, "I can't have that." And they'll say, "Of course you can." And I'll say, "No I can't. I'm a diabetic." And they'll say, "No you're not." Okay! I guess I'm not?!? Or they'll say, "Well, it's Christmas time so it won't hurt you." Why is it different at Christmas? Somebody else asked me how I got it. And these are nurses! Sometimes I am tempted to say, "Well, I just picked it up off the street." The questions can be so bizarre.

It was hard, at first, to say, "Could I have my dressing on the side?" Or, "What's in the fish?" It was like I was telling the whole world I was a diabetic and I didn't want that yet. It doesn't bother me now, but then I didn't want anybody to know I was "sick." Because you don't want to be treated differently. You don't want to be labelled. I think that's why people don't want to say what they are. We're all people and we all have different feelings about being diabetic. And we shouldn't be labelled just because we are diabetic. Everybody is an individual. But people seem to want to label all the diabetics together. And we shouldn't be labeled.

I don't have to check my blood sugar every day any more. I can do it four to five times a week. Because my hemoglobin A1c -- for three times now it's been in the normal range. But if I'm sick -- if I've got a cold or the flu -- then I do it at least once a day. And I do notice that if I get sick my blood sugar goes up. Once I had the flu and a cold at the same time and it ran around 20 mmol/l for two or three days. I don't get sick very often, thank goodness. But if I do, I notice that I feel different than I used to.

When I get hyperglycemic, I get a headache almost instantly. That's how I found out I was diabetic. I mean, I know it's in my family. I hummed and hawed about it for months. I'd do little things like not have as much sugar and stuff. I wasn't prepared to give in yet. But finally I went in for a physical and my doctor ordered a blood sugar. It was 18 mmol/l! The office phoned me and said, "The doctor needs to see you tomorrow and it's very important so make sure you're here." And it didn't even hit me. I was thinking, "Oh my God! He found a lump or something." I didn't even think about diabetes. So by the time I got there at four o'clock I was a basket case. I told my doctor, "My God, she scared the hell out of me." And he said, "Well, your blood sugar is a bit high but you're not going to keel over or anything -- unless you keep it at that." That's how I found out. I don't remember what he told me the first time we talked. He told me I was type 2 and I know he talked to me for about 45 minutes. I have no idea what he said. When I saw him the next time I said, "What did you tell me again?" And he said, "Well, I told you all about it." I said, "You must have been talking to a wall. I don't remember anything."

I've had a couple of people say that I'm lucky because I'm just on pills. I guess if I have to be on something, I guess that's better. But I don't like either, thank you very much. I really do hope I never become insulin requiring. I don't want to give myself needles and test more often and that sort of stuff. But if I did need to I probably would. I'd say no for a while and it wouldn't work so I would do it. It's like so many things -- you say you wouldn't or you can't -- and you do it anyway.

The first time I felt low [hypoglycemic] we were really, really busy at work -- we were just going. All of a sudden I thought, "God, I'm feeling dizzy." And then I thought, "Did I have lunch today? Did I? Yes I did. No, I didn't finish my lunch!" And I went and got a can of juice and had half of it and in five minutes I was like a different person. In some ways it's kind of scary. I think you feel worse when it drops than when it goes up. I don't usually have any problem doing long scrubs -- not if I have breakfast. But I carry my dextrose [sugar] with me. I think one day when the scrub was seven hours long I was getting a little low. I said, "Somebody go find me some juice. That'd be good."

It is kind of scary -- the complications. I was talking to one of the anaesthetists and he said, "Well, you look at this person. We're doing surgery on this guy and he's diabetic. He still smokes. He doesn't do any exercise. He doesn't look after himself. So he's not doing any of the things to make himself better. He was told, when he walks, to make sure he has good shoes and good socks and not to get sores on his feet." That's what we were fixing -- his feet. They were gross. I mean, I understand that diabetics don't heal as well, but this was neglect. And I thought, "You silly bugger. You're not that old. You've got to take care of yourself." And it's not really such a chore. You improve your way of eating and you can live a normal life and you can do the things you want to do. That's what I do. My husband has a cousin who's insulin dependent and he just lives the way he wants to live. If he's going out for dinner then he takes more insulin -- which is not really good. He's 56 and he's got retinopathy. He hasn't really protected himself. It's like, "Well, I've got the beast and it can do what it wants." I see enough things at work that happen from diabetes every day. And I think, "Oh God, could that happen to me?" So you worry about it a little bit. I realize I have to look after myself. I realize I can't have chocolate. I mean, I have to look after myself. I don't have a problem with that. But I asked the guys [the doctors], "Is this really serious? These things aren't all going to happen to me, are they?" And they said, "No, you're type 2." Well, where does it say that? So I thought in myself, "Well, I'll keep my blood sugar where my doctor wants it to be." And I feel fine and I sort of have to go with that. I don't know if there's anything else to do.

I guess in one way it was a good thing that it happened to me because I eat much better. I watch what I eat and I watch my weight. I still carry ten extra pounds but my weight has stayed the same --give or take a little bit. But it was hard to accept that it was me. It took months. I suppose what it's done for me -- it's kept me younger. I can still ski with my daughter. I can still take my walk. I can still do my hiking. And I'm not really that tired. I can't do everything I used to be able to in a day. That frustrates me, but that's just age. It has nothing to do with diabetes.

People don't understand this doesn't go away. My husband says, "Well, the doctor's got you on pills now. Your blood sugar is fine. So you're fine." But that's a non medical person. I told him, "You have to remember, if I get really dizzy or I faint, or something, just give me orange juice." He says, "Oh yeah, okay." I said, "I'm serious. I'll always have orange juice in my pack -- or some kind of juice. So feed me orange juice. If in doubt, give me orange juice." Because you never know what might happen.

It was interesting how the kids reacted. My youngest one, she was eleven then -- where did she pick up her concept of what a diabetic was? -- her first thoughts were, "How long are you going to be here? Does it mean you're going to die? Is it like cancer?" I told her it's not like that at all. My son teases me. He'll say, "Mom, are you all screwed up because of your diabetes? Is that why you're treating me like this? You must have been mixed up last night when you said I couldn't have the truck." Yeah, right! But they know what to do. I didn't want to scare them but they had to know what could happen. And I also told them, "If in doubt, phone 911 and they'll tell you what to do."

I'm allergic to metal so I can't wear a medic alert bracelet but I do carry a card. And that's the first place they look, if something happens to you, in your wallet. Well, if you open my wallet it's right there. I tried two or three bracelets but I just got a rash and an itch -- it just wasn't worth it. So I do have a card in my wallet and a thing in my truck that says I'm a diabetic.

In May we're going to hike the Grand Canyon. I've been talking to people and they said because of the change in altitude and the long hike that I want to keep my blood sugar up. And it's so hot that I need to take sugar replacements. My doctor said, "For this trip you're not going to worry about how much sugar is in it. Whatever sugar is in it, you're going to need it." So I can have things like trail mix and peanuts -- all the things I don't get as often. But there are people who say, "You're going to do that? Are you sure you're going to be okay?" I say, "What?!? Don't say because I'm a diabetic I can't do it. I'm not stupid, if there's a problem I'll ride a donkey out -- I'm taking my plastic[credit card]. But my intent is to hike in and hike out. I'm not going to quit doing things just because I'm diabetic."

It's got good points and bad points. I don't have a problem that I'm a diabetic any more. That's what I am. But it's not my life. I don't want to focus too much on diabetes. I think as you get older you need to take care of yourself. And if you don't take care of yourself then you're going to have a lot of these problems. Not just being diabetic. There are all sorts of problems you could get into because you're not looking after yourself.

Sheilagh: I'm Not Mrs. Perfect

I have found that diabetes educators tend to have a belief that people react when they find out they have diabetes by asking, "Why me?" I think they stereotype. Well, I didn't react that way at all. I was about 59 at the time and my reaction was, "Well, I've had a good run for it." I've never had any physical problems. Very few people get through their lives without something. I wasn't jumping up and down saying, "Oh goody! I've got a chronic illness." But I had been feeling terrible for so long that I was relieved to have a name for it. And besides -- Why not me? When I went to the diabetes education centre other people had different reactions. Lots of different reactions. I think everybody uses their own psychological approach to life.

Anyway, I had been feeling terrible for probably a year. I didn't have thirst. I had a combination of exhaustion and fatigue -- they were two different things. And literally, I was just pulling myself along from day to day. I was going in to see my doctor. He seemed to feel generally, although he was too kind to say so, that the trouble was in my mind. I got very desperate and all of a sudden one day I realized he wasn't going to help me. He didn't know what to do. So I thought, "I'm going to have to do it myself." I didn't really know where to start but I knew my brother had diabetes so I thought, "That's where I'll start." I went to the library and went through all the books on diabetes looking for symptoms. All of a sudden I was looking in this book and it said, "Itching" and I thought, "That's it!" I had been having itching like you would not believe. I mean, it was terrible -- it made me want to scream. So I phoned my doctor and said I thought I should have my blood sugar checked. He sort of said, "Well, if you insist." I went and had it tested that afternoon and at eight o'clock the next morning his nurse called and said the doctor would like to speak to me. My blood sugar was 25 [mmol/l]! So that's how I found out.

When I was diagnosed, my doctor just put me on glyburide and handed me a diet sheet. He said the diabetes education centre would contact me and then he went on holidays. This was in July and I didn't hear from the centre until the beginning of

September. But I was taking the glyburide and I was on this diet and I was exercising. When I got to the diabetes education centre they were taking our blood four or five times a day. My blood sugar was down to 2.1 [mmol/l]! They were pumping me full of digestive biscuits. But I wasn't feeling any hypoglycemic reaction at all.

When the diabetes education centre saw the diet sheet I had been given they went, "Tsk! Tsk!" It wasn't the acceptable diabetic diet. It went back to an older era. So I threw it away. But I wish I had hung onto it. The food was much more interesting and it was easy for me to follow because the food tasted good. It just wiped the sugar out of your diet which was not, for me, the real problem. Now they're into no fat, no nothing and I can't do it. It demands that I be Mrs. Perfect and I can't.

I found out about self blood sugar testing at the diabetes education centre. I don't think my doctor then knew anything about it. At the centre there was a doctor who came to talk to us. I asked how often I should check my blood sugar. And she said, -- I guess because I had kept my blood sugar down so well -- so she said, "Every six weeks or a month." I did that for quite some time. But that was not really good. You know, what if you slip from your diet or you're not getting as much exercise? So now I generally do it more often. Sometimes I'll test myself six times a day for a couple of days. Just to see that the balance is continuing. But I don't always do it that often.

You should have seen me the first time I had to poke my finger for a blood sugar. I was working at the time and I sat there at the kitchen table and I looked at the bloody thing and I just couldn't bring myself to do it. But I didn't have a lot of time. I had to get it done and get off to work. As I sat there I finally thought, "You know if you had to tell anybody about this you would feel very humiliated." So I did it. Once I did, it was really a nonissue. But I still can't do it on my little finger. I get a real pain in there. So I use my thumb instead. The skin is rather thick and callused but it's better than suffering. I'm a slow bleeder anyway so it's a real pain doing it. I have to hold my hand down and rub it and even then I don't get that much blood out.

One of the annoying things is that in order to get Pharmacare coverage [of diabetic supplies] you have to go in every few years and prove that you can run your glucometer. Now think about it, I run a business from my home. So I have to stop and take my twenty four dollar an hour time and go in to do this. It takes the nurse -- how much does she get paid? -- probably half an hour to administer a test to prove that I haven't forgotten how to ride a bicycle. That's what it amounts to.

I've been running my own little research study lately. Because I don't want to go on taking metformin. I wanted to check to see how well it is controlling my blood sugar --it isn't. I've been testing the metformin with exercise, the glyburide with exercise, nothing with exercise and so on. I've got about six days or a week of results. The glyburide is the best in terms of keeping my blood sugar down. Taking nothing and exercising is second best. The metformin is the worst. So I have an appointment with my doctor on Thursday and I'm going to take this in for her to review. I wouldn't go on with the metformin anyway. There's no reason to spend your life between the living room and the toilet. I get an almost convulsive diarrhea. Where ever you are you <u>have</u> to get to a bathroom and its very inconvenient. [One of the primary side effects of metformin therapy is diarrhea (Canadian Pharmaceutical Association [CPA], 1998.)]

I also have another problem I haven't resolved yet. My waking blood sugar is higher than the blood sugar I went to bed with the night before. Quite noticeably -- about two and a half points. My doctor thought that my liver is making glycogen [a common problem in type 2 diabetes] so I tried snacking at night but it didn't work. Well, it may have made some difference but not enough. But even though my fasting blood sugar is high, as soon as I get onto my daily schedule it comes right down. For example; this morning I had a fasting blood sugar of 8.7 [mmol/l] but an hour and a half after my breakfast I had a blood sugar of 5.5 [mmol/l]. I don't know what the answer is but maybe I'll be able to find out something.

I went to see a nutritionist because I have a great deal of difficulty with the diet. What I really wanted was to talk to somebody who could tell me how I could best fit my appetites -- by that I don't mean just my appetite but the various foods that I particularly like -- into a diet that would help keep my blood sugar down. But there were problems. First of all she was incapable of thinking of it otherwise than as a weight loss thing. Which might have been legitimate, but for me it was secondary. So when I mentioned to her that I really enjoyed cheese she was disapproving. What I was supposed to do was stop eating cheese -- cheese has fat in it. She looked at me as though this desire of mine to have some Gorgonzola was absolutely mad and if I was the right kind of person I wouldn't have these desires. And it's sad because there were any number of helpful things that she could have said. How about, "Let's go over a range of ways you could do it. Maybe you could let yourself have cheese on the weekend, etc." That's what we did with our kids and candy when they were growing up. They were perfectly happy. That appeared to serve their need for candy.

I don't really have any of the damage that can happen from diabetes. As far as one can tell. I had my kidneys tested and they are functioning really well for my age. I have no loss of feeling in my feet. I do have cataracts forming in my eyes which could theoretically be encouraged by the diabetes. But considering my eyes and my age, that's not too likely. So somehow, over the last seven years, I've been doing enough of the right thing. And possibly I've been lucky. I do know exactly what all the complications are. My brother got all of them before he died and they were awful. He wasn't well controlled although he told me that he'd, "Had his blood sugar under control for years." But he had never taken his own blood sugar. He went to a lab once a month -- max, and had bloodwork. And he thought this was enough. Well, your blood sugar goes up and down, up and down, up and down all the time. I don't think he ever really had a clue about what was going on. And I don't think he wanted to be informed: He wanted to be made better. Anyway, his complications really brought it home to me that I don't want to have these kind of things. He had neuropathy in his gut -- I didn't even know about that possible complication -- and he was incontinent in every possible way. It was very hard for him because he was very conscious of people's opinions of him. So I definitely don't just wander around gaily, not aware of what can happen. And I am absolutely aware it is my own responsibility. But I'm not Mrs. Perfect. I'm doing at any given time what I can. I just have to hope. I do exercise regularly. And I do generally try to adhere to my diet. But sometimes I just really say, "The hell with it!" So I just have to hope it's enough.

I actually think the diabetes educators are too careful. They don't want to make you feel bad or scared. And they don't want you to make diabetes the whole focus of your life. But sometimes terrifying people works. I was a very heavy smoker and then my kids went to school. This was when they were starting to brainwash kids against smoking. They showed them pictures of the lungs of people who were smoking. And my kids were terrified that mommy was going to die. That's why I quit, basically. I mean my kids were terrified by it. And so, terrifying people works. And I don't think most people with diabetes have any conception of how totally it can take over your body. Maybe they should know.

I've really had to struggle with the diet. Sometimes all the pressure on being "good" can make me feel very, very uncooperative. So I say, "Don't try to change totally from the diet you grew up with. That's asking too much of yourself. The best thing to do is work with what you have. Take a good look at your own tendencies." One of the things I do -- I'm a cheese lover -- and what I will often do for lunch is get some French bread and some of my cheeses. I will have a little nip of this and that. After a certain period of time I really feel that I've had a very pleasant meal. And it falls considerably short of what I might have eaten if I had been trying to adhere to a diet that said, "At this point you can have one slice of bread with half a teaspoon of butter."

I don't know how many people lead the kind of life that allows them to work out this exchange business. Especially in terms of saying, "Okay, I'm going to eat this many calories at this meal and they have to be broken up in this way." It just doesn't fit with my world. I'm almost always busy. I visit grocery stores on my way to and from other places. So suppose I reach 5:30 and I'm really tiring out. And I realize I only have one vegetable at home. Am I really going to stop at the grocery store and then go home and cook? Also, I think trying to follow that regime ends up with you thinking as a "diabetic." In other words, it's good to think about your condition but it should be in the context of being a normal human being and this is part of who I am.

You know, up until I was twenty one I was skinny. I was really skinny. I looked really skinny. And this was in the day of Shirley Temple -- with dimples everywhere. And my parents really worried because I didn't look the way nice little girls were supposed to look. But when I look back I was full of energy. I was always off doing something or other. I wasn't very interested in food. So there was absolutely no health reason for my parents to worry about it, but they did worry about it. Then when I went to University I was 5'8" tall and I weighed 117 pounds. I was still perfectly healthy. I had to take a medical in my first year -- everybody did. And the doctor told me to put on more flesh. He said, "eat all the candy that you want and when you're having meat, eat all the fat off the meat." So I guess at some point I started to eat. And you know, now they link type 2 diabetes very closely to obesity. So I would have been better off to stay skinny. Because genetically I come from a fat family. It is simply a fact that on both sides of my family there is a tendency toward fat.

I have a lot of questions about diabetes. And the idea of leaving it all up to the doctor never crossed my mind. I want to know about how my body is working. And besides, there's no point in constantly going in to your doctor about the same problem. The doctor can help with specific problems but in between that, you've got to do it. I can go to my present doctor and tell her how I'm doing. I can say, "I've been doing really badly." And that's okay because she knows and I know that it's up to me. The bottom line is, I'm the one who's living it.

Xandra: The Hardest Thing To Learn Was Balance

I found out I had diabetes at my routine physical two years ago. I found out a few other things, too, so it took the edge off finding out I had diabetes. High blood pressure and having an enlarged heart were more shocking. The biggest stress was the blood pressure, strangely enough. I was in a state of shock for probably three or four months --. just having that whole conglomeration of things thrown at me at once. And I was angry with my doctor because my blood pressure had been up a couple of times before and he'd been passing over it all the time -- and then, all of a sudden, finding out he'd been letting it go so long that my heart is enlarged. I had all these things to deal with and it took me probably a year to even feel comfortable with the challenge of trying to modify my diet in so many directions.

I do have a glucometer -- a really nice little one. I use it strictly when I'm not feeling well. If I don't feel well, I check my blood pressure to see if my blood pressure's off. I check my sugar to see if my sugar's off. And then I say to myself, "Okay, if both of those things are reasonable then I probably am sick and I should go to the doctor." I do them as a check to make sure that I'm not just running to the doctor for something I could figure out myself.

I did check on a daily basis for a while. Until I got a pattern and was convinced the pattern wasn't going to change. My fasting blood sugar was in the 6.8 - 6.9 [mmol/l] range when I was diagnosed. It's still staying around that -- it's usually under 7.0 [mmol/l] when I take a fasting reading. I'm not a very severe diabetic. I would imagine that if I lost some weight maybe I could even be under the line.

I think I focus a little bit more on the heart and the blood pressure because that is harder to keep in line than my blood sugar. And yet -- you know, when my blood pressure is up -- if I know I'm under stress -- I purposely don't go to the doctor until I know I've brought it down, or given it a chance to come down. Only if I find it up on a regular basis will I bring it to his attention, because I don't want him to increase my medication unless I really need it. The same thing, I think, would hold for blood sugars. I do it once in a while to see if I'm still in the same ball game. And I don't want to go on medication if I don't have to. It's in the back of my mind that I want to keep an eye on things.

Occasionally I find that I get really low blood sugar. Even though I don't use pills just diet. If I don't eat -- if I'm running around and stuff and I don't eat -- I find all of a sudden that I get low. I feel shaky. I've learned to ask for orange juice -- one glass will do it for me. Now I've never been in a position of having my kit with me to be able to really measure it. But since sugar will clear it up I assume it is low. It's only happened to me maybe two or three times.

I have very dry skin and I have a lot of itches. You see, I also have low thyroid and the combination of the two is the problem. After two years I have finally realized this is a diabetes related condition. It has been a really miserable condition to deal with. The itching is a real distraction and the next thing you know you're scratching where you shouldn't be scratching in public. Before I realized it was just dry skin I used to go around scratching my arms all the time. I'd be talking to people and not realize what I was doing. I was not conscious of it. I find it most frustrating because you can't really solve it. I have used a special soap that has moisturizer added but no scent in it -- and it has tar in it. I have to oil my body very freely. This was such a big shock to me because I used to have oily skin. I never even had hand lotion in the house. Now I have to moisturize head to toe.

I was already familiar with the diabetic diet because my husband had been a type 2 diabetic and his was more severe than mine. So that didn't impact me as much as it could have. I already knew about a lot of the foods and the artificial sugars and the diet foods. But I also have to try to reduce fat and salt -- because of the blood pressure. So I'm trying to prepare food that has no salt, no sugar, no fat. That has been the hardest thing to find my way through.

I went to about three nutritionists. One was this girl who has a degree in foods or something. She was terrible. She just kept handing me computer printouts on analyzing my diet. And all she told me was that I wasn't eating enough -- calories I guess. I'm not eating enough calories?!? And of the calories I was eating, too many were fat and not enough fruit and vegetables. And I thought, "Honey, I already knew that and I'm paying you $85 for this?!" What I had asked her for was specifics in terms of how to prepare food with no sugar, no salt, no fat. It was easier for my husband. He didn't need all the salt and fat reductions. He just needed the sugar reduction. Since I learned it for him they've changed somewhat so I had to buy some new books.

I tried the Dean Ornish cardiac diet -- it's absolutely strict. You only have about 10% fat. But I found I couldn't stay with it. So I'm back to a modified diet. I'm not cutting anything out, but cutting everything down.

One thing I find difficult with the diet is that the nutritionist will say you get so many of these kinds of foods, and so many of these kinds of foods, and so many of these kinds of foods -- in a day and you can spread them around the way you want. Now it's very easy as long as you're eating **a** potato. But if I'm putting potato into a mixed dish then I find that very hard to measure. And I don't eat that much of individual things.

I'm not that good at my diet, to tell you the truth. I don't measure like I used to with my husband. I used to measure everything. I never had a problem with the meat. I was supposed to eat three ounces and my husband was supposed to eat four ounces. I was able -- in almost any kind of meat -- to tell how much I should have. But when it came to portions of vegetables -- with each vegetable being different -- I used to keep a list on the fridge for my husband. It had the freebies and everything. It was always there for him. But I don't like vegetables. I don't eat vegetables. Well, I'm having to learn to eat vegetables and fruit in place of sweets. I have to talk myself into veggies. I like peas and corn and carrots and I love salad. But in some books peas and corn are in with the starches instead of with the veggies. I particularly don't like broccoli or cauliflower or any of the foods that have a little bit of bitterness in the taste. In fact, I hate them so much that if I go out to somebody's house for dinner I'll just pass them right on. I know that I'm being rude but I think it's better than upchucking all over the table.

I'm really terrible with my eating habits and food is a real headache to me. I've tried recipes but then people always stick in there something like broccoli and artichokes and liver and spinach. So I do have a problem. But I like salads and I've really been delighted with those ultra low fat dressings. There's some people who really don't like them but I like them. I started out with light and now I've gone to the ultra light.

Another problem -- when I dieted before I became a diabetic -- I got down to 150 pounds from around 200 pounds. When I was hungry I would have fruit juice. But they have sugar and salt. So between the diabetes and the high blood pressure I'm really limited now to the amount of juice I can drink. But you see, I don't really enjoy eating an apple. I like the taste, but -- I just have to be in the mood to eat an apple.

I must admit that the diet food has been something that absorbs a lot more of my time. I spend a lot of time thinking about what to make and what to eat. For a while I wasn't eating prepackaged foods. I made everything myself. I was making my own homemade soups and stews and things and putting them in the freezer. So that I would have prepared foods -- homemade prepared foods. But I just found I spent all day in the kitchen. And since my move -- Its only been three weeks -- I have been buying more prepared foods.

I am much more conscious of food. Specific occasions when I'm a guest and somebody else is preparing the meal I have to think to myself, "All right Xandra, is it worth it to say something or can you find a polite way to say no? Or maybe I'll have half -- because I can always blame it on my weight instead of the diabetes. Or is this a situation where I have to be nice to this person or they'll be upset so I'll go along with it this time?"

The hardest thing is when I'm out. You can go to some restaurants and have no trouble at all finding the right kind of food. But you can go to others and it's deadly. And if there isn't anything good on the menu then I blow the diet. It's even harder with the fat -- it really is. And I do decaffeinated coffee because of the blood pressure -- and some places don't serve it. BC is very good. I was in Ontario when my mother was ill, and it was very difficult. I would say of any ten restaurants I went into -- maybe one would have a low fat meal and maybe two would have decaffeinated coffee. And you'd be surprised how many times in these restaurants, they put sugar in simple things like soups and sauces. It's the multiplicity of the problems that gives me fits.

If people start telling me to eat or not eat -- on occasion I've been known to be rude. I don't think it's anyone's business but mine. But I find that people are more respectful now. There's been enough written and said and done that people are better. People are saying no to sugar and fat and booze and coffee -- so I think people are much better.

I have heard that everybody should have a chronic disease -- because you do tend to think about taking care of yourself. It just happened that I wound up getting three of them at once. But I suppose it's very true. Because until then, when I had aches and pains I would tend to neglect them, or forget about them, or not worry about them. "Oh, I'm all right." So I think it does make you a little more aware of what's happening to your body. You're listening to it more carefully.

I do a lot of exercise -- every day I do a half hour of aerobics. And I feel good about how much better I feel now. I mean, a year ago I was using a walker. I had to use a walker whenever I went anywhere. So this is a big improvement.

I have a nursing background so I know about the complications. I don't think a lot about them but it's one of those things that is vaguely in the back of your mind. I watch my toes very carefully. Or if I cut myself I just watch to make sure -- but I find that I'm not slow healing. I've been checked out for the heart, too. Because I have so many of the preconditions for a heart attack. They put me through the whole caboodle. And when I go in and have my eyes tested, I make sure that I have a medical doctor. I probably pay more attention than I would have if I were not a diabetic. But I don't think about it all the time.

One thing I really hate. When you go to the specialist -- eye or ear or whatever -- and I have all these things to tell them about. I hate that. I'm really selfconscious because I've got all these things wrong with me. I guess I can't stop thinking that part of it is my own fault. Like feeling if I lost weight I would probably clear up a lot of these problems. So I'm feeling guilt.

One of the hardest things to learn was balance. I knew that stress was behind a lot of things. Now stress isn't really the cause but stress is the aggravator that brings them on. And I realize I have had a stressful life. When I was a single mom and I was dealing with a lot of stress -- I was a single mom with three kids and I went back to school to get my degree -- and I used to think to myself, "You know, I'll bet you I'm not going to have as smooth an aging process as my mother." Because my mother was allowed to stay home and while she had problems she never had the kinds of things to deal with that I've had to deal with. And I believe that I'm probably going to live more of the man's life span than the woman's life span. I just think that based on my own self and my observations of the people who have had very stressful lives. So getting the balance was a very difficult thing. Also, its very humbling. Because you realize where you thought you were superwoman -- you aren't.

John: I Like To Ignore It, As Much As I Can

I was diagnosed four to five years ago. I found out about it by visiting my doctor with an unassociated problem. I hadn't seen him in quite a long time so he suggested I have a physical. I left the office with him saying, "Get out of here, you're 100%." Then I had a call the next day saying, "Come back. I need to talk to you." And they had identified by my urine sample that I was diabetic. It was confirmed the following day by a blood test. I guess if I'd thought about it I did have symptoms -- urination at night. And I did have thirst but I wasn't really aware of it. And I was trying to cure that the wrong way -- by drinking either milk or orange juice. I could drink a pint at a time.

I was angry! I was so angry! I started to exercise my body as hard as I could. I was already quite active but I increased that -- because I don't like medication. So I started jogging, actually jog/walk -- six miles a day -- sometimes twice a day. At first I was walking very fast. Then I began to walk the distance between two lampposts and then run to the next lamppost. Then I stepped that up to walk a lamppost -- run two lampposts. Some days I'd just run until I couldn't run anymore. I exercised a lot. I was dealing with the anger in that way. I was bloody angry. Why me? -- after being healthy and active. But then -- I've always wondered if my over consumption of alcohol had much to do with destroying my body? I don't have an answer for that. The doctor I have thinks that if you have more than two beer a day you're tending towards alcoholism. But the era I grew up in you finish work and it's time to unwind. So you go to the bar. I have cut down. But in the last couple of months I find I'm drinking almost daily. I think it's being bored and retired. So I have to think about that.

I did take my weight down. I was probably 182 pounds and now I'd say I'm about 175 pounds. I don't weigh myself very frequently. Actually, my doctor told me he wanted to see me at 165 or 162 pounds. I said, "You've got to be crazy! Number one -- I feel good. Number two -- I'm starting to feel weak where I was feeling good. I'm not going to do that. I'd be like a walking candle." I'm not fat and I feel good and it's not an exact science, anyway.

I'm not worried about them but I am aware of the possibility of complications -- like losing your toes and going blind and becoming sexually impotent and kidney disease. Yeah, I know about them. I don't think I'm a stupid person but life goes on. I'm going to get even more angry if I lose toes or become blind -- but what can you do? I'm not playing with the risk of complications but I do feel quite satisfied that I am as healthy as I can be at almost 60.

I hate going to the doctor. I avoid him. He's a very good doctor. I just hate going to doctors. So I had a pharmacist who was just refilling my prescription. Finally he declared that he couldn't fill it any more times for me. So I had to go back to the doctor -- that was after about two years. My blood sugar was 10 [mmol/l] and my doctor gave me a prescription with three more refills. So presumably he's happy. I think they like you in the 6-7 [mmol/l] range. But my, maybe, convoluted thinking says, "Okay, he's happy. I'm happy." I don't feel affected. I don't have any symptoms that I'm aware of. So I just like to carry on as best I can without going into higher doses of medication. I guess if I was a different kind of person I'd attend the doctor more frequently and let him nag me. But I just don't have that kind of relationship with my doctor. I don't want to go in and cry on his shoulder all the time. I've never found it necessary to do that. I stay away from him.

I did become aware of my diet. Which I didn't think was that bad. My wife and I went to a nutritionist. I hoped that diet and exercise would do the trick for me, but it didn't. So I started off with half a 5 mg tablet of glyburide a day. I went for bloodwork once a week but the medication dose kept going up. Now I take 5 mg twice a day. The blood sugar didn't really go down very fast.

I did make some changes in my diet. I eat minimum eggs -- minimum fat -- lots of veggies. I've forgotten the exchanges now. I practiced them for a while but there was nothing in there that was different from the diet I was used to. I did cut out quite a bit of red meat. I wasn't inclined to eat a lot of desserts. And when I did they were usually minimum sugar -- like fruit. So what I did was stop sugars absolutely. I don't eat cakes or candies anymore. Before, my brown bag lunch usually contained a candy bar and in the evening my wife would occasionally feed me chocolate rosebuds, or whatever. But I gave those up. It really wasn't a drastic change for me. I didn't have a problem with it. I identified where the sugars were and I just cut them out. I think I'm regulated now to the point where I know how much I should have and its just an automatic thing. I don't overeat. And most of what I'm eating is of a healthy nature. I guess I am more aware of what I'm eating than I ever was before. But I think I ate a pretty balanced diet before, too.

When I eat out I enjoy Chinese food. I reconcile within myself that they use minimal amounts of meat. Some of the sauces may contain sugar but it's not an excessive amount. And its loaded with veggies and rice. So I've worked that out.

Initially I tested my urine for sugar using strips. I would cut them in half because a friend of mine who is also a diabetic said that was the cheapest way to do it. But I found it difficult to do them. I gave up testing quite a while ago. When it seemed there wasn't any improvement I got tired of doing it. And I was bound and determined to solve this on my own. I don't want to pay 80-100 bucks for a glucometer. And the strips are also expensive. You're a captive audience -- it's ridiculous. I would resist doing it. Besides, if I were to test my blood every day I would become more concerned about the diabetes than I am by carrying on feeling normal. I think that would bother me more. So I like to ignore it as much as I can.

I did hide my diabetes for a little while. But I have no problem these days saying, "I can't eat that because I'm a diabetic." It doesn't bother me. It did in the beginning but it doesn't now. I've reconciled that within myself.

I hope someday that we will have a patch for people who have to inject themselves. I don't think I could inject myself every day. I think I would have to find an easier way out of this world than injecting myself with insulin every day. But lots of people do it. I'm not sure what would happen if I had to face it.

I didn't know of any family history of diabetes. But just before Christmas I was visiting my Mom in Scotland. She had just been identified as borderline diabetic. But who knows from 20 - 30 - 40 or more years ago? Who was diabetic and was just going along - hadn't been diagnosed? Because I could have gone along for who knows how many years until I wasn't feeling great and had to go visit the doctor. So who knows?

Graham: I've Got to Get Regimented

My parents came over to visit me from England and I was drinking all this water with the meal we were having. I drank something like thirteen glasses of water. And my mother said, "That's the first sign of diabetes." She knew because apparently since I've immigrated to Canada my father has got it. He's 73 and he's just taking a very small dose of the drug. And then, like a month later -- BINGO -- I found out I had it. I don't remember feeling tired or anything. But looking back, I was drinking a lot.

I was diagnosed in either August or September -- officially, I think it was September. I was quite amazed that I got diabetes. Because until I had two knee ops [operations] I was as thin as a lath. And I used to work -- before I came to Canada I would work between 60 and 85 hours a week. And I'd still find time to play two games of squash. I was running up fire escapes and ladders and all sorts of thing. So I was quite surprised!

When I got told that I had diabetes, as I went out of the surgery [doctor's office] I thought, "Why me? What did I do wrong?" I walked about ten paces, stood at the curb and waited for the traffic -- maybe 15 seconds -- and before I got to the car I thought, "You've got it. You have to deal with it. Let's get on with it." Well, there's only me that can deal with it. I can't go and get somebody to deal with it for me.

I feel sorry for anybody who's suddenly been given this and is facing the same problems I did. I was just smacked in the face. I know how I felt when I was waiting to get to the diabetes [education] course. I'd say to my G.P., "Hey, I don't know what I'm doing here. I'm just waiting." I felt lost. And anyway, I feel knowledge of this is not great. And what there is around, is confusing. I find some of the books that I've tried to read too confusing. They don't really speak to you. They are rather too clinical or too medical. I saw a video that the American Diabetes Association and some famous sports person did. I got it sent from the Vancouver Library and borrowed it. I turned it off after about twelve minutes. I couldn't watch any more. I was frightened to death.

It's funny, I've never taken sugar since I was 15. Maybe even 14. I just got up one day and said, "I don't want it any longer." I'm not a dessert person. My brother and sister are. Myself, I was never that way. Nanaimo bars, cakes -- I've never bothered with them.

I'm a night time person. Always have been. I can go all day without eating. I'm amazed at people who say, "I haven't eaten for four hours. I'm starving." You see, I've always had this ability to get up and just have a coffee. And a tea in the afternoon. And then at six o'clock -- not really even then. No, I'll eat at about ten o'clock in the evening. Probably I'm paying a penalty for that. It started when I delivered papers in England. The first day I was out I'd had my breakfast and I felt bloated. I didn't know what was up. And the next day, the same thing. So I cut breakfast out straight away. When I started to work my parents were trying to make me eat breakfast -- I didn't want it. That set the pattern. Then I'd try to eat something at lunch time at work. And afterward you're got a foreman saying, "Get to work!" So then it became a stretch. And I don't feel hungry.

But I can be quite disciplined. Like, sometimes when I see the guys I used to work with and they'll say, "Oh, we're going over to McDonalds." And then they'll say, "Oh, I'm having a Big Mac® combo." And I'll say, "I'll just have one of those 69 cent hamburger things." Or, "I'll just have a coffee." Because I think to myself, "I could be nailing myself to a wall, eating that stuff."

I seem to be very loose with the regime right now. I've got to get back into it. I have to. I do go through good periods where I'm really on cue. When I worked we used to go out for meals a lot but once I got told that I had diabetes, I used to just do my own food. Like a salad. Or I'd take cottage cheese with me. If I thought I'd be working late I'd have my container with two sandwiches of rubberized, so called cheese slices. They told me about them at the diabetes course. But I've sort of slipped by the wayside, lately. Now I'm trying just to eat smaller.

I don't like eating first thing in the morning. It's a pain. But when I was doing it properly, before, I'd just go have a slice of toast and put one of them obnoxious 78% reduced fat cheese slices on it. They're actually made from cheese -- not cheese product -- so they cost more. But now I'm terrible. I skip a meal and then I think, "I better eat something." But because I like being up at night, I tend to eat then. It's funny, when I go to my brother's place they'll say, "Do you want something to eat?" And I'll say, "Oh no. I'll just have a coffee and maybe a dry piece of bread." And they'll say, "No, have something. Think of your diet." I'm terrible. Sometimes I find that I'm so busy that (a) I forget to eat and (b) I forget to take my tablet. But I realize that I've got to get it -- I've got to be regimented. I would say a lot more regimented.

I'm terrible. You could give me a litre of orange juice and I'd drink it. Because I love it. When I used to play squash I'd probably eat three grapefruits and maybe four granny smith apples every day. I couldn't be bothered eating a sandwich at lunch but I'd eat a couple of apples and a grapefruit. And I was thin as a rail.

Occasionally I've gone to the pub with my partner and I'll have a beer. I'd be conscious of it and I'd just have the one. And it didn't make any difference. One week I went and on one night I had three beers -- three pints, which is very unusual. And I got up in the morning and my blood sugar was just 8.9 [mmol/l]. I Couldn't believe it! I was thinking, "Oh, it's going to the other end of the scale. You're going to get a 10.0 [mmol/l]." But about two months ago I got up one morning -- I hadn't got a clue -- and it went up to just under 12 [mmol/l]. It scared the hell out of me. And yet, I felt fine. But it's just the one time.

You know, I've gone to that diabetic course and my doctor just said to me, "You're on your own." But I don't understand a single thing about carbohydrates. It was just too quick. I haven't got a clue. Somebody needs to smack me on the head and sit me down and tell me what to eat. At the course, the dietitian had this sheet. I was dishonourable. I tried to pinch it. I would have if I could have got away with it. It had information like, a milkshake has like 26 spoonfuls of sugar. And so on and so on. I said, "Can't I have it?" And she said, "No, it's the only one I've got." But, see I can understand that -- don't have a milkshake because you're gonna have 26 spoons of sugar in one thing. But if it's -- there's χ carbohydrates and ... it's over me.

At the course they would get into these arguments about margarine. "This one has a bit more water in it -- that's why they call it light." I don't need that. I need somebody to say, "You should take one potato and one serving of ..." I actually believe that most of the guys that were on the course -- some of them were with their wives -- but it was just going zzzzzz -- right over their heads. There wasn't enough time and it wasn't in layman's terms. And it is such an important thing. They also said that soups are not good for you -- commercially made soups. But they said that homemade soups are perfectly okay. But here's the problem. If I was at my Mom's and she made soup there'd be lots of salt in it. Because she loves salt -- she's addicted. It's terrible. So this is what I mean about explaining about foods. I openly stood up and I said to them, "Look, I'm thick. I'm a mongrel. Just tell me in layman's terms." I don't need hifaluting explanations. I just need straightforward things. And then when I see the results, then I can scrape a little deeper -- learn more. I'm actually learning more just by trying things out. No one told me I could do that.

One thing that's a killer -- the price of anything special. I found the equivalent of Chips Ahoy® cookies. Not for me, but just for people who come in. It said they were okay for diabetics. So I tried one and I have to admit that you can't tell there's no sugar in them. But they nail you [your wallet] for it.

... I've had more needles this last six months. I can't believe how many I've had. I bought the machine [glucometer] straight away when I was diagnosed. But I didn't realize -- I couldn't prick myself. When I went to the diabetic group I had them in an uproar. It took me 45 minutes to do it. Now I don't think much of it. But I hate it when it doesn't puncture. I've found that shaking my fingers before I puncture helps. I do that and then just squeeze it before I even try to puncture it. Then it's okay. Sometimes I've done it down around the side [of the finger]. I find down there pretty good for getting blood but I find that some fingers bleed really quickly and others don't.

The first couple of weeks I was doing blood sugar tests three times a day. What I do now is take the one reading in the morning and I've got an idea. And then as long as the one in the evening is -- when I say evening I mean around five o'clock or six o'clock -- is around 5.5 [mmol/l] or 6.5 [mmol/l] or even 7.0 [mmol/l], I'm not bothered. But if it was like 9.0 [mmol/l] or something, then I would take one before I'd go to bed. I'd test again. But usually it's just the evening one.

I've stopped metering a couple of times -- for a break. My fingers were getting sore. I was only using two fingers for a while -- I learned not to do that! I've tried to use my thumbs but it was a complete and utter waste of time. When I hit a place that I've used recently before -- Yeow! Occasionally I've done it and thought, "I've hit the bone!" I thought, "Wow, that hurt!" Once, the cap [on the automatic lancet] broke so I had to use the one that goes in deeper. I didn't think it would make that much difference. And then, "Yeow!" I'll not do that again!

I was disappointed with the drug stores. Because they're pushing a certain brand of meter. I just find it distasteful. I mean really, they don't care. I had this sheet from the machine I got and it said I could buy test strips in 200's. They [the drug store] said, "No, you can't." I said, "It's printed right here." But they won't do it. They just gave me a 1-800 number. They were quite willing to sell me ten strips for $10.09. And then I found out that I could buy them in sets of 200 for $40. So I said to them, "You're not very good. I don't get any choice. I have to do this. You sell me ten for about $10 and I can get 200 for $40." It makes me angry that they're making money out of somebody's misery. It just puts me off. But I've tested it [glucometer] a couple of times against the lab and it was pretty good. It was within the tolerance. So that's good.

I asked the doctor about that one blood test [HgA1c]. Apparently it stays for so long in your system. It lasts for three to four months. And when you take that as the average for me, then that's fine. So he's happy [the doctor]. I was pleased that the average was 6.6 [mmol/l] . And that's with me being, sort of, at times, being loose with it. So I want to get back playing squash and get my weight down again. I did it before and I can do it again. I was walking five miles a day but then I got laid off and my schedule's all gone to whack. But I used to live for squash. So I've decided to get back down in weight and start playing again. I wasn't really exercising but now I'm legging it around chasing work and my weight is starting to drop. If I start playing squash again I think I can get down and reduce the tablet. They said at the diabetes group that if I lost another ten pounds there's a chance I could probably drop one tablet. I've just sort of slipped by the wayside. So I made a pact with myself on Friday that I'm going to get back this week to walking every night. And back to organized. I have good motivation. I can't give myself an injection. I can't. I can't. I'm feared to death. I can't. And that's a good thing, to me.

I've had a couple of shakes [hypoglycemic episodes] when I was walking. I felt fine and we were just walking down the driveway and then I felt terrible. The people who were with me couldn't believe it. I'd been told that candy was good and I threw eight or nine down my throat but they've not done me any good. When I've gone for a walk I usually take the glyburide an hour or two before. And I'm thinking, "Well, you're sweating. It's really good." But then if you have glyburide and then your body's kicking in. The body kicks in and sends the insulin through and then the tablet is adding too much to it so then your body can't cope. You're stuck in overload. That would explain why I've suddenly got the shakes. And actually, three times I've had it [hypoglycemia] within the same 50 meters. I was really confused at Christmas -- with all the snow. Because I was out there like a raving banshee -- at 6:30 in the morning. I shoveled out not only our drive but the whole road. Everything. To get the vehicles out. I was out there probably from 6:00 to 7:00 in the morning and I was getting back in -- probably 8:00 to 9:00 at night. And I felt brilliant. I was expecting to get shaky. But I didn't. I was really happy and it gave me a bit of a confidence boost because I was worried because I'd moved out of physical industry. I sat down and I thought, "Would I be able to make the grade?" Like, when you've got to straighten steel beams and you can't get them to a hydraulic press. The old fashioned way is to warm them up and then you have to smack them with a sledge hammer. You're wielding a 20 pound sledge hammer. I haven't done it for, like, five years. But I was worried. Do I have the energy? But now I know I do have the energy. I was on cloud nine when I was moving all that snow. And yet, sometimes when I'm walking I get really shaky. I've had it three or four times when I'm walking. It scares me.

One thing that really upsets me. What if I was back in the engineering industry again? I would be using my hands all the time. Because in that type of industry you're using your hands and you get grime in -- even though you use barrier creams. It's black and no matter how much you try you can't clean your skin. It would be bad for testing my blood sugar. So it's a saving grace that I'm not in any type of industry any more.

Another thing that comes to mind. If I apply for some jobs they will ask if I have diabetes. I know I've seen that before on applications. So do you turn around and say, "Yes," and then not get the job. Or say, "No," get the job and then deal with the problem?

I can remember at a young age feeling sorry for people with diabetes because of the needles. And also, the idea of losing a limb. Well, I get very blasé and cocky and, "I can beat this." And then it suddenly -- you know, I can be driving down the road and it suddenly hits me -- 1300 people lost their legs to diabetes!

In the film I watched [from the Vancouver Library] there was one thing that I remembered. She [the sports figure with diabetes on the videotape] said there are days when it's like carrying another person on top of you. She's got that to a T. I think that if you get the disease you work far harder because (a) your back is against it and (b) you don't want people to know. You know what I mean? You're trying to have a normal life.

Jane: Just Enough To Scare Me

I don't really tell people I have diabetes. It doesn't come up in conversation. It's not important enough to worry about. My daughter came out for her reading break -- she's at Ryerson studying nutrition -- and she said, "Let's go out for lunch." And I said, "Well, I've got to watch because I can't have some things because I'm diabetic." And she said, "Why didn't you tell me this before? Why am I just finding out about this now? I would appreciate learning about this because it might affect me." And I'd never even thought about it. I mean, she's there -- we're here. I never mentioned it.

I was diagnosed, I'm not quite sure, it was about four years ago. I just went to the doctor complaining because I was always tired. It was borderline then. Just enough to scare me and make me work on it. My reaction was, "Oh yeah? What else is new?" Just because -- the weight is a problem. I started at 266-267 pounds. My doctor sent me to a dietitian at one hospital and I was with her for two years or so. I went down to 232 pounds. But it was such a hassle getting into town to see her every week. And it wasn't worth it, so I just let it ride. Then I was back up to 255 pounds and I called back again. They transferred me to a different hospital and then I transferred to this third one. I've been going there every two weeks or so, since last June. I'm down to 242 pounds. I want to be down to 230 pounds. That seems to be where I usually stop. So if I can get below 230 pounds I should be fine. I find it helpful seeing the dietitian. Just knowing that somebody's going to be checking on me.

I don't use any pills -- just diet. I use the glucometer though. Usually once a day. But if it starts creeping up -- like, I've had it up to about 6.9 [mmol/l] and that day I'll maybe use it three times to make sure I level out. I usually do it in the morning, which is usually high anyway. Because apparently I'm someone who has artificially high readings in the morning. Then I drop right down. By noon I can be all the way down to 4.3 [mmol/l].

I've never had my blood sugar done in the lab since the first couple of times. I guess it isn't high enough to worry about. I do take my blood sugars with me to the dietitian. She checks them every time. But if anything happened I'd be the first one to call the doctor anyway. Because I am keeping track.

I try to just eat a reasonable diet. Eat basically what comes along but try to eat more vegetables. One time I took the dietitian a list of what I'd eaten and she said, "What, no vegetables?" I guess I wasn't getting enough of them. I'm not into eating as much salads and things. I'll go on fits and spurts where I seem to feel I'm missing that. Then I'll live on salads for a couple of weeks.

I've found that what helps me most is writing down what I eat. Not how much I've eaten but the fact that I'm eating that item. I have to watch. I like potatoes and gravy. So I write that down so I know I've had them. Then I feel guilty so I don't have so much the next day.

The food part is always there for me. I mean, I didn't used to be that conscious of food. If I was hungry I'd eat. And whatever would tickle my fancy, I'd go for it. But now it's a twenty four hour thing -- FOOD. I get up in the morning and the first thing is, "What am I going to have for breakfast?" Usually I'll have a bowl of cereal in the morning. And then, "Now that I'm eating breakfast, what do I have for lunch and what will I get out for supper?" I might have a sandwich and a cup of soup at lunch. But if I know I'm having a full dinner I'll only have the soup or the sandwich.

The first dietitian I went to was very adamant about the fat content of what I was eating. I found it quite difficult to stick within those limits. And she had cut out proteins altogether. I brought the diet book that she had given me to the dietitian I'm going to now and she said, "Well, it's quite unusual. We don't do it that way anymore." This one spreads the protein all through the day. I know that I noticed the protein lack. I feel hungry a lot sooner. My thing for about a year was pepperoni and cheese on toast for breakfast. I could go almost until supper without being hungry. But if I don't get enough protein at breakfast I'll be ready to almost pass out before noon. I think some people metabolize proteins better, anyway. My stepdaughter won't eat as much protein. She figures, "Okay, I've had my protein for the day." She'll save it and have it with her dinner -- maybe. She doesn't seem to miss it. But I do.

The thing I found most difficult was adapting to sugar substitutes. It just, sort of, turned my stomach. Upset my stomach something awful. But I got to the point where if it was really cold and I was really thirsty, I could drink it. I can drink it now -- any kind of diet -- as long as I like it. And I like the Splenda® . But every once in a while I'll take a sugar cube instead of the diet sugar. It doesn't seem to make much difference.

I want to keep track of my sugar levels and try to get my weight down so I don't get complications. I know one older fellow who's just about lost his legs because he ended up with gangrene in his feet. I wouldn't want that. And I've got bad eyes to begin with so I don't want it affecting my eyes. I had them checked both last year and this year. I think the fear makes you watch what you eat. It's nothing really definite but there's a feeling there -- I'm going to get you.

I went to a diabetes workshop a few weeks ago. It was quite an interesting night. They had everybody up doing line dancing. To get us moving. It's a case of, you do the moving you burn off the sugar. I need to do it. I need to get out and take a walk after lunch or after supper. Exercising is so darn expensive. I love swimming but it's three dollars a crack to go. And line dancing is five dollars a night. Forget it.

I used to do volunteer babysitting down at the YMCA. My main target was to get my kids exercising. And when you babysat you got credits towards classes. But the one exercise class I did go into I couldn't keep up with what they did. So that went by the wayside. I never did collect on all the credits I got for volunteering.

And there's that thing on television. The string one. [A reference to a television commercial that says, "Think of this string as your life. If you have diabetes, fluctuations in your blood sugar can affect not only the quality of your life but the length of your life. (Shoppers Drug Mart, 1997.)] It makes you stop and think. You know, the thread goes up and down and every hump shortens your life. And you're beginning to wonder whether or not the little peaks that you do -- because they're so small, just a difference of one point, or whatever -- are they affecting my life?

And I do wonder whether or not my kids are going to get it. I worry about it. I feel sort of guilty -- like it's something I did.

CHAPTER FOUR: THE ROAD GOES EVER ON AND ON:

THE MEDICAL NARRATIVE

The Road goes ever on and on
   Down from the door where it began.
Now far ahead the Road has gone,
   And I must follow, if I can,
Pursuing it with eager feet,
   Until it joins some larger way
Where many paths and errands meet.
   And whither then? I cannot say. (Tolkien, 1966a, p. 41)

This chapter describes the medical narrative related to diabetes including the pathophysiology, history, epidemiology, treatment, and complications of diabetes. It is written for the lay reader in order to provide a background for understanding the other narratives in the thesis. In addition, it functions as a literature review of the current medical and nursing literature on diabetes.

The medical narrative, the road for understanding diabetes from a medical perspective, truly does go on and on. Research is ongoing and adds to and changes the knowledge available. From ancient times to the present, medical personnel have tried to understand diabetes and find a cure. And the journey continues....

The Map: An Overview Of Diabetes

What Is Diabetes?

Diabetes is a chronic disruption in the way the body processes glucose, a form of sugar in the blood (IDF, 1994). Normally, the pancreas produces insulin, a hormone which allows glucose, a form of sugar produced during food digestion, to enter the body's cells from the blood. Glucose acts as the body's fuel. In diabetes, there is a defect in insulin secretion, in insulin action, or a combination of these factors (Meltzer et al., 1998).

There are several different types of insulin deficiency. The first is the absolute lack of insulin. This is most common in type 1 diabetes. Generally, the beta cells in the pancreas have been destroyed and are therefore incapable of producing insulin (Meltzer et al., 1998). It is also possible to have a relative deficiency of insulin. A relative deficiency of insulin occurs when there is insufficient insulin present to allow glucose to be transported into the cells. The deficiency of insulin is usually the result of a combination of two factors: a) decreased insulin secretion and b) insulin resistance. Type 2 diabetes encompasses a range of these two problems (Meltzer et al., 1998). Diabetes is a lifelong condition. Although there are treatments, there is no cure (IDF, 1992). Diabetes also has a natural tendency to progress as pancreatic function tends to deteriorate over time (Turner, Cull & Holman, 1996).

What Is Insulin?

Insulin is a protein hormone comprised of a chain of 51 amino acids produced by the pancreas (McDowell & Gordon, 1996). The pancreas is a gland in the abdomen which is located below and behind the stomach. Within the pancreas are areas of tissue called islets of Langerhans. The islets contain cells called beta cells which produce insulin (McDowell & Gordon, 1996). The pancreas also produces enzymes which are used in food digestion, and glucagon, a hormone which stimulates the liver to release glycogen, the storage form of glucose (McDowell & Gordon, 1996).

Insulin is used to assist the cells in moving glucose from the blood into the cells. Cells use glucose as their fuel. However, cells have a membrane around them which prevents glucose from freely entering cells. Insulin signals the cells that they should allow glucose to penetrate the cell membrane. Insulin also allows the body to store glucose in the liver and muscles for future use (Krall & Beaser, 1989).

Generally, the pancreas continuously secretes a small amount of insulin. When food is eaten, the secretion is increased (McDowell & Gordon, 1996). The beta cells in the pancreas measure the blood sugar and secrete insulin in the precise amount needed (Guthrie & Guthrie, 1991). In fact, it is almost impossible to raise the blood sugar of people who do not have diabetes for any length of time because the normal pancreas is capable of secreting insulin in whatever quantity is required. However, if insulin is not present in sufficient quantities then glucose "backs up" into the blood. This leads to an elevated blood glucose [sugar] level and the diagnosis of diabetes (Krall & Beaser, 1989).

Diabetes Historically

There are reasonably accurate medical descriptions of diabetes from 1500 BC. However, it was probably the Greek physician Aretaeus who first named the condition diabetes. The term diabetes comes from the Greek and means to flow through, which characterizes the large amounts of urine produced in those with diabetes. Later the word mellitus, a Latin word meaning sweetened was added. Therefore, diabetes mellitus literally means sweet urine (Krall & Beaser, 1989). In the 1600s diabetes was colloquially known as the "pissing evil" (Nathan, 1997).

Although diabetes had been recognized as a serious medical condition for many centuries it wasn't until the 1860's that the condition began to be understood. The pancreatic tissue which produces insulin was first described by Langerhans, and was later named after him -- the islets of Langerhans. In 1889 it was noted that removing the pancreas from dogs resulted in symptoms of diabetes. At this time the only treatment for diabetes was a regime of organized starvation which included almost no carbohydrates. However, even on this regime the majority of people with diabetes died rapidly (Krall & Beaser, 1989).

In 1921, Frederick Banting and Charles Best, working at the University of Toronto, isolated insulin from pancreatic tissue of animals (Krall & Beaser, 1989). They received the Nobel prize for their discovery (Nathan, 1997). The first definitive treatment of diabetes, injection of exogenous insulin occurred in 1922 (Rayfield & Solimini, 1992). Today, there are a variety of sources of insulin including beef, pork and human insulin [created through genetic engineering]. However, insulin is not a cure for diabetes - only a treatment (Krall & Beaser, 1989).

Statistics About Diabetes

Worldwide

In 1994 the IDF estimated that there were over 100 million people in the world with diabetes. This is approximately 6% of the world's population. This estimate has more than tripled over the last decade. In 1991 the World Health Organization declared there is "an apparent epidemic of diabetes ... throughout the world" (IDF, 1994, p. 6). The increase in the incidence of diabetes is believed to be the result of global aging and a change in lifestyle toward western eating habits. In addition, some ethnic groups may have a genetic predisposition to the development of type 2 diabetes (IDF, 1994). It is estimated that at least half of all people with diabetes have not yet been diagnosed and are therefore unaware of their condition (IDF, 1994).

Those with type 1 diabetes have a 6% chance of passing diabetes on to their children. Children of those with type 2 diabetes have a 25% chance of developing diabetes (Jovanovic-Peterson, Biermann & Toohey, 1996).

North America

In North America, diabetes is the third largest cause of death by disease. This may actually be an underestimation as death certificates often do not cite diabetes as the underlying cause of death. For example; the person died of heart disease which occurred as a complication of diabetes (Tan & Wornell, 1991).

Canada

Recent statistics suggest that approximately 1.5 million Canadians have been diagnosed with diabetes (Meltzer et al., 1998). This is approximately 5% of the population. It is estimated that another 750,000 have diabetes but have not yet been diagnosed (CDA, 1995). One Canadian is diagnosed with diabetes every six minutes (CDA, 1997b).

Although there are no national data on the incidence of diabetes within Canada, two regions [PEI and Montreal] participated in an international study on diabetes incidence. It was found that rates varied widely between the two centres with PEI having markedly higher rates. The reason for this difference is unclear (Tan & Wornell, 1991).

First Nations groups in Canada generally have a high frequency of diabetes. However, a national survey of First Nations groups demonstrated that rates of diabetes vary from region to region. Generally, the rates increase from North to South, from West to East, and from remote to urban areas (Young, Szathmary & Evers, 1990).

The cost of treating people with diabetes is estimated to be between five and six billion dollars annually. This money is allocated to a number of areas including acute care hospitals, physician billing, supplies, medicines, and home care (CDA, 1997a).

Classifications of Diabetes

The 1998 clinical practice guidelines for the management of diabetes in Canada recommend the use of four classifications of diabetes (Meltzer et al., 1998).

Type 1 Diabetes

In the past, this type of diabetes was called insulin dependent diabetes mellitus [IDDM] or juvenile diabetes ("Diabetes: Living," 1992). In type 1 diabetes the pancreas produces little or no insulin. Most people with type 1 diabetes are diagnosed prior to age 30. A type 1 diabetic requires daily injections of insulin for the remainder of his/her life. Approximately ten percent of all people with diabetes are classified as type 1 (Pritchard, 1996).

Type 2 Diabetes

In the past, this type of diabetes was called noninsulin dependent diabetes mellitus [NIDDM] or adult onset diabetes ("Diabetes: Living," 1992). In type 2 diabetes the pancreas does not make a sufficient amount of insulin for metabolism. Also, insulin resistance may be present. This means that even though insulin is produced the cells do not respond to it normally. Consequently, the insulin is less effective (Meltzer et al., 1998). Type 2 diabetes is more common than type 1 diabetes. Approximately 90 % of diabetics are classified as type 2 (Pritchard, 1996). Type 2 diabetes occurs most commonly, although not exclusively, in people over 40 who are overweight (CDA, 1995). Type 2 diabetes occurs more frequently in women, possibly because women have a higher percentage of body fat, even when at normal weight, which may predispose them to insulin resistance (Jovanovic-Peterson et al., 1996).

Treatment for type 2 diabetes includes a balanced diet, exercise and weight loss [if necessary]. If these are ineffective in decreasing blood glucose levels then oral antidiabetic agents can be used to further lower blood glucose. Many people with type 2 diabetes eventually need insulin injections to control their blood sugar (CDA, 1995). However, they are still classified as type 2 because although they use insulin to provide better blood sugar control they are not dependent upon insulin to survive (Morsiani, 1989).

Gestational Diabetes

Gestational diabetes develops during pregnancy and generally disappears after delivery of the baby. Women with gestational diabetes require careful monitoring of their blood sugar to avoid complications for mother or baby. Approximately half of all women who are diagnosed with gestational diabetes will eventually develop type 1 or type 2 diabetes (Morsiani, 1989).

Other Specific Types

There are many other defects which may cause diabetes. These include genetic defects, pancreatic diseases, certain infections, certain drugs and chemicals, and endocrine disorders (Meltzer et al., 1998).

In addition to the three main classifications of diabetes there are two other diagnoses which are related to diabetes. Impaired glucose tolerance [IGT] and impaired fasting glucose [IFG] are diagnosed in individuals who have somewhat elevated levels of blood glucose, but which are not yet high enough for a diagnosis of diabetes (Meltzer et al., 1998). In IGT the blood glucose levels are elevated in response to the ingestion of carbohydrate but there is a normal fasting blood glucose level (Meltzer et al., 1998). Individuals with IFG have a high fasting level of blood glucose but do not demonstrate elevated levels in response to carbohydrate ingestion (Meltzer et al., 1998). Individuals with either IGT or IFG are at an increased risk of developing diabetes and approximately one third will eventually develop diabetes (IDF, 1994).

Who Is At Risk For Developing Diabetes?

People who fall into the following categories are at a higher risk for developing diabetes. However, the fact that one or more risk factors are present does not mean that diabetes will inevitably develop. People who are aware of their increased risk should consider regular medical examinations so that if diabetes does occur it will be diagnosed quickly. The first step in preventing the complications of diabetes is the recognition and treatment of the disease (CDA, 1997b).

- Overweight -- especially those with abdominal obesity ("The epidemic," 1995).
- Inactive (CDA, 1997b).
- Over the age of 45 (CDA, 1997b).
- Of Aboriginal, African, Asian or Hispanic descent (Meltzer et al., 1998).
- A first degree relative of a person with diabetes (Meltzer et al., 1998).
- Have given birth to a baby weighing over 4 kg (9 lbs.) (CDA, 1997b).
- Frequent and/or acute stress -- stress can trigger diabetes in those with a genetic predisposition to the disease (Rayfield & Solimini, 1992).
- Those born at a low birth rate may have an increased risk of diabetes (Steven, 1995).

A Thousand Mile Journey Begins With A Single Step: Diagnosing Diabetes

Symptoms of Diabetes

Diabetes, because it can affect the entire body, can create a wide array of symptoms. However, the onset of type 2 diabetes is often insidious. Many people with type 2 diabetes have few or no symptoms. This is probably because the blood sugar level rises gradually, resulting in less acute symptoms (Nathan, 1997). Many people with type 2 diabetes are diagnosed during a routine physical examination or in connection with other, often unrelated, health problems (CDA, 1995). However, the most common symptoms are as follows:

- Frequent urination (CDA, 1997b).
- Thirst (CDA, 1997b).
- Changes in appetite -- especially increased appetite (CDA, 1997b).
- Fatigue (CDA, 1997b).
- Blurred vision (CDA, 1997b).
- Unexplained weight loss -- this is much less common in type 2 diabetes (CDA, 1997b).
- Irritability (CDA, 1997b).
- Abdominal cramps (CDA, 1995).
- Frequent infections, especially of skin, gums, or bladder (CDA, 1995).
- Cuts or bruises that are slow to heal (CDA, 1995).
- Itchiness (CDA, 1995).
- Numbness, tingling, or burning in hands or feet (Krall & Beaser, 1989).

- Vaginal infections in women (Krall & Beaser, 1989).
- Impotence in men (Krall & Beaser, 1989).
- Postprandial reactive hypoglycemia -- a syndrome of sweating, rapid heart rate and mild mental confusion which occurs after a meal which is high in carbohydrates and low in fiber (Morsiani, 1989).

Laboratory Tests For Diagnosing Diabetes

Most physicians will routinely conduct screening tests for those at a high risk for developing diabetes. Those who believe they are at risk should ask their physician for screening. The most common screening tests are the fasting blood glucose and the random blood glucose (Guthrie & Guthrie, 1991). If these tests are equivocal a further test, the oral glucose tolerance test, may be conducted to confirm the diagnosis (McDowell & Gordon, 1996).

Random Blood Glucose

A random blood glucose is often part of a complete medical examination. It is a simple method of checking blood glucose which can be drawn at any time of day. However, blood glucose varies considerably with eating, so it is less sensitive than a fasting blood glucose. Therefore, mildly abnormal results must be followed up with further testing (Guthrie & Guthrie, 1991).

The normal range for a random blood glucose is between 4.4 and 6.7 mmol/l. A random blood glucose of greater than 11.1 mmol/l along with symptoms of diabetes is diagnostic of diabetes (Meltzer et al., 1998). However, levels between 6.7 and 11.1 mmol/l must be investigated further, either with a fasting blood glucose or an oral glucose tolerance test (McDowell & Gordon, 1996).

Fasting Blood Glucose

This is the most common test for diagnosing diabetes because it is almost always elevated in those with diabetes (Guthrie & Guthrie, 1991). A fasting blood glucose is a simple blood test taken after an overnight fast -- nothing to eat or drink except water for at least ten hours (McDowell & Gordon, 1996).

The normal range for a fasting glucose is between 3.5 and 5.5 mmol/l (McDowell & Gordon, 1996). A fasting glucose of less than 5.5 mmol/l indicates that a person does **not** have diabetes. A fasting blood glucose between 6.0 and 6.9 mmol/l generally indicates impaired fasting glucose (Meltzer et al., 1998). However, further testing such as an oral glucose tolerance test should be done to confirm the diagnosis (McDowell & Gordon, 1996). A fasting blood glucose greater than 7.0 mmol/l on two occasions leads to a diagnosis of diabetes (Meltzer et al., 1998).

Oral Glucose Tolerance Test

The oral glucose tolerance test is usually used only if previous testing has been equivocal (McDowell & Gordon, 1996) because it is a more complicated, time consuming and expensive test (Guthrie & Guthrie, 1991).

The procedure for an oral glucose tolerance test is as follows: For three days prior to the test the patient should eat a diet high in carbohydrates and continue to participate in normal activities. A low carbohydrate diet or bedrest will confound the results of the test (McDowell & Gordon, 1996). After an overnight fast of ten to sixteen hours a fasting blood glucose is drawn (McDowell & Gordon, 1996). The patient then drinks a special glucose containing solution. A blood test is drawn 120 minutes after the glucose solution

(Meltzer et al., 1998). The test may be extended for longer periods of time, from three to six hours (Guthrie & Guthrie, 1991).

The possible results are as follows:

- A fasting blood glucose greater than 7.0 mmol/l leads to a diagnosis of diabetes (Meltzer et al., 1998).
- A fasting blood glucose between 6.1 and 6.9 mmol/l leads to diagnosis of impaired fasting glucose (Meltzer et al., 1998).
- At two hours after the glucose solution a blood glucose level above 11.1 mmol/l along with an fasting blood glucose level about 7.0 mmol/l leads to a diagnosis of diabetes (Meltzer et al., 1998).
- At two hours after the glucose solution a blood glucose level between 7.8 - 11.0 mmol/l with a fasting glucose below 7.0 mmol/l leads to a diagnosis of impaired glucose tolerance (Meltzer et al., 1998).

Watching The Road: Monitoring Diabetes

Laboratory Tests For Monitoring Diabetes

Most physicians will periodically run laboratory tests to determine the overall effectiveness of diabetes control (McDowell and Gordon, 1996). There are three main tests for monitoring diabetes control.

Fasting Blood Glucose

Fasting blood glucose may be used as a monitoring tool as it provides a relatively accurate indication of blood glucose throughout the day (McDowell & Gordon, 1996).

Post Prandial Blood Glucose (two hour)

This test, also called a two hour p.c., is often used to measure the effectiveness of glucose lowering drugs (Guthrie & Guthrie, 1991) because it is drawn two hours after a normal meal and can therefore determine how high the blood glucose rises after eating (American Diabetes Association [ADA], 1996).

Glycated Hemoglobin

This test is also known as the hemoglobin A1c test (Jovanovic-Peterson et al., 1996) or the glycosylated hemoglobin test (Guthrie & Guthrie, 1991). The glycated hemoglobin test measures the average blood glucose over a three month period (Jovanovic-Peterson et al., 1996). When the blood glucose is elevated, hemoglobin in the blood converts from hemoglobin A to hemoglobin A1c. Once it is converted it cannot revert back to hemoglobin A and therefore remains in the blood for the life of the blood cell, approximately 120 days (Jovanovic-Peterson et al., 1996). Therefore, a measurement of glycated hemoglobin will give an indication of the average blood glucose over that period of time (Jovanovic-Peterson et al., 1996).

The glycated hemoglobin test may be done at any time of day (ADA, 1996). It is particularly useful in determining the overall effectiveness of the diabetic care plan (ADA, 1996). However, glycated hemoglobin should not replace self-monitoring of blood glucose because it cannot provide minute to minute information on blood glucose levels (ADA, 1996).

Urine Glucose

When blood glucose levels are high, sugar spills into the urine. Therefore, it is possible to get some information on blood glucose by testing the amount of sugar present in urine (Guthrie & Guthrie, 1991). However, because the renal threshold, the level at which the kidneys begin to spill sugar, varies from person to person, it is not generally considered an effective method of monitoring blood glucose (Krall & Beaser, 1989). In addition, the renal threshold is always above 10 mmol/l so that urine glucose can be absent and the blood glucose may still be abnormal (Krall & Beaser, 1989).

Levels Of Glucose Control For Adults And Adolescents With Diabetes Mellitus

	Levels			
	Ideal	Optimal	Suboptimal	Inadequate
Glycated Hemoglobin	0.04 - 0.06	< 0.07	0.07 - 0.08	>0.08
Fasting or premeal blood glucose	3.8-6.1	4.0 - 7.0	7.1 - 10.0	>10.0
Glucose level 1 - 2 hours after a meal	4.4 - 7.0	5.0 - 11.0	11.1 - 14.0	> 14.0

Source: Meltzer et al., 1998, S12.

The 1998 clinical practice guidelines for the management of diabetes in Canada (Meltzer et al., 1998) define the levels of blood glucose control as follows:

- Ideal levels -- these are within the normal range for those who do not have diabetes. A few diabetics may be able to achieve these results, however, it should not be expected of the majority of those with diabetes.
- Optimal levels -- blood glucose results at this level are close to normal and will reduce the risk of developing long term complications. Some people will find these results difficult to achieve and maintain.

- Suboptimal levels -- The majority of diabetics can achieve these blood glucose results. However, to reduce the risk of complications for most people it would be best to attempt to achieve better blood glucose control.
- Inadequate glucose levels -- These levels usually result in symptoms of hyperglycemia and are associated with a much higher risk of long term complications. Adjustments in treatment are required to achieve better blood glucose control (Meltzer et al., 1998).

Self Monitoring Of Blood Glucose

Studies have indicated that keeping blood glucose as close to normal as possible is instrumental in preventing or delaying complications (Guthrie & Guthrie, 1991). Therefore, most physicians recommend that diabetics monitor their blood glucose levels. Self monitoring involves pricking a finger with a lancet to obtain a drop of blood. This blood is applied to a special test strip and after a period of time a blood glucose result is obtained (McDowell & Gordon, 1996). Many people use blood glucose monitors, often called glucometers, that provide an automated reading of the test strip (Hillson, 1996). It is also possible to use strips which are read by measuring the colour obtained against a control panel of colours (Hillson, 1996). Both techniques, if done properly, provide accurate results (Hillson, 1996). As every type of strip uses a slightly different method, it is important to read and follow instructions carefully. Anyone using a glucometer should periodically, at least once per year, verify the accuracy of the machine by doing simultaneous laboratory and blood glucose readings. The results should differ by no more than 15% (Meltzer et al., 1998).

Each diabetic should check with his/her physician to determine the appropriate frequency and timing of tests (ADA, 1996). The most common testing times include: fasting (before breakfast), before lunch, before supper, before bedtime, 1-2 hours after each meal, and 2-3 a.m. (ADA, 1996). The following are general recommendations for frequency of testing. Type 2 diabetics on insulin should test two to four times per day at varied times (ADA, 1996). Type 2 diabetics on glucose lowering drugs should test one to two times per day, once before breakfast and one other time that varies from day to day (ADA, 1996). Type 2 diabetics who control their blood glucose with diet and exercise should test once per day and vary the timing between fasting and one to two hours after a meal (ADA, 1996).

Each diabetic should also ask her/his physician to provide information about recommended blood glucose levels. However, the recommendations seen on page 88 -- Levels of Glucose Control for Adults and Adolescents with Diabetes Mellitus -- are useful as basic guidelines (Meltzer et al., 1998).

Many people feel they are more in control of their diabetes when they perform self monitoring (Fox et al., 1984). The most common complaints regarding self monitoring are sore fingers and the inconvenience of testing (Fox et al., 1984). Sore fingers often occur when the finger is squeezed to get a sufficient drop of blood (Hillson, 1996). This can be avoided by ensuring hands are warm before testing (Hillson, 1996). Shaking the hand vigorously prior to testing can also improve blood flow, lessening the risk for sore fingers (Hillson, 1984).

Blood glucose self monitoring results should be recorded so that any patterns can be identified (Fox et al., 1984). In addition, changes to the care plan may be based on the self monitoring results (Fox et al., 1984). For example: frequent hyperglycemic or hypoglycemic attacks may require changes in drug dosage, meal plan or exercise plan. Consultation with a physician may be warranted if sudden changes in results occur (McDowell & Gordon, 1996). This is important because type 2 diabetes has a natural tendency to progress (Morsiani, 1989). Careful self monitoring can ensure that optimum treatment is begun as soon as possible.

The Inevitable Detour: Acute Complications of Diabetes

Acute Hypoglycemia

Hypoglycemia is one of the acute complications of diabetes. It occurs when blood glucose drops below normal levels. There is no formal definition of hypoglycemia (Pergallo-Dittko, 1995). However, most people develop symptoms of hypoglycemia when their blood sugar is between 3.0 and 3.5 mmol/l. However, people whose blood sugars tend to be high may have symptoms if their blood sugar drops below 4.0 mmol/l. (Nathan, 1997).

Precipitating Factors

The basic cause of hypoglycemia is an overavailability of insulin. In people with type 2 diabetes, hypoglycemia only occurs in those who are treated with insulin, sulfonylurea, or meglitinide oral agents. The biguanide, alpha glucosidase inhibitor, and thiazoledinediones do not produce hypoglycemia on their own (Nathan, 1997). There are several possible reasons for the over availability of insulin:

- Too much insulin, sulfonylurea, or meglitinide -- which stimulate the pancreas to produce more insulin, therefore if the dose is too high, hypoglycemia may result (McDowell & Gordon, 1996).

- Decreased food intake or a delayed or missed meal (Pritchard, 1996).
- Increased exercise -- exercise increases the sensitivity of the cells to insulin so that a smaller amount of insulin will have an increased effect (McDowell & Gordon, 1996).
- Alcohol ingestion -- alcohol reduces the ability of the liver to produce glucose in response to a low blood sugar level (McDowell & Gordon, 1996).

Signs and Symptoms

There are numerous signs and symptoms of hypoglycemia. Most people will only experience a few symptoms and each diabetic will experience a different set of symptoms (Guthrie & Guthrie, 1991). Some individuals, especially those who have had diabetes for several years, may have few or no symptoms of hypoglycemia (Guthrie & Guthrie, 1991). However, hypoglycemia can be life threatening so anyone with diabetes should develop a list of their particular symptoms. In addition, family, friends and associates should be aware of the symptoms so that they can treat hypoglycemia appropriately (Guthrie & Guthrie, 1991).

The following are common signs and symptoms of hypoglycemia:

- Nervousness (Guthrie & Guthrie, 1991).
- Weakness (Guthrie & Guthrie, 1991).
- Shakiness (Pergallo-Dittko, 1995).
- Sweatiness (Pergallo-Dittko, 1995).
- Headache (Pergallo-Dittko, 1995).
- Blurred vision (Pergallo-Dittko, 1995).
- Hunger (Pergallo-Dittko, 1995).
- Irritability or belligerence (Guthrie & Guthrie, 1991).
- Disorientation or confusion (Guthrie & Guthrie, 1991).
- Lightheadedness or dizziness (Guthrie & Guthrie, 1991).

- Uncontrolled laughter (Guthrie & Guthrie, 1991).
- Sudden changes in mood (Guthrie & Guthrie, 1991).
- Convulsions (Guthrie & Guthrie, 1991).
- Palpitations (McDowell & Gordon, 1996).
- Tingling of lips, tongue or fingers (McDowell & Gordon, 1996).
- Pallor (McDowell & Gordon, 1996).
- Inability to concentrate (McDowell & Gordon, 1996).
- Elevated pulse (Pergallo-Dittko, 1995).
- Visual hallucinations (Bernstein, 1990).
- Poor coordination (Bernstein, 1990).

Treatment

When symptoms of hypoglycemia are detected, it is best to check blood sugar immediately. If this is not possible then it is better to treat as if hypoglycemia is present. This is because hypoglycemia can progress rapidly and if left untreated can result in a comatose state (McDowell & Gordon, 1996).

Treatment of hypoglycemia begins with the ingestion of approximately 10-20 grams of simple carbohydrate. Addition of complex carbohydrates, proteins or fats will delay the absorption and are not appropriate treatment for hypoglycemia (Nathan, 1997). The following are examples of 10-20 grams of simple carbohydrate: 4-6 ounces of juice or regular soda (Nathan, 1997) or 5 Life Savers® (Graham, Biermann & Toohey, 1995)

Once the carbohydrate has been eaten, blood sugar should be rechecked in 10-15 minutes. Generally, the symptoms will disappear within this period of time. If blood sugar monitoring is not possible and symptoms continue you should treat again with another 10-20 grams of simple carbohydrate (Krall & Beaser, 1989). Be cautious, as it is very easy to overtreat hypoglycemia which may result in lasting hyperglycemia.

Therefore, having access to a glucometer and immediate blood glucose results is useful to confirm the effectiveness of treatment (Graham, Biermann & Toohey, 1995).

Once the initial treatment of hypoglycemia is completed it is necessary to assess whether further precautions are necessary. If the next meal or snack is not scheduled for within the next hour then the initial carbohydrate should be followed up with a snack that includes protein and complex carbohydrate [for example; crackers with cheese or peanut butter] (Guthrie & Guthrie, 1991).

In some cases, hypoglycemia will progress to the point where the individual is unconscious. This is more likely in individuals who are treated with insulin. Many individuals who are prone to severe hypoglycemic episodes keep glucagon, an injectable hormone that results in the release of glucose from the liver, on hand. Family and friends of such individuals can be taught how to inject glucagon when necessary (McDowell & Gordon, 1996).

Prevention

Hypoglycemia can be prevented by understanding the precipitating factors (Pergallo-Dittko, 1995). Eating meals and snacks at regular times will help to avoid hypoglycemia (Pergallo-Dittko, 1995). Check blood glucose level before exercise and eat a snack if blood glucose is less than 5.6 mmol/l (Pergallo-Dittko, 1995). If consuming alcohol, be sure to eat some carbohydrate to compensate for the hypoglycemic effect of the alcohol (Pergallo-Dittko, 1995). Also, it is important to wear an identification bracelet or carry some identification so that should a severe episode of hypoglycemia occur, those treating you will know the appropriate measures to take (Pergallo-Dittko, 1995).

Acute Hyperglycemia

When glucose, because of a lack of insulin, is unable to move into the cells it builds up in the blood. This condition is called hyperglycemia and is an acute complication of diabetes (Rayfield & Solimini, 1992). Hyperglycemia is generally defined as a blood glucose above 10.0 mmol/l (ADA, 1996).

Precipitating Factors

The overall cause of hyperglycemia is too much glucose and a relative lack of insulin (Guthrie & Guthrie, 1991). The most common causes of hyperglycemia include:

- A missed pill or dose of insulin -- leading to a decrease in available insulin (Guthrie & Guthrie, 1991).
- An increased consumption of calories or carbohydrates -- leading to an increase in glucose in the blood (Guthrie & Guthrie, 1991).
- A decreased amount of exercise -- leading to decreased insulin sensitivity (McDowell & Gordon, 1996).
- Fever, infection, illness or stress -- result in bodily stress which increases blood glucose (McDowell & Gordon, 1996).
- Interaction of other medications (McDowell & Gordon, 1996).

Signs and Symptoms

The main symptoms of hyperglycemia are similar to the initial symptoms of diabetes; frequent urination, thirst and hunger (Guthrie & Guthrie, 1991). Other symptoms include a dry mouth (ADA, 1996) and nausea and vomiting (McDowell & Gordon, 1996). However, it is difficult to diagnose hyperglycemia from symptoms alone

(ADA, 1996). The use of blood glucose self monitoring can be used to diagnose hyperglycemia. The is essential because frequent or chronic hyperglycemia increases the risk of developing chronic complications (ADA, 1996).

Treatment

Determination of the cause is an important part of treatment of mild hyperglycemia. For example, if the cause is a missed dose of an oral antidiabetes agent or a lack of insulin, then this can be quickly remedied (Guthrie & Guthrie, 1991). If the cause is related to fever, infection, illness, or interactions of other medication, the assistance of a physician should be sought (Krall & Beaser, 1989).

To treat blood glucose between 10.0 mmol/l and 13 mmol/l -- take a walk or some other exercise. If a snack or a meal is due it should be smaller than usual. Check blood glucose again in one to two hours (ADA, 1996).

To treat blood glucose between 13 mmol/l and 19.5 mmol/l -- test urine for ketones. If ketones are present contact physician. Remember that people with type 2 diabetes may not produce ketones when hyperglycemic because of the presence of their own insulin. If ketones are not present, exercise and recheck blood glucose in one to two hours. If blood glucose level has not decreased, or has increased, contact physician (ADA, 1996).

To treat blood glucose over 19.5 mmol/l -- call physician immediately. If physician is not available, go to hospital emergency room (ADA, 1996).

Unfortunately, type 2 diabetes has a natural tendency to progress and become more severe (Morsiani, 1989). Therefore, if despite careful attention, hyperglycemia occurs regularly it is important to seek the attention of a physician (McDowell & Gordon, 1996).

At that time, it may be necessary to change the treatment regimen, to regain control of blood glucose levels (McDowell & Gordon, 1996).

Prevention

Prevention of hyperglycemia involves avoiding the common causes. The following actions may prevent hyperglycemia:

- Take oral antidiabetes agents at regular times each day (Guthrie & Guthrie, 1991).
- Follow a meal plan which has been approved by a physician or dietitian (Guthrie & Guthrie, 1991).
- Eat meals and snacks at regular times (Guthrie & Guthrie, 1991).
- Avoid simple sugars, except in small amounts (Guthrie & Guthrie, 1991).
- Exercise regularly (Guthrie & Guthrie, 1991).
- Be aware of possible interactions between other medications and blood glucose (Guthrie & Guthrie, 1991).
- Avoid stress, as much as possible (Guthrie & Guthrie, 1991).
- Seek medical attention for any illness (Guthrie & Guthrie, 1991).

All of these activities will help to keep blood glucose at a more stable level (Guthrie & Guthrie, 1991).

Hyperosmolar Nonketotic Syndrome

People with type 2 diabetes may, in situations of severe stress, develop a syndrome called hyperosmolar nonketotic syndrome (Krall & Beaser, 1989). The cause of hyperosmolar nonketotic syndrome is a rapid increase in blood glucose as a result of illness or intense emotional stress (Pergallo-Dittko, 1995). During illness, glucose is released from the liver, resulting in an increased blood glucose and an increased need for insulin. This syndrome most often occurs in type 2 diabetics who are over 60 years of age and who fail to recognize the significance of their increasing symptoms (McDowell & Gordon, 1996).

The main features of hyperosmolar nonketotic syndrome are:

- Very high blood osmolarity [the blood is very concentrated] -- because the body tries to lower blood glucose levels by increasing urine output (Krall & Beaser, 1989).
- Very high blood glucose with levels generally above 50 mmol/l (McDowell & Gordon, 1996).
- High levels of sodium in the blood [hypernatremia] -- as the body dehydrates, sodium levels rise (McDowell & Gordon, 1996).
- Severe dehydration -- due to increased urine output (Krall & Beaser, 1989).
- Low levels of potassium in the blood [hypokalemia] -- potassium is lost in the urine (McDowell & Gordon, 1996).
- Coma (McDowell & Gordon, 1996).

Hyperosmolar nonketotic syndrome is a medical emergency and the individual must be treated in hospital with intravenous fluids, potassium replacement and insulin (Guthrie & Guthrie, 1991).

Hyperosmolar nonketotic syndrome can be prevented by careful management of diabetes. It is important to monitor blood glucose when ill. Also, even if one is not eating due to illness, oral antidiabetes agents still need to be taken, to deal with the glucose released from the liver (Krall & Beaser, 1989). Anyone with type 2 diabetes who has two consecutive blood glucose readings about 16.5 mmol/l (Pergallo-Dittko, 1995) or consistently about 13.2 mmol/l (ADA, 1996) should immediately consult a physician (Pergallo-Dittko, 1995).

The Long And Winding Road: Lifestyle Modifications For the Treatment of Diabetes

Basic Dietary Information

Proper nutrition is the cornerstone of good diabetes control however, it is a very complex topic (Meltzer et al., 1998). This discussion provides only very basic nutritional information. It is intended only to assist with the developing of awareness of the importance of proper nutrition. It is recommended that all persons with diabetes should receive individualized nutritional counselling regarding their diabetes (Meltzer et al., 1998).

Those type 2 diabetics who are obese should attempt to lose weight as obesity leads to insulin resistance (McDowell & Gordon, 1996). Losing as little as ten pounds can improve blood glucose and decrease insulin resistance (Henry, 1996). For those individuals who need to lose weight, the basic diet should be restricted in calories with an increase in complex carbohydrates and fibre to assist insulin receptors to function more normally (Jovanovic-Peterson et al., 1996). All diabetics should space meals four to six hours apart to allow blood glucose to return to a fasting level before the next meal ("Nutrition," 1994). Consistent meal and snack times assist the pancreas to release insulin more normally (Beaser & Hill, 1995).

Carbohydrate

Carbohydrates should comprise approximately 55% of total calorie intake (Meltzer et al., 1998). The majority should be complex carbohydrates such as bread, potatoes, pasta, rice or beans which increase the blood glucose more slowly (McDowell & Gordon, 1996). Simple sugars should be limited or avoided in foods that are obviously sweet, such as regular soda, chocolate etc., because they raise blood glucose rapidly (Guthrie & Guthrie, 1991). Foods containing sugar can be included as part of the total amount of carbohydrates, however, they should not exceed 10% of the total daily intake of carbohydrates (Meltzer et al., 1998).

Protein

Protein foods should comprise approximately 15% of total calories (Meltzer et al., 1998). High protein diets, which may increase the risk of kidney disease, should be avoided as the risk of kidney disease is already elevated in those with diabetes (McDowell & Gordon, 1996). In addition, protein choices should primarily be those with lower fat, such as chicken and fish (McDowell & Gordon, 1996).

Fat

Fat intake should be limited to a maximum of 30% of total intake to assist in reducing the risk of developing vascular disease (Guthrie & Guthrie, 1991). In addition, the main aim is to reduce saturated fat -- the type of fat that is most associated with vascular disease (McDowell & Gordon, 1996). Saturated fat is found in animal fats such as butter and meat fat, and in tropical oils such as coconut and palm oils (Guthrie & Guthrie, 1991). The intake of saturated fat should be no more than 10% of total daily calorie intake (Meltzer et al., 1998).

Fibre

There are two types of fibre; soluble and insoluble. Soluble fibre binds to carbohydrate and slows its absorption, thereby lowering blood glucose ("Nutrition," 1994). Soluble fibre is found in fruit and legumes (McDowell & Gordon, 1996). Insoluble fibre is often referred to as bulk or roughage McDowell & Gordon, 1996). It is useful in preventing constipation and may provide a feeling of satiety (McDowell & Gordon, 1996). Insoluble fibre is found primarily in grains and vegetables (Guthrie & Guthrie, 1991). The recommended intake of fibre is 30 gm per day (McDowell & Gordon, 1996). However, those who have **not** been eating a high fibre diet should increase their intake gradually to avoid abdominal discomfort and flatulence (Guthrie & Guthrie, 1991). In addition, it is important to drink sufficient water, six to eight glasses a day, to allow the body to use the fibre efficiently (Beaser & Hill, 1995).

Nutritional Supplements

Eating a balanced diet generally provides sufficient amounts of vitamins and minerals ("Nutrition," 1994). However, recent studies have identified some nutritional supplements as potentially useful in the treatment of diabetes. However, these studies are only in the initial stages (Steven, 1995). As some supplements may be toxic in large doses, it is important to check with a physician before adding nutritional supplements to any treatment regimen (Beaser & Hill, 1995).

Vitamins

Poorly controlled diabetes leads to the loss of B vitamins in the urine. Deficiency of B_6 has been connected to impaired glucose tolerance (ADA, 1996). Niacin should be avoided by diabetics as it may raise the level of glycosolated hemoglobin (Baker & Campbell, 1992). Vitamin C, which is an antioxidant, may assist in preventing some of the long term complications of diabetes (Beaser & Hill, 1995). However, those who use urine testing for self monitoring should avoid Vitamin C as it may cause inaccurate test results (Baker & Campbell, 1992). Vitamin E, another antioxidant is useful in improving insulin uptake into cells (Baker & Campbell, 1992). In addition, it may also help to protect against coronary artery disease (Mann, 1997).

Minerals

Chromium is believed to assist in the regulation and improvement of insulin activity (Steven, 1995). Chromium deficiency may lead to increased blood glucose levels (ADA, 1996). However, there is no indication that chromium improves glucose tolerance in those with an adequate chromium status (Schmidt, 1995). Copper and Manganese deficiencies have been linked to impaired glucose tolerance (ADA, 1996). In one small study, patients given manganese supplements did improve glucose control (Baker & Campbell, 1992). Magnesium deficiency may occur if blood glucose control is poor, leading to increased insulin resistance (ADA, 1996). It may also contribute to glucose intolerance and high blood pressure (Steven, 1995). It is probably worth supplementing magnesium if blood glucose is poorly controlled (Schmidt,1995). Zinc, at either very high or low levels, impairs insulin secretion (Schmidt, 1995). Individuals with poor blood glucose control may consider zinc supplementation because of the risk for zinc deficiency (Schmidt, 1995). However, zinc supplements should be used cautiously because high levels may further impair insulin secretion (Schmidt, 1995).

Evening Primrose Oil

Some studies have demonstrated that the use of the active ingredient in evening primrose oil [gamma linoleic acid or GLA] may be useful in the treatment of diabetic neuropathy and retinopathy (Steven, 1995). However, the dose needed to effect improvement is very large -- twelve times the recommended dose (Steven, 1995).

Therefore, further studies are required before this supplement can be widely recommended (Steven, 1995).

Special Diets and Diabetes

Vegetarian

The ovolacto vegetarian diet, which includes eggs and dairy products, may be a good choice for diabetics. This is because it is high in fibre and complex carbohydrates (Krall & Beaser, 1989). In addition, the beans which provide the majority of the protein in a vegetarian diet, raise blood sugar very slowly (Lowe & Arsham, 1992). A vegan diet, which contains no animal products may also be appropriate for diabetics but requires more caution (Krall & Beaser, 1989). This is because it requires careful combinations of foods to provide a sufficient protein intake (Krall & Beaser, 1989). It is recommended that the assistance of a physician and/or a dietitian be sought before attempting to follow a vegetarian diet (Krall & Beaser, 1989).

There is also some evidence that a vegetarian diet may reduce the risk of developing diabetes (Snowdon & Phillips, 1985).

Quick Weight Loss Diets

These types of diets are often advertised on television or in magazines. Unfortunately, most of them don't work and may result in a lowered metabolism which will make future weight loss even more difficult (Beaser & Hill, 1995). In addition, many fad diets do not provide balanced nutrition which is necessary for blood glucose control (Beaser & Hill, 1995). Those using oral antidiabetes agents to control blood glucose should be especially cautious because of the risk of developing either hypoglycemia or hyperglycemia (Beaser & Hill, 1995).

The best way to lose weight is to make small modifications to eating habits to allow weight loss at a rate of one half to one pound per week (McDowell & Gordon, 1996).

Very Low Calorie Diets

These diets, which generally include less than 800 calories per day, need to be carefully supervised by a physician to prevent electrolyte imbalances and maintain lean muscle tissue (Wing, 1995). There is some evidence that very low calorie diets [VLCD] may be useful in obese people with type 2 diabetes because they result in quick and dramatic weight loss with concurrent reduction in blood glucose levels (Wing, 1995). However, the majority of people who use VLCD do gradually regain the weight that was lost. Consequently, further research into how to maintain weight loss on a long term basis is required (Wing, 1995).

Fasting

Generally, fasting is not recommended for those with diabetes (Krall & Beaser, 1989). This is because fasting lowers insulin levels and encourages the breakdown of muscle for energy (McDowell & Gordon, 1996). However, those who wish to fast, for religious or other purposes, should consult with a physician and/or a dietitian for assistance in safe fasting (Krall & Beaser, 1989).

Sweeteners

Sweeteners can be classified into three primary groups: sugars, sugar alcohols [polyols], and nonnutritive sweeteners. The impact on blood glucose by each group is different.

Sugars

Sugars are a form of carbohydrate and therefore are digested to form glucose and become energy for the body (CDA, 1998). Sugars occur naturally in fruits, vegetables, and milk (CDA, 1998). There are also pure sugars, such as table sugar and honey, which provide calories without providing other significant nutritional value ("Position of the American," 1998). Until recently it has been believed that those with diabetes must avoid pure or simple sugars because they would dramatically increase blood glucose levels ("Nutrition recommendations," 1994). However, new studies have shown that sucrose [table sugar] raises blood sugar at about the same rate as bread or potatoes ("Nutrition recommendations," 1994). Therefore, it is now accepted that pure sugars, in limited quantities, may be safely included in a diabetic diet (CDA, 1998). To include pure sugars in the diet, they must replace other sources or carbohydrate, such as fruits, vegetables, or starches, not be used in addition to the usual carbohydrate intake (CDA, 1998). The important feature is the total amount of carbohydrate that is consumed, rather than the specific source of the carbohydrate ("Nutrition recommendations," 1994). However, because pure sugars do not provide other nutrients they should probably not replace more than 10% of the total daily intake of carbohydrate (CDA, 1998). A professional such as a dietitian or a nutritionist can assist individuals with diabetes to determine how much sugar can be included in the diet. There is no evidence that any pure sugar is a better choice for those with diabetes (Graham, 1998). It is still generally recommended that highly sweetened foods, such as regular sodas, be avoided (Vessby, 1994).

There are many forms of simple sugars and they are included in many processed foods (Graham, 1998). Food labels list ingredients in order of most to least content within the specific product. Therefore, foods which list sugar(s) among the first ingredients are high in sugar content and should be consumed in limited amounts (Graham, 1998).

Sugar Alcohols

Sugar alcohols are derivatives of sugar with a structure that resembles alcohol ("Sweeteners," 1996). Although they probably contain similar calories to sugar, it appears that because sugar alcohols are absorbed slowly and incompletely, humans only metabolize a portion of the calories in sugar alcohols ("Position of the American," 1998). Consequently, sugar alcohols result in a slow rise in blood sugar which does not require as much insulin to be absorbed ("Sweeteners," 1996). In addition, they do not cause cavities because they are not broken down by oral bacteria ("Sweeteners," 1996).

While sugar alcohols can be used by those with diabetes, their use is limited because they often cause intestinal gas and/or diarrhea when consumed in moderate to large quantities ("Nutrition recommendations," 1994). There are many "sugar free" products including candy, chocolates and gum, which are sweetened with sugar alcohols and may be used in small amounts by those with diabetes ("Nutrition recommendations," 1994).

Nonnutritive Sweeteners

Nonnutritive sweeteners are sometimes referred to as intense sweeteners because they are greatly sweeter than sugar ("Sweeteners," 1996). There are five nonnutritive sweeteners available in Canada

Saccharin

Saccharin was the first noncaloric sweetener and is approximately 300 times sweeter than sugar ("Sweeteners," 1996). Unfortunately, it has a bitter aftertaste which many consumers dislike ("Sweeteners," 1996). It was widely used for many years but in the

1970's a concern that it might be carcinogenic led to a reduction in its use ("Sweeteners," 1996). More recent studies have not demonstrated an increased risk of cancer ("Sweeteners," 1996).

Cyclamate

Cyclamate is a nonnutritive sweetener which is 30 times sweeter than sucrose ("Position of the American," 1994). Cyclamate was widely used in the 1960's however, there has been concern that it is a carcinogen, or, that in combination with carcinogens that it may promote tumour growth ("Is the artificially sweetened," 1992). Nevertheless, cyclamate is approved for use in over 50 countries, including Canada ("Position of the American," 1994).

Aspartame

Aspartame, often sold as Equal® or Nutrasweet®, is now the most common nonnutritive sweetener. It is a protein and therefore it contains four calories per gram. However, as it is 200 times sweeter than sugar it requires much smaller amounts to obtain equal sweetness ("Position of the American," 1994). Aspartame becomes bitter when exposed to high temperatures so it is not suitable for cooking or baking ("Position of the American," 1994). Aspartame is found in many commercial products such as gum, diet sodas etc. ("Sweeteners," 1996).

Acesulfame Potassium (Ace-K)

Acesulfame potassium is a synthetic, noncaloric sweetener which is 200 times sweetener than sucrose (Freeze, 1995). It has not been tested in diabetics, but in nondiabetic subjects it did not change insulin or blood glucose levels (Freeze, 1995). It has therefore been approved by Health Canada for use by those with diabetes (Freeze, 1995). The CDA is encouraging further testing in those with diabetes (Freeze, 1995). Acesulfame potassium is often blended with other sweeteners, both nutritive and nonnutritive, to produce better tasting products (Freeze, 1995). Therefore, diabetics should carefully read labels for the possible presence of nutritive sweeteners, which will affect blood glucose levels, along with Acesulfame potassium in commercial products (Freeze, 1995).

Sucralose

Sucralose is a noncaloric sweetener which is made from sugar, but due to chemical changes, is no longer sugar ("Sucralose update," 1994). It is commonly known as Splenda®. Sucralose is 600 times sweeter than sugar and is extremely stable at all temperatures, therefore, it may be used in cooking, baking and freezing ("Sucralose update," 1994). Like Acesulfame potassium, when it was approved by Health Canada it had not been testing in diabetics, however, studies in nondiabetics demonstrated no increase in insulin production or blood glucose following ingestion of sucralose ("Sucralose update," 1994). Newer research has demonstrated that this also applies to those with diabetes (Mezitis et al., 1996).

When purchased as Splenda®, sucralose is combined with other ingredients to provide form and texture. Splenda® granular uses maltodextrin [a food starch] as a bulking agent which does provide a small amount of carbohydrate (1/2 gram of carbohydrate per teaspoon). Splenda® packets use a combination of maltodextrin and dextrose and contain 1 gm of carbohydrate per packet. (D. Arnott, personal communication, October 27,1998).

Foot Care

People with diabetes are at risk for complications of the feet (Lupo, 1997). This is because the combination of decreased sensation from neuropathy, and decreased circulation due to peripheral vascular disease, and a decrease in defense against infection due to hyperglycemia increase the likelihood that minor injuries/ulcers will progress to a more serious state (Levin, 1997). Complications of the feet are a major source of illness, disability, and mortality in people with diabetes (Lupo, 1997).

Foot complications generally result from either an injury in which a small skin break allows bacteria to enter leading to infection (Lupo, 1997) or an ulcer which develops from repetitive stress on an area of the foot [i.e. pressure from an ill-fitting shoe] (Levin, 1997). Either of these conditions can progress from mild to a life threatening infection such as gangrene (Lupo, 1997).

Screening

Everyone diagnosed with diabetes should have his/her feet carefully assessed at the time of diagnosis and at least yearly thereafter (Clark, 1996). One useful assessment tool is the monofilament, a piece of nylon similar to a piece of fishing line which is specially designed to test sensation. The monofilament is pressed steadily against the skin of the foot. Anyone who cannot feel the monofilament is at an increased risk of developing foot injuries/ulcers (Lupo, 1997). Anyone who is at an increased risk should have the frequency of assessment increased (Meltzer et al., 1998). For example, those with neuropathy should be assessed every six months (Haas, 1995). Those with a combination of neuropathy and foot deformity should be assessed every three months (Haas, 1995).

Finally, anyone who has had a previous foot complication should be assessed monthly (Haas, 1995).

Treatment

Because diabetics face an increased risk of infection, any foot injury must be taken seriously (Haas, 1995). It is also important to remember that if neuropathy is present there may be no pain, even with very serious problems (Haas, 1995).

Minor cuts or blisters should be cleansed with soap and water and covered with an antibiotic ointment, and a bandage (Lupo, 1997). Observe the area daily for any signs of infection such as warmth, redness, or swelling. Should these occur an immediate consultation with a physician is warranted as any infection must be treated aggressively (Meltzer et al., 1998). Treatment of more serious foot injuries or any foot ulcer requires the assistance of specialists with experience in diabetic foot care (Meltzer et al., 1998).

Prevention

As minor foot injuries/ulcers are at a high risk for progressing to more serious conditions, it is extremely important that anyone with diabetes practice preventative foot care. Daily foot care should include:

- Daily inspection of the feet including the top, bottom, and between the toes looking for any injuries, changes in shape, color, or temperature. Anyone who is unable to inspect his or her own feet should ask a relative or friend complete this activity (Lupo, 1997).
- Wash feet daily with a mild soap. Dry carefully, especially between the toes (Levin, 1997).
- Moisturize feet daily, but not between the toes (Lupo, 1997).

- Do not soak feet (Lupo, 1997).
- Cut toenails straight across and smooth the edges with a file (Lupo, 1997). If toenails are abnormally hard or deformed they should be cut by podiatrist (Lupo, 1997).
- Never walk barefoot and avoid sandals and high heels which do not provide sufficient protection or cushioning (Lupo, 1997).
- Wear properly fitting shoes to avoid areas of pressure (Lupo, 1997).
- Do not use over the counter products to treat corns/calluses -- see a podiatrist instead (Lupo, 1997).
- Avoid heating pads, electric blankets, and hot water bottles, especially if neuropathy is present (Lupo, 1997).
- Do not smoke -- the majority of diabetics who require amputation are smokers (ADA, 1996).
- Maintain good blood glucose control which will help prevent neuropathy and will decrease the risk of infection (Beaser and Hill, 1995).

Exercise

Exercise is very valuable for people with type 2 diabetes because of the beneficial effects of increased insulin sensitivity leading to decreased blood glucose, decreased blood pressure, and improvement of lipid levels in the blood (Meltzer et al., 1998). In addition, exercise may prove useful in weight loss (McDowell & Gordon, 1998). The overall effect of exercise will generally be an improvement in blood glucose control and, for some people, a reduction in the need for blood glucose lowering medications (Meltzer et al., 1998). Therefore, unless there are contraindications to exercise, it should be an integral part of diabetes treatment (Henry & Genuth, 1996). While any activity is better than no activity (Norton, 1995), low to moderate intensity exercise will lower blood glucose levels both during and after exercise (Meltzer et al., 1998). Some recommended activities include walking, cycling, and swimming, (Norton, 1995).

Anyone with diabetes who is beginning an exercise program needs to consult with his/her physician prior to starting the program (Norton, 1995). This is because those with diabetic complications may need to take special precautions during exercise (Meltzer et al., 1998). For example, those with neuropathy should probably avoid jogging due to the risk of developing blisters or ulcers on the feet which may not be noticed due to lack of pain (Norton, 1995). In addition, those with retinopathy, nephropathy, or cardiovascular disease generally need to avoid activities which raise blood pressure such as volleyball, racquetball, and weight lifting (Norton, 1995). Finally, anyone who has not been exercising should start very slowly [i.e. 5 to 10 minutes per day] and gradually increase to longer periods of time (Norton, 1995). This approach will significantly reduce the risk of injury (Norton, 1995).

For those with type 2 diabetes who are exercising to optimize their blood glucose control, timing of exercise is important (Graham, Biermann & Toohey, 1995). The best time to exercise for this purpose is approximately 60 to 90 minutes after eating (Graham, Biermann & Toohey, 1995). This is because exercise at this time will decrease the amount the blood sugar level rises after a meal. In addition, hypoglycemia due to exercise is less likely after a meal (Graham, Biermann & Toohey, 1995).

Precautions

- Check blood glucose prior to exercise. If blood glucose level is less than 5 mmol/l a snack is required before exercising (Meltzer et al., 1998). If blood glucose is greater than 15 mmol /l exercise should be deferred until blood glucose is lower (Meltzer et al., 1998). This is because when blood glucose is elevated exercise can cause blood glucose to rise even higher (Graham, Biermann & Toohey, 1995).
- Stop exercising if you develop a headache, feel weak or shaky, or become nauseous. Check blood sugar level (Norton, 1995).
- Carry quick acting carbohydrate so that signs of hypoglycemia can be treated immediately (Graham, Biermann & Toohey, 1995).
- Carry diabetes identification so that rescue personnel will know you are diabetic (Norton, 1995).
- Check feet for blisters/cuts/irritation before and after activity (Meltzer et al., 1998).
- Drink water while exercising to avoid dehydration (Norton, 1995).
- Stop exercising if you develop chest/arm pain. Call a physician immediately (Norton, 1995).
- Remember that exercise has a prolonged effect on blood glucose levels and hypoglycemia may occur for several hours after exercise (Graham, Biermann & Toohey, 1995).
- Anyone who uses insulin needs to be sure to inject in a site away from actively exercising extremities (Meltzer et al., 1998).

The Banting & Best Road: Medical Management of Diabetes

Oral Antidiabetes Agents For Treating Type 2 Diabetes

Oral antidiabetes agents [pills] are generally used to treat type 2 diabetes when diet and exercise alone have not been sufficient to lower blood glucose to an acceptable level (Hoyson, 1995). In order to achieve blood glucose control, approximately 90% of those with type 2 diabetes will eventually require drug therapy (Turner & Holman, 1995). Oral antidiabetes agents are not a substitute for diet and exercise, they are an adjunct (Henry & Genuth, 1996). There are five classes of drugs which are available in Canada for the treatment of type 2 diabetes.

Sulfonylureas

The sulfonylureas was the first class of oral antidiabetes agent for type 2 diabetes and has been available since the 1950s (Hoyson, 1995). They were discovered when a researcher noticed that patients using sulfa antibiotics sometimes developed hypoglycemia (Hoyson, 1995). There are a number of sulfonylureas available for the patient with type 2 diabetes (CPA, 1998).

Sulfonylureas work by stimulating the pancreas to secrete more insulin (CPA, 1998). Although sulfonylureas are generally quite effective in lowering blood glucose levels there are some people who, even with the maximum dosage, will not achieve acceptable blood glucose levels. This is referred to as primary failure and it occurs in approximately 10-20% of people who try sulfonylureas (Nathan, 1997). The reason for primary failure is unknown (Nathan, 1997). In addition, although sulfonylureas may initially be effective, they often gradually cease being effective over time (Nathan, 1997). This is called secondary failure and occurs in approximately 10% of people using them per year of use

(Cefalu, Colwell, & King, 1996). Therefore, after ten years of use the majority of patients will no longer be able to achieve an acceptable blood glucose level with sulfonylureas alone (Cefalu et al., 1996). When sulfonylureas do not sufficiently control blood glucose they may be combined with the other classes of drugs (CPA, 1998).

There are several common side effects of the sulfonylureas. The first of these is weight gain which is a concern because increased weight often leads to increased insulin resistance (Cefalu et al., 1996). For this reason, the sulfonylureas are generally not the first choice for type 2 diabetics who are obese (Cefalu et al., 1996). Another common side effect of sulfonylurea administration is hypoglycemia (Hoyson, 1995). Anyone using a sulfonylurea should be aware of the possibility of hypoglycemia and understand how to both avoid and treat hypoglycemia, should it occur (Hoyson, 1995). A final possible side effect is an intolerance to alcohol which is seen in some people who use sulfonylurea drugs. This intolerance is demonstrated by facial flushing, nausea and a rapid pulse (CPA, 1998).

Biguanide

The only biguanide currently available in Canada is metformin (Glucophage®) (CPA, 1998). The exact method by which metformin lowers the blood sugar level is unknown (CPA, 1998). It is believed the metformin decreases the release of glucose from the liver and may increase insulin sensitivity within cells (Cefalu et al., 1996). Metformin does not increase insulin secretion and therefore does not generally cause hypoglycemia (Dunn & Peters, 1995). Interestingly, metformin does not affect the blood glucose levels of people who are not diabetic (Cefalu et al., 1996).

Metformin is generally equally effective as the sulfonylureas at reducing blood glucose levels (Dunn & Peters, 1995). Because it does not cause weight gain and may even cause appetite suppression, it is generally the first choice for type 2 diabetics who are overweight (Hoyson, 1995). If metformin is not effective in lowering blood glucose to an acceptable level it may be combined with the other classes of drugs (CPA, 1998).

The most common side effects of metformin are gastrointestinal symptoms such as diarrhea, abdominal discomfort, nausea, and decreased appetite (CPA, 1998). Most of these symptoms can be treated by beginning treatment with a small dose and then slowly titrating the dose upwards until an acceptable blood glucose level is achieved (Dunn & Peters, 1995). In addition, taking metformin with food may minimize gastrointestinal side effects (Dunn & Peters, 1995).

Alpha Glucosidase Inhibitor

The only alpha glucosidase inhibitor available in Canada is acarbose (Prandase®) (CPA, 1998). Acarbose functions by inhibiting an enzyme which delays the absorption of carbohydrate from the intestine resulting in a slower rise in blood glucose after meals (CPA, 1998). On its own, acarbose does not cause hypoglycemia (Cefalu et al., 1996).

Acarbose is somewhat less effective than either the sulfonylureas or metformin at lowering blood glucose. However, it is often effectively combined with other antidiabetes agents to achieve acceptable blood glucose levels (Cefalu et al., 1996). In addition, to be effective, acarbose must be taken with the first bite of the meal (CPA, 1998).

The major side effects of acarbose are gastrointestinal symptoms, especially flatulence, bloating and diarrhea (CPA, 1998). These symptoms are the result of the fermentation of unabsorbed carbohydrate in the intestine (CPA, 1998). For this reason, the intake of foods containing sucrose [cane sugar, table sugar] should be limited to decrease the possibility of side effects (CPA, 1998). Side effects can also be decreased by starting with a low dose and slowly titrating the dose upward to an effective level (CPA, 1998). In addition, side effects generally diminish as duration of treatment increases (CPA, 1998). However, acarbose is not a good choice for patients with inflammatory bowel disease such as irritable bowel syndrome [IBS], Crohn's disease, or ulcerative colitis (Cefalu et al., 1996). Finally, patients who are at risk for hypoglycemia due to their concurrent use of sulfonylureas should understand that symptoms of hypoglycemia must be treated with glucose [for example, purchased glucose tablets] rather than sucrose as acarbose delays the absorption of the sucrose (CPA, 1998).

Meglitinide

Currently, the only meglitinide available in Canada is repaglinide (Gluconorm®). Repaglinide works by increasing insulin secretion, however it is not a sulfonylurea and its duration of action is much shorter than the sulfonyureas (Marbury, Huang, Strange & Lebovitz, 1999). Therefore, the incidence of hypoglycemia is significantly reduced with repaglinide (Marbury et al., 1999).

Repaglinide is as effective at reducing blood glucose levels as the sulfonyureas (Clark, 1998) and may be combined with metformin for an increased effect (Brodows, 1998). Repaglinide must be taken with meals and should not be taken if a meal is skipped (Brodows, 1998). Taking repaglinide without food dramatically increases the risk of hypoglycemia (Elliot & Chan, 1998).

The most common side effect of repaglinide is hypoglycemia, therefore, patients should be informed of the signs/symptoms and the treatment of hypoglycemia before beginning repaglinide (Marbury et al., 1999). Other side effects include minor weight gain and increased appetite (Marbury et al., 1999).

Thiazolidinediones

This class of oral antidiabetic agents, also called glitazones, currently includes only one drug in Canada, rosiglitazone (Avandia®), although others are available internationally. Rosiglitazone functions by decreasing insulin resistance through increased insulin sensitivity in muscle, fat, and liver cells (Lipkin, 1997). This class of drugs also decreases the production of glucose by the liver (Teter, 1997). Rosiglitazone does not increase insulin secretion (Saltiel & Olefsky, 1996).

Approximately 25% of patients do not respond to the thiazolidinediones (Saltiel & Olefsky, 1996). The reason for this lack of response remains unclear but may be connected to decreased levels of circulating insulin in some people (Saltiel & Olefsky, 1996). However, in those who respond to this class of drugs, the effectiveness appears to be similar to sulfonylureas or metformin (Clark, 1998). Rosiglitazone may be combined with other oral antidiabetes agents for an increased effect (Saltiel & Olefsky, 1996).

Generally, rosiglitazone appears to be well tolerated with few side effects (Teter, 1997). However, another drug in this class, not available in Canada, has demonstrated a serious risk for increased liver enzymes, an effect which is dangerous and may require withdrawal of the drug (Lipkin, 1999). Therefore, liver function should be assessed prior to beginning treatment with rosiglitazone, after one month of therapy, every two months for the first year, and at least yearly thereafter (Lipkin, 1999). Anyone who develops abdominal pain, especially with concurrent nausea and vomiting, dark urine, or jaundice should immediately seek medical attention (Lipkin, 1999).

Insulin And Type 2 Diabetes

Many people with type 2 diabetes will initially attain reasonable blood glucose control with diet and exercise and/or oral antidiabetes agents (Meltzer et al., 1998). However, as duration of diabetes increases, it becomes likely that many people will require insulin to maintain acceptable blood glucose levels (Meltzer et al., 1998). A recent study in the United Kingdom suggested that by six years after diagnosis approximately 50 % of patients with type 2 diabetes need insulin (Turner & Holman, 1995). Insulin therapy may be added to the use of oral antidiabetes agents, or may be used alone (Meltzer et al., 1998).

Insulin must be injected because as a protein it is digested in the stomach and becomes inactive (Guthrie & Guthrie, 1991). In addition, it is important to understand that insulin is not a drug, it is a hormone that is being replaced because the pancreas is not producing enough insulin to maintain acceptable blood glucose levels

Insulin is available in a variety of preparations (Strowig, 1995). Traditionally, insulin came from beef or pork sources (Strowig, 1995). However, genetic engineering has allowed the manufacture of "human" insulin which more closely approximates the insulin produced by nondiabetic individuals (Strowig, 1995). Generally, human insulin is preferred because many people develop allergies to beef or pork insulin (Strowig, 1995).

Insulin preparations are available in four primary types:

- Ultra rapid acting -- begins to work in approximately one half hour, peaks in one hour, and lasts approximately three to four hours (Emilien, Maloteaux, & Ponchon, 1999).

- Rapid acting -- begins to work in approximately 1/2 to 1 hour, peaks in 2 to 4 hours, and lasts approximately 4 to 8 hours (CPA, 1998).
- Intermediate acting -- begins to work in approximately 1 1/2 to 2 1/2 hours, peaks in 6 to 12 hours, and lasts 4 to 24 hours (CPA, 1998).
- Long acting -- begins to work in approximately four hours, and lasts 24 or more hours (CPA, 1998).

Insulin is administered following a variety of regimens, usually from one to four injections per day and often combining a variety of insulin types to achieve the best possible blood glucose control (Meltzer et al., 1998). A physician can determine the best treatment regimen for each individual (Meltzer et al., 1998).

There are a number of precautions which those using insulin need to be aware of. In particular, anyone using insulin must be careful to regulate food intake and exercise in concert with peak action times of the insulin to decrease the risk of hypoglycemia (Strowig, 1995). Injection sites need to be rotated to avoid problems at the injection site (Guthrie & Guthrie, 1991). Injection sites include the upper arms, abdomen, thighs, and back (Guthrie & Guthrie, 1991). Finally, weight gain is common in those with type 2 diabetes who use insulin (Henry, 1996).

The Road Not Taken [Hopefully]: Chronic Complications Of Diabetes

Nephropathy

Nephropathy is a long term complication of diabetes which affects the kidneys. Although the exact cause is unclear (Zawada, Boice, & Santella, 1994) it is believed that high blood glucose levels damage the small blood vessels in the kidney, eventually resulting in nephropathy (ADA, 1996). As the blood vessels become damaged they are less able to effectively filter the blood. Eventually, if nephropathy progresses, toxic waste builds up in the blood (Lowe & Arsham, 1992). Approximately 20-30% of people with diabetes develop nephropathy (ADA, 1997). The damage to the kidneys in nephropathy is gradual and effective treatment can delay the progression (Meltzer et al., 1998). However, without treatment nephropathy can progress to kidney failure. Nephropathy is the primary cause of kidney failure in Canada (Meltzer et al., 1998).

Risk Factors

The primary risk factors for the development of nephropathy are: Longer duration of diabetes, especially longer than 10 years (Irvin, 1996). Poor blood glucose control which allows hyperglycemia to damage the small blood vessels of the kidneys (Irvin, 1996). The presence of cardiovascular disease, peripheral vascular disease or retinopathy (Irvin, 1996). A family history of high blood pressure (Irvin, 1996). A family history of kidney disease (Irvin, 1996). Male gender, nephropathy is twice as common in men as in women (Robertson, 1995).

Diagnosis and Screening

Microalbuminuria -- very small amounts of albumin in the urine -- is the earliest sign of nephropathy (Meltzer et al., 1998). Microalbuminuria can be detected by a simple random urine sample (Meltzer et al., 1998). Anyone who has a positive sample [evidence of microalbuminuria] should have repeat tests done over a period of three months to confirm the diagnosis (Meltzer et al., 1998). All people with type 2 diabetes should be screened for nephropathy, with the microalbuminuria urine test, at the time of diagnosis and then annually (Meltzer et al., 1998).

Treatment

Once nephropathy has been diagnosed, strict blood glucose control is essential to reduce continuing damage to the kidneys (Zawada, Boice, & Santella, 1994). Blood pressure control is also essential to slow the progression of kidney damage (UKPDS Group, 1998a). If blood pressure is elevated, dietary sodium intake should be reduced (Irvin, 1996). There is also evidence that a decrease in dietary protein intake may slow the progression of nephropathy (Meltzer et al., 1998). It is recommended that a dietitian assist in the process of reducing protein to ensure adequate nutrient intake (ADA, 1997). In addition, anyone with nephropathy should stop smoking as smoking is a major risk factor for the progression of nephropathy ("Consensus statement," 1996). Treatment with medications, specifically the ACE [angiotensin converting enzyme] inhibitors, are useful in the treatment of nephropathy (Meltzer et al., 1998). If nephropathy progresses to the stage of kidney failure, treatment includes dialysis and possibly a kidney transplant (Zawada, Boice, & Santella, 1994).

Those with nephropathy should have blood and urine tests to measure kidney function at least twice a year (Meltzer et al., 1998).

Prevention

Prevention, or delay of progression, of nephropathy may be achieved through the following actions:

- Urine screening for microalbuminuria once per year (Meltzer et al., 1998).
- Good blood glucose control -- the severity and duration of high blood glucose levels is a critical factor in the development of nephropathy (Henry, 1996). Although it is

best to aim for blood glucose levels close to normal, any improvement will be beneficial ("Consensus statement," 1996).

- Good blood pressure control -- it is recommended that blood pressure be maintained ≤ 130/85 mm/Hg (Meltzer et al., 1998).
- Seek prompt treatment of urinary tract infections as they can damage the kidneys. Signs of urinary tract infections include painful urination, frequency, and cloudy or bloody urine (Beaser & Hall, 1995).
- Do not smoke ("Consensus statement, 1996).
- Avoid high dietary protein intake (Irvin, 1996)

Neuropathy

Neuropathy is defined as nerve damage which occurs as a result of diabetes (Beaser & Hill, 1995). Approximately 50% of those with diabetes for longer than ten years will develop neuropathy (Meltzer et al., 1998). The cause of neuropathy is not completely understood but it is believed that sugar in the blood causes swelling in the sheath which surrounds nerves. This swelling leads to nerve damage (Beaser & Hill, 1995). There are three types of neuropathy; sensory, motor and autonomic.

There are a number of risk factors which are known to increase the likelihood of developing neuropathy. The primary risk factors seem to be age and duration of diabetes (McDowell & Gordon, 1996). It is widely accepted that the longer one has diabetes, the more likely one is to develop neuropathy (Morsiani, 1989). Poor blood glucose control also increases the risk of developing neuropathy (Guthrie & Guthrie, 1991). The United Kingdom Prospective Diabetes Study [UKPDS] a large study which researched type 2 diabetes, determined that good metabolic control reduced or delayed the onset of neuropathy by 60% (UKPDS Group, 1998a). Finally, excessive alcohol intake may also increase the risk of developing neuropathy as alcohol also damages the nerves (Morsiani, 1989).

Neuropathy can be prevented or delayed by controlling the risk factors: Maintaining good blood glucose control is almost certainly the most important factor (Beaser & Hill, 1995). In addition, a decrease in alcohol intake may be useful (ADA, 1996). Finally, all diabetics should be tested yearly for the presence of neuropathy (Meltzer et al., 1998).

Sensory Neuropathy

Sensory neuropathy results from damage to the sensory nerves, those used in touch and feeling (ADA, 1996). It can occur in virtually any nerve, although it most often affects the arms, legs, hands, or feet (Beaser & Hill, 1995). Sensory neuropathy results in pain which ranges from minor to severe (Beaser & Hill, 1995). Other symptoms include; itching, tingling, burning, aching, overly sensitive skin, and a feeling of pins and needles (ADA, 1996). Often the pain is worse at night (McDowell & Gordon, 1996). As damage to the nerve progresses the pain may disappear and be replaced by numbness. This is because the nerve is dying, once the nerve is dead it does not regenerate (Beaser & Hill, 1995). Loss of sensation increases the risk that minor injuries will be ignored and progress to severe problems (Beaser & Hill, 1995). For example; a small blister may become infected because it is not painful (Beaser & Hill, 1995).

The most common type of sensory neuropathy is called distal symmetrical polyneuropathy. It affects the nerves in both feet, resulting in pain (McDowell & Gordon, 1996). Treatment generally involves normalizing blood glucose which generally results in a lessening of symptoms (Guthrie & Guthrie, 1991).

Motor Neuropathy

Motor neuropathy results when the nerves which allow voluntary movement are damaged by diabetes (Guthrie & Guthrie, 1991). Without nerve inervation, the muscle fibre shrinks and becomes weak (Guthrie and Guthrie, 1991). Common symptoms of motor neuropathy are abnormally sensitive skin and muscle weakness (Guthrie & Guthrie, 1991).

Diabetic amyotrophy is a common form of motor neuropathy (McDowell & Gordon, 1996). The nerves to the muscles in the thighs are damaged and result in difficulty rising from a sitting position, walking, and climbing stairs (McDowell & Gordon, 1996). Pain is also common in amyotrophy (McDowell & Gordon, 1996). Most patients do recover slowly, over a period of one to two years, with physiotherapy and better glucose control (McDowell & Gordon, 1996). However, some patients will eventually become severely disabled by amyotrophy (McDowell & Gordon, 1996).

Another common form of motor neuropathy results in foot drop when the muscle that raises the foot is damaged (Beaser & Hill, 1995). Foot drop is generally treated with the use of a brace and usually improves over time (Beaser & Hill, 1995).

Autonomic Neuropathy

Autonomic nerves control the body's involuntary responses. These nerves control the heart, lungs, bladder, digestive system, blood vessels, and sex organs (ADA, 1996).

Autonomic neuropathy affecting the gastric system is called gastroparesis. Symptoms include; a feeling of fullness, nausea, vomiting, diarrhea, and constipation

(Bloomgarden, 1995). Treatment typically involves prescription medications (Beaser & Hill, 1995) and a diet low in fat and fibre, which slows the emptying of the stomach (Bloomgarden, 1995). For some people, eating smaller, more frequent meals will help to decrease the symptoms (Beaser & Hill, 1995).

Neuropathy of blood vessels leads to postural hypotension, a decrease in blood pressure when rising from a lying or sitting position (Beaser & Hill, 1995). Rising quickly will generally result in weakness and dizziness (Guthrie & Guthrie, 1991). It can be treated with medication to raise blood pressure (Beaser & Hill, 1995).

Neuropathy of the bladder creates a condition called neurogenic bladder which is an inability to sense when the bladder is full (ADA, 1996). The result may be frequent urinary tract infections (ADA, 1996). A regularly scheduled bathroom routine, such as every two hours, may be useful (Beaser & Hill, 1996).

Retinopathy And Other Complications of the Eyes

The eyes are an area of the body that is very vulnerable to the effects of diabetes (Beaser & Hill, 1995). There are a variety of ways in which the eyes can be affected: blurred vision, double vision, cataracts, glaucoma, and retinopathy are all possible complications for those with diabetes (Beaser & Hill, 1995).

Blurred Vision

Blurred vision can be a symptom of diabetes because elevated blood glucose results in fluid shifts in the eye causing swelling in the lens and leading to difficulty in focusing (Beaser & Hill, 1995). Blurred vision is often present prior to diagnosis of diabetes and can also occur at times of poor blood glucose control (Guthrie & Guthrie, 1991). Typically, vision improves with good blood glucose regulation (Beaser & Hill, 1995).

Therefore, it is best to wait until blood glucose is in control before determining the need for prescription eyeglasses (Guthrie & Guthrie, 1991).

Double Vision

Double vision occurs as a result of neuropathy to one set of eye muscles (Krall & Beaser, 1989). Double vision generally improves gradually over several weeks to months and usually results in a complete recovery (Krall & Beaser, 1989).

Cataracts

A cataract is a cloudiness in the lens of the eye which results in decreased vision (Beaser & Hill). When cataracts occur in those with diabetes, they tend to develop at an earlier age than in nondiabetics (Guthrie & Guthrie, 1991). This is because high blood glucose leads to an accumulation of glucose in the lens (Morsiani, 1989). The glucose converts to sorbitol, a sugar alcohol, causing swelling in the lens and disruption of the lens fibres (Morsiani, 1989).

Cataracts can be treated by surgical removal and replacement with an artificial lens (McDowell & Gordon, 1996). Cataracts can be prevented by maintaining good blood glucose control (Lowe & Arsham, 1992). Some studies indicate that supplementation of bioflavanoids may reduce sorbitol in tissues and therefore help to prevent cataracts (Lowe & Arsham, 1992). In addition, everyone with diabetes should have a yearly eye exam by an ophthalmologist (ADA, 1996).

Glaucoma

Glaucoma is a buildup of fluid in the eye which leads to an elevated intraocular [in eye] pressure (ADA, 1996). Anyone can develop glaucoma, with those over forty being at a higher risk (Beaser & Hill, 1995). Although the reason is unclear, those with diabetes also have an increased risk of developing glaucoma (ADA, 1996).

Glaucoma can be easily diagnosed by an ophthalmologist using a simple procedure to measure the pressure in the eye (Beaser & Hill, 1995). Glaucoma can be vision threatening and some forms of glaucoma have few symptoms, therefore, it is essential to have regular, once yearly, tests for glaucoma (ADA, 1996). One type of glaucoma, acute angle glaucoma, develops rapidly. Symptoms of acute angle glaucoma include eye pain, excessive tearing, blurred vision, and seeing coloured halos around lights (ADA, 1996). These symptoms require emergency treatment (ADA, 1996). The usual method of treatment for glaucoma is eye drops to reduce the pressure in the eye (Beaser & Hill, 1995).

Retinopathy -- Definition and Cause

Retinopathy is damage to the retina, the lining of the back of the eye (Beaser & Hill, 1995). The retina has many tiny blood vessels which are easily damaged by diabetes because they are sensitive to high blood glucose levels (Beaser & Hill, 1995). One study demonstrated that 40% of people with type 2 diabetes have some retinopathy at the time of diagnosis (Bloomgarden, 1995). Diabetic retinopathy is the primary cause of blindness in adults in North America (Meltzer et al., 1998).

There are two stages of retinopathy; background retinopathy and proliferative retinopathy (Beaser & Hill, 1995). However, everyone with retinopathy does not necessarily progress through both stages (Morsiani, 1989). Some people with severe background retinopathy never develop proliferative retinopathy and others with only minor background retinopathy quickly develop proliferative retinopathy (Morsiani, 1989). The reason for this is unclear, nevertheless, those with background retinopathy should be followed carefully by an ophthalmologist so that treatment of any proliferative retinopathy can begin immediately (Morsiani, 1989).

Background Retinopathy

Background retinopathy, also called nonproliferative retinopathy (ADA, 1996), occurs when damage to the small capillaries in the retina causes blockage (McDowell & Gordon, 1996). In order to cope with the decreased blood supply, other capillaries dilate and develop bulges called microaneurysms (ADA, 1996). Microaneurysms can be seen during a retinal eye examination as tiny red dots on the surface of the retina (McDowell & Gordon, 1996). The microaneurysms create weak spots which may leak, leaving a waxy deposit called exudate on the retina (Guthrie & Guthrie, 1991). The exudates are visible, during an eye examination, as yellowish areas on the retina (McDowell & Gordon, 1996).

Usually background retinopathy does not affect vision and does not require treatment (Lowe & Arsham, 1992). However, when the microaneurysms leak into the centre of the retina -- the macula -- macular edema may develop (McDowell & Gordon, 1996). Macular edema, a swelling of the macula, may impair central vision, particularly the area used for reading (McDowell & Gordon, 1996).

Proliferative Retinopathy

Proliferative retinopathy occurs as more areas of retina become ischemic, lacking in blood supply (McDowell & Gordon, 1996). The ischemia leads to the development of many new blood vessels (McDowell & Gordon, 1996). These new blood vessels are very fragile and often rupture and bleed into the vitreous humor, the clear, gel like fluid that fills the eye (Beaser & Hill, 1995). The blood in the vitreous blocks the light from the retina, interfering with vision (McDowell & Gordon, 1996). Usually, vision slowly improves but anyone with sudden vision changes should immediately consult an ophthalmologist (McDowell & Gordon, 1996). Hemorrhaging of these new blood vessels in the eye can also cause scar tissue (Guthrie & Guthrie, 1991). The scar tissue contracts, pulls on the retina and causes a retinal detachment (Guthrie & Guthrie, 1991). Retinal detachment can lead to blindness and must be treated immediately (Guthrie & Guthrie, 1991).

Retinopathy is often present with few symptoms, therefore it is extremely important to have yearly eye examinations by an ophthalmologist (Krall & Beaser, 1989). However, the following symptoms require immediate attention: sudden loss of vision (Beaser & Hill, 1995), severe eye pain (Beaser & Hill, 1995), a feeling that a curtain is descending (Beaser & Hill, 1995), floating spots (ADA, 1996), shadows or dark areas in vision (ADA, 1996), or straight lines that do not look straight (ADA, 1996). Any of these symptoms should be taken seriously because the earlier proliferative retinopathy treatment is begun the better the chance that vision will be preserved (Krall & Beaser, 1989).

Treatment of Retinopathy

Background retinopathy does not require treatment other than frequent eye examinations to detect proliferative retinopathy (Krall & Beaser, 1989).

The most common treatment for proliferative retinopathy is laser photocoagulation (McDowell & Gordon, 1996). The light from the laser burns the retina and prevents the development of new blood vessels (Beaser & Hill, 1995). Laser treatment may decrease vision slightly, especially if the proliferative retinopathy is extensive, but the overall benefit of preventing severe vision loss usually outweighs the risk (McDowell & Gordon, 1996).

Retinal detachment is generally treated with a surgical procedure called scleral buckling which pushes the sclera, the white of the eye which covers the surface of the eyeball, against the retina, thereby restoring vision (Guthrie & Guthrie, 1991).

Large hemorrhages into the vitreous which do not resolve spontaneously can be treated with vitrectomy, a surgical procedure that removes the vitreous and may restore vision (McDowell & Gordon, 1996). The vitreous is usually replaced with salt solution (Guthrie & Guthrie, 1991).

Prevention

Prevention of retinopathy is the best possible treatment (Nathan, 1997). It is estimated that early detection and treatment can prevent 95% of vision loss (Klein, Klein & Moss, 1996). The following actions are useful in preventing retinopathy:

- Have an eye examination by an ophthalmologist at least every two years (Meltzer et al., 1998).
- Keep blood pressure normal -- hypertension increases the risk for retinopathy -- keeping blood pressure in tight control resulted in a 34% reduction in the risk of retinopathy (UKPDS Group, 1998a).
- Seek immediate help for any changes in vision so that any necessary treatment can begin (Beaser & Hill, 1995).
- Maintain good blood glucose control -- maintaining near normal blood glucose levels

resulted in an approximately 25% reduction in the risk of retinopathy (UKPDS Group, 1998a).

- Stop smoking -- it is believed that smoking may increase the risk background retinopathy will progress to the more dangerous proliferative stage (Morsiani, 1989).
- Decrease alcohol consumption -- there is evidence that alcohol consumption is strongly connected with the development of retinopathy (Morsiani, 1989)
- Keep cholesterol and triglyceride levels normal -- there is evidence that normal cholesterol levels may reduce exudates, the deposits left from leaking blood vessels (Meltzer et al., 1998).

Vascular Complications

Vascular complications of diabetes are caused by atherosclerosis, commonly called hardening of the arteries, which affects the large blood vessels in the body (Haas, 1995). These large blood vessels supply blood to the heart, the brain, and the peripheral blood vessels in the arms and legs. Atherosclerosis causes blood vessels to stiffen and damages the inner lining of the blood vessel which makes it difficult for blood to pass (Lupo, 1997). Atherosclerosis occurs at an earlier age, develops more rapidly, and is more severe in those with diabetes (Savage, 1996). In addition, although in the nondiabetic population, being female significantly reduces the risk of developing atherosclerosis, diabetes appears to eliminate this advantage (McDowell & Gordon, 1996). In those with type 2 diabetes, up to 75% of deaths are attributed to vascular disease (Savage, 1996).

Risk Factors for the Development of Atherosclerosis

There are numerous risk factors for development of atherosclerosis:

- Aging -- the older one is the higher the risk of atherosclerosis (Haas, 1995).
- A family history of heart disease (Haas, 1995).
- Longer duration of diabetes (Colwell, 1996).
- Low birth weight (Stern, 1996).
- Obesity -- especially abdominal obesity (Turner et al., 1998).
- Smoking (Turner et al., 1998).
- Consistently elevated blood glucose levels -- hemoglobin A1c level greater than 6.2% with increasing risk for higher levels (Turner et al., 1998).
- Recurrent spikes in blood glucose following meals ("Developments," 1996).
- Lack of exercise (Turner et al., 1998).
- Elevated blood pressure (Turner et al., 1998).
- Hyperinsulinemia -- [high levels of insulin in the blood] it is not yet clear how hyperinsulinemia increases atherosclerosis, however, hyperinsulinemia is common in those with type 2 diabetes due to insulin resistance (Turner et al., 1998).
- Increased LDL cholesterol [the "bad" cholesterol] and total cholesterol levels in the blood (Turner et al., 1998).
- Decreased HDL cholesterol [the "good" cholesterol] (Turner et al., 1998).
- Increased triglyceride levels in the blood (Savage, 1996).
- Increased alcohol intake -- this is associated with both high blood pressure and changes in cholesterol and triglyceride levels in the blood (McDowell & Gordon, 1996).

Coronary Artery Disease

Coronary artery disease is caused by atherosclerosis in the blood vessels that supply the heart (Haas, 1995). As a result, the heart may not receive a sufficient supply of oxygen and other nutrients (Haas, 1995). The risk of developing coronary artery disease is increased twofold in men with diabetes and three to fourfold in women with diabetes (Meltzer et al., 1998).

There are three primary manifestations of coronary artery disease:

- Angina -- chest pain caused by intermittent lack of blood supply to the heart (Guthrie & Guthrie, 1991).
- Myocardial infarction -- a heart attack caused by blockage of a coronary artery (Guthrie & Guthrie, 1991).
- Cardiomyopathy -- damage to the heart muscle by lack of blood supply over time (Haas, 1995).

Signs And Symptoms

Coronary artery disease is often asymptomatic in those with diabetes (Meltzer et al., 1998). Those with symptoms often have atypical symptoms, for example, jaw, neck and/or back pain, as opposed to the more familiar crushing chest pain (Robertson, 1995). There is also a higher incidence of "silent" heart attack, one without any symptoms (Meltzer et al., 1998). Often, coronary artery disease is only diagnosed through the use of medical tests such as a stress test or electrocardiogram (Haas, 1995).

Carotid Artery Disease

The carotid arteries supply the brain with the blood, therefore, atherosclerosis in these arteries decreases the amount of oxygen that reaches the brain (Guthrie & Guthrie, 1991).

There are two primary manifestations of carotid artery disease:

- TIA [transient ischemic attacks] -- often called "small strokes," TIAs are the result of an intermittent lack of blood supply to the brain (Haas, 1995).
- Stroke -- caused by blockage of one of the arteries to the brain, or by hemorrhage within the brain (Guthrie & Guthrie, 1991). The risk of stroke is increased twofold in men with diabetes and three to fourfold in women with diabetes (Meltzer et al., 1998). In addition, strokes in diabetics are more severe, have a higher recurrence rate, and a higher mortality rate, especially in patients with higher blood glucose levels (Haas, 1995).

Signs and Symptoms

There are a number of symptoms of carotid artery disease:

- Memory lapses (Robertson, 1995).
- Weakness or numbness on one side of the body (Robertson, 1995).
- Dimming or loss of vision in one eye (Robertson, 1995).
- Difficulty speaking or understanding speech (Robertson, 1995).
- Dizziness or lightheadedness (Robertson, 1995).
- Unsteadiness or falls (Robertson, 1995).
- Fainting (Guthrie & Guthrie, 1991).

Peripheral Vascular Disease

Peripheral vascular disease occurs when atherosclerosis reduces the circulation to the arms and legs. However, typically the problems occur in the legs as walking and standing require increased peripheral blood flow (Guthrie & Guthrie, 1991). Diabetics are at increased risk for development of peripheral vascular disease (Meltzer et al., 1998). Approximately 10% of type 2 diabetics have some peripheral vascular disease at the time of diagnoses (McDowell & Gordon, 1996). Those with peripheral vascular disease are at a higher risk for development of gangrene and resulting lower limb amputation (Meltzer et al., 1998). This is because neuropathy, resulting in decreased sensation to the feet, combined with the poor circulation of peripheral vascular disease, can easily result in a minor injury progressing to gangrene (Meltzer et al., 1998).

Signs and Symptoms

There are many symptoms of peripheral vascular disease:

- Pain in legs when walking which resolves with rest (Beaser & Hill, 1995).
- Slow healing of cuts and scratches (Beaser & Hill, 1995).
- Reddened feet on sitting (Beaser & Hill, 1995).
- Pale feet when feet are raised (Beaser & Hill, 1995).
- Loss of hair on feet and legs (Beaser & Hill, 1995).
- Pain in legs and feet at night (McDowell & Gordon, 1996).
- Cool or cold feet (Lowe & Arsham, 1992).

Screening and Diagnosis

Patients with diabetes need to be assessed regularly for the various risk factors of atherosclerosis (Clark, 1996). A fasting blood lipid profile [total cholesterol, LDL cholesterol, HDL cholesterol and triglyceride] should be completed on diagnosis and repeated every one to three years (Meltzer et al., 1998). The feet should be examined regularly for signs of peripheral vascular disease and/or trauma (Meltzer et al., 1998). Pulses in the feet and legs should be assessed at least annually (McDowell & Gordon, 1996). Any indication that atherosclerosis is developing should be followed up with more intensive, and possibly more invasive, testing to make a definitive diagnosis (Haas, 1995). Blood pressure should be assessed regularly so that any elevation may be recognized and aggressively treated (Meltzer et al., 1998).

Treatment

There are a number of treatments which are helpful in treating vascular disease:

- Do not smoke -- one cigarette can impair circulation for at least one hour (Robertson, 1995).
- Tight blood pressure control -- aim for blood pressure < 130/85 mm/Hg. Medications may be required to achieve this goal (Meltzer et al., 1998). Keeping blood pressure below this level led to a decrease in the mortality rate in those with diabetes (UKPDS Group, 1998b).
- Medications may be prescribed to improve blood supply to the heart (Haas, 1995).
- Dietary changes to improve blood lipid levels (Meltzer et al., 1998).
- Exercise -- functions to improve blood lipid levels (McDowell & Gordon, 1996).
- Reduce alcohol intake (McDowell & Gordon, 1996).

Prevention

Prevention may be achieved through addressing the various risk factors:

- Maintaining a healthy weight (Meltzer et al., 1998).
- Not smoking (Turner et al., 1998).
- Maintaining good blood glucose levels and especially avoiding wide variations in blood glucose (Haas, 1995).
- Maintaining blood pressure < 130/85 mm/Hg (Meltzer et al., 1998).
- Maintaining good blood lipid levels (Meltzer et al., 1998).
- Reducing alcohol intake (McDowell & Gordon, 1996).

In addition, all diabetics who are over 30 and who have other risk factors for vascular disease should take 80-325 milligrams of aspirin per day as a preventative strategy (Meltzer et al., 1998).

Sexual Issues

Male Sexuality & Diabetes

Impotence is a common and often undiagnosed complication of diabetes (McDowell & Gordon, 1996). Impotence, more correctly called erectile dysfunction, is defined as "the inability to attain and/or maintain penile erection sufficient for satisfactory sexual performance" (National Institutes of Health, 1993, p. 83). Erectile dysfunction occurs at an earlier age in men with diabetes than in the general population (Spollett, 1999) and often results in decreased libido (Guthrie & Guthrie, 1991), depression (Guthrie & Guthrie, 1991), loss of self esteem (Setter, Baker, Campbell & Johnson, 1999), and problems with relationships (Setter et al., 1999).

The cause of erectile dysfunction in men with diabetes is complex and is believed to be a combination of multiple factors:

- Autonomic neuropathy -- the nerves to the penis become damaged therefore sexual stimulation does not result in penile erection (McDowell & Gordon, 1996).
- Blood vessel disease -- the penis requires an increased blood supply to become erect (McDowell & Gordon, 1996).
- Psychological factors -- depression is a common cause of erectile dysfunction and is also common in people with a chronic illness (Spollett, 1999). In addition, erectile dysfunction can cause stress which further hinders the ability to perform sexually (Setter et al., 1999).
- Medications -- some common medications, including some blood pressure reducing medications, antidepressants, gastrointestinal medications, and recreational drugs may cause erectile dysfunction (Spollett, 1999).
- Hormonal disorders -- although rare, hormonal disorders should be ruled out in any diabetic male with erectile dysfunction (Spollett, 1999).

Treatment

There are a number of treatment options for men with erectile dysfunction:

- Vacuum devices -- these devices cause erection by creating a vacuum around the penis. Once erection is achieved a rubber band is placed around the base of the penis to maintain the erection (McDowell & Gordon, 1996).
- Oral medications -- the medication Viagra® has been used to treat erectile dysfunction. However, it is less effective in those with diabetes (Setter et al., 1999).

Other oral medications have also been used with limited success (Spollett, 1999).

- Intrapenile injections -- the patient injects medication into the penis which causes erection. Although this method is frequently successful, many men are uncomfortable with the process (Setter et al., 1999).
- Penile implant -- there are variety of types of penile implants to treat erectile dysfunction. While generally effective, the risks and benefits of the surgery must be balanced (Setter et al., 1999).

The factors that help prevent other complications of diabetes will also be useful in preventing erectile dysfunction in men with diabetes. No smoking, acceptable blood pressure, and good blood glucose control will all reduce the incidence of erectile dysfunction (Spollett, 1999).

Female Sexuality & Diabetes

The effects of diabetes on female sexual functioning is less well understood than the effects on male sexual functioning (Guthrie & Guthrie, 1991). Although the research in this area is sometimes contradictory, it appears that women with diabetes are at increased risk of developing decreased sexual desire, may experience pain during intercourse, and experience slow or inadequate lubrication (Enzlin, Mathieu, Vanderschueren, & Demyttenaere, 1998). These dysfunctions are two times more common in women with diabetes than in the general population (Enzlin et al., 1998). The cause of female sexual dysfunction related to diabetes is unclear, but is believed to be related to neuropathy (Enzlin et al., 1998). There has been little research on treatment or prevention of female sexual dysfunction in women with diabetes although, as with many other complications, keeping blood glucose in control is believed to be helpful (ADA, 1996).

Side Roads: Other Factors Which May Have an Impact on Diabetes

Alcohol

People with diabetes need to be especially cautious about drinking alcohol. This is because the presence of alcohol in the blood is perceived by the liver as a toxin. Consequently, the liver focuses on removing the alcohol from the blood. This focus inhibits the ability of the liver to produce glucose (McDowell & Gordon, 1996). Therefore, hypoglycemia may occur when a diabetic, especially one who uses insulin or a sulfonylurea, drinks alcohol (Bell, 1996). Also, symptoms of hypoglycemia can mimic the symptoms of inebriation, so that treatment of hypoglycemia is delayed (McDowell & Gordon, 1996).

In addition, those who take sulfonylureas need to be aware of a possible interaction between alcohol and the drug which can result in the side effects of intense facial flushing, headache and nausea (Krall & Beaser, 1989).

However, moderate intake of alcohol is generally not a problem for those with diabetes, as long as precautions are taken. It is extremely important **not** to drink alcohol on an empty stomach (ADA, 1996). In addition, it is prudent to eat small amounts of carbohydrates while drinking (McDowell & Gordon, 1996). If drinking occurs in the evening, a bedtime snack is essential because alcohol induced hypoglycemia can persist for as long as 12 hours (ADA, 1996). It is important to check blood sugar frequently during and after drinking to watch for alcohol induced hypoglycemia (ADA, 1996). Carrying diabetic identification such as a medic alert bracelet is also useful. If serious hypoglycemia occurs, onlookers, including emergency personnel, may assume that the person is simply intoxicated. Diabetic identification will remind them of the possibility of hypoglycemia, so that proper treatment can occur (McDowell & Gordon, 1996).

While alcohol does contain carbohydrates, when consumed in moderate quantities, it does not require insulin to be metabolized and does not significantly increase blood sugar. However, consumption of a large amount of alcohol may result in an initial rise in blood sugar, followed later by alcohol induced hypoglycemia (Guthrie & Guthrie, 1991). This is because during the time the liver is focused on removing alcohol from the system, it often fails to produce glucose in response to hypoglycemia (ADA, 1996). In addition, diabetics should generally avoid sweet wine, regular beer and mixed drinks such as wine coolers because of their significant carbohydrate content (Bell, 1996).

Tobacco

Those with diabetes should avoid all tobacco products as both diabetes and tobacco increase the risk of developing vascular disease (Krall & Beaser, 1989). A diabetic who smokes significantly increases the risk of having a heart attack, stroke, or peripheral vascular disease (McDowell & Gordon, 1996). In addition, nicotine is a powerful blood vessel constrictor and will significantly decrease the amount of blood which can pass through blood vessels (Guthrie & Guthrie, 1991). If blood vessels are already damaged by diabetes, the risk of insufficient blood supply is dramatically increased. Ninety percent of diabetics who require amputations are smokers (Jovanovic-Peterson et al., 1996).

Illness

One of the body's responses to illness is to increase the production of glucose from the liver for use in the fight against the infection (McDowell & Gordon, 1996). In addition, body cells become less responsive to insulin during illness (Hillson, 1996). Both of these reactions may lead to hyperglycemia during illness (ADA, 1996).

At the first sign of illness it is important to begin testing blood glucose regularly (McDowell and Gordon, 1996). Testing should occur at least four to five times a day (CDA, 1996). Diabetic pills and/or insulin should continue to be taken because blood glucose is likely to be elevated (McDowell & Gordon, 1996). If possible, it is best to continue to eat (ADA, 1996). To prevent dehydration, drink water or other sugar free liquids at a rate of one cup per hour (ADA, 1996). This is especially important in cases of fever, diarrhea, or vomiting (ADA, 1996). Avoid caffeine containing fluids which tend to be dehydrating (ADA, 1996). If blood glucose is less than 13.2 mmol/l and eating is difficult, try eating small amounts of carbohydrate containing food or fluid every hour (McDowell & Gordon, 1996). Aim to eat 10-15 grams of carbohydrate each hour (McDowell & Gordon, 1996). If blood glucose is greater than 10 mmol/l, stick to sugar free liquids (CDA, 1996).

Keep a record of blood glucose results, symptoms and food/fluid intake (ADA, 1996). This will be useful if physician consultation is required. Do not exercise as physical exertion will tend to raise blood glucose levels (Lowe & Arsham, 1992).

The following situations require physician input:

- Illness lasting longer than twenty four hours without improvement or if illness is very severe (CDA, 1996).
- Diarrhea or vomiting lasting longer than four hours (CDA, 1996).
- Blood glucose persistently above 13.2 mmol/l (ADA, 1996).

- Chest pain, difficulty breathing or abdominal pain (ADA, 1996).
- Symptoms of dehydration such as dry or cracked lips or tongue (ADA, 1996).
- Inability to hold down any fluids for more than four hours (CDA, 1996).

It is possible that insulin may be required to bring blood glucose levels back to normal. This does not necessarily mean that insulin will be required forever (Hillson, 1996).

Medications Which May Effect Blood Glucose Levels

Many drugs, both prescription and over the counter can affect blood glucose. These drugs may cause hyperglycemia or hypoglycemia. Anyone who is unsure of the effect of specific medications on diabetes should consult with a physician or a pharmacist.

Medications Which May Cause Hyperglycemia

- Diuretics -- certain types of diuretics, often called water pills, especially the thiazide diuretics, may increase insulin resistance (McDowell & Gordon, 1996). They may also suppress insulin secretion (Guthrie & Guthrie, 1991). Diuretics are prescription drugs which are often used to treat high blood pressure (Guthrie & Guthrie, 1991).
- Estrogen -- Oral contraceptives or hormone replacements containing estrogen increase glucose production by the liver and may increase blood glucose levels (Lowe & Arsham, 1992).
- Steroids -- There are a variety of steroids used to treat many different conditions. They effect blood glucose by stimulating the liver to produce glucose (Guthrie & Guthrie, 1991). Any form of steroid; pills, joint injections, even skin creams can effect blood glucose (Guthrie & Guthrie, 1991).

- Adrenaline -- there are many synthetic forms of adrenaline which can suppress insulin secretion and increase glucose production. These substances can be found in over the counter decongestants and appetite suppressants. Speak to a pharmacist or a doctor if you are concerned about the possible presence of adrenaline in a particular drug (Guthrie & Guthrie, 1991).
- Throat Lozenges -- Most cough candies contain some form of sugar and should therefore be used with caution by those with diabetes (Bayer, 1998). Cough candies that are labeled sugar free generally use a sugar alcohol, such as mannitol, sorbitol or xylitol as a sweetener. In small doses sugar alcohol does not affect blood glucose significantly. However, in large doses it can increase blood sugar and may also act as a laxative (Cyr, 1984).
- Chewable Vitamins -- Many chewable vitamins contain sugar to make them palatable (Bayer, 1998). However, there are products which are truly sugar free (Bayer, 1998). Check with your pharmacist to determine an appropriate vitamin supplement (Bayer, 1998).
- Cough Syrups -- Many cough syrups contain sugar and even those that are labelled sugar free may use honey as a sweetener (Bayer, 1998). However, there are products which are truly sugar free (Cyr, 1984). Check with your pharmacist to determine an appropriate cough syrup (Bayer, 1998).
- Marijuana -- Although marijuana does not in itself affect blood glucose the use of marijuana use often leads to "the munchies," a craving for sweets, which may then cause increased food intake and hyperglycemia (Guthrie & Guthrie, 1991).

Medications Which May Cause Hypoglycemia

- Some antibiotics may work in concert with sulfonylureas and result in hypoglycemia (McDowell & Gordon, 1996).
- Aspirin -- Aspirin and other nonsteroidal antiinflammatory drugs (NSAID's) which are available over the counter, especially in high doses, may lower blood glucose levels (McDowell & Guthrie, 1996).
- Beta Blockers -- These prescription drugs are used to treat high blood pressure and/or angina. They may block the production of glucose from the liver leading to hypoglycemia (Guthrie & Guthrie, 1991).
- Erythromycin & ketaconazole (and other drugs which decrease liver enzymes) will prolong the effects of repaglinide and cause hypoglycemia (Elliot & Chan, 1998).

CHAPTER FIVE: AND MILES TO GO BEFORE I SLEEP:

THE NARRATIVE OF THE SELF

And miles to go before I sleep,
And miles to go before I sleep. (Frost, 1995, p. 207)

This chapter will focus on my personal journey as a diabetic. It begins with my diagnosis and continues to the present day. Being a diabetic is, as one writer described it, "a full-time job, seven days per week, 52 weeks per year" (Armstrong, 1987, p. 559). And this job will continue, barring some medical breakthrough, for the rest of my life. So I have both miles to go before I sleep tonight and miles to go before my final "sleep."

This chapter includes three disparate forms of personal writing. Incident narratives describe actual experiences in my life since I became diabetic. The narratives were generally written as a process of working through issues of being a diabetic and to make meaning of my experiences. Poems are used to more symbolically describe my feelings and experiences. Often, poems can articulate feelings that are difficult for me to write about in prose. Finally, journal entries further elucidate my life with diabetes using two different styles of writing. The first I call the "emotional voice," because it describes my emotions related to my diabetes. The second form of journal writing can be called the "reflective voice," and is a more cognitive analysis of my experience of being diabetic. While some journal entries clearly reflect one of these specific styles of writing, in other entries the styles are intertwined to create a fuller description of my experiences. Therefore, I have chosen to identify my journal writing only as "Journal Entry." Journal entries are not dated because although I am a habitual journalist, I generally only date entries of particular significance to me. However, to provide readers with some sense of the evolution of the writing over time it may be useful to place some of the incident narratives in a temporal context. The thesis was written over a five year period with Hearing the Words occurring at the time of diagnosis, A Feeling of Failure approximately one year later, A License to Drive approximately two years after diagnosis, The Birthday Gift approximately three years after diagnosis, and The Many Faces of Diabetes approximately five years after diagnosis. The other incident narratives, poems and journal entries are organized primarily chronologically, although there are some entries which are not in chronological order. This is because in some cases it seemed valuable to include a reflective writing that provides some analysis of the more emotional writing of other entries.

Hearing the Words

I knew I had diabetes when I heard the following message on my answering machine. "Sue, this is Dr. L.'s office calling. We need to see you about the results of your bloodwork. Please call for an appointment." It doesn't sound particularly disturbing, does it? But I knew that a fasting blood glucose had been drawn two days earlier to provide further information after an elevated result on a random blood glucose test. As a nurse, I knew this meant the result was not normal. The only logical conclusion was that I had diabetes.

Tears filled my eyes as I prepared something to eat. It was dinner time but I was afraid to eat. And yet, I wanted to eat because that had always been one of my primary coping mechanisms. I knew that I would never again be able to look at food as sustenance and comfort. Suddenly, food had become the enemy -- something that I loved and yet would now have to ration. I felt as if I was caught in a web and the strands were tightening around me. What kind of changes would be required? And would I be able to make them?

The next day I saw my general practitioner. When she showed me the blood results I immediately burst into tears. I cried for the entire visit -- it felt as if there were an ocean of tears inside me waiting to burst free. My physician tried to reassure me. She told me that my blood sugar wasn't really very high, as far as diabetes goes. She said I had time to change my eating patterns. And that I wasn't in danger of complications at the moment. I heard it all -- and continued to cry.

I left the office thinking, "how can this be happening to me?" I had already been through so much in the last month. One of my aunts had experienced a serious stroke, a long-standing disability in my shoulders was worsening, and I had just been diagnosed with Sjogren's syndrome, an autoimmune form of arthritis. It was all just too much to take. I felt as if my entire life was falling into pieces around me -- I was totally overwhelmed. And now this! I felt that a vengeful deity must have something in for me. How much more difficult a disease could I have been given? I have always had problems with eating, often tending towards compulsive overeating. And now I would have to find a way to change this pattern. How would I cope? Where would I get the strength?

The Prisoner

The woman sits
        frozen.
                She is free,
                        but feels imprisoned.
By what?
        It is an intangible prison,
                unseen by others,

but existing
in the mind of the woman.
She knows she could escape
from this imagined prison,
but she cannot.
Trapped in her own fears
she waits --
painfully,
longingly,
for release.

Journal Entry: Whenever I told people I was diabetic they would ask whether I needed injections. When I told them I was diet/exercise controlled they would invariably tell me how lucky I was. But in fact, I didn't feel lucky at all. The feelings I had were very strong and I kept wondering if I was overreacting. After reading Living with Diabetes (Maclean & Oram, 1988), I was reassured by the following quote, "The three people who had non-insulin dependent diabetes had reactions similar to insulin dependent people even though this form of diabetes is considered less serious by the medical profession" (p.16.) Although this validated my feelings, I continued to feel extremely distressed.

Trapped

The sugar God appeared
and grabbed me.
Held me tightly.
I could not escape.
I cried:
great tears,
a waterfall,

a rushing torrent,
an ocean.
I begged.
I pleaded with the God
but it was to no avail.
I was trapped;
wound in a web
made of sugar I cannot eat.
Surrounded by a wall
of rules I cannot forget.
Forever to be reminded
of the God who is always there.
Forever to be reminded
of the diagnosis I now bear.

Journal Entry: "I feel the terrible sense of claustrophobia that comes from knowing there is nothing you can do about a situation that is intolerable but tolerate it" (Berg, 1994, p. 61). This statement describes exactly how I feel about my diagnosis of diabetes. It feels absolutely intolerable and yet I have no choice but to tolerate it. I guess the important thing is that I learn to tolerate it in the healthiest way possible. I could try to ignore it but the consequences are too severe. I could try to tolerate it by eating differently but I believe I will have difficulty doing that on a long term basis. The only really healthy way to address my diabetes is to work with the issues that I have around food and hope this will make me able to cope with the changes that I need to make. I have used food as a comfort mechanism. I have to learn how to eat for nutrition -- and not for other reasons. I also have to learn how to stop when I am no longer hungry.

Journal Entry: There is a terrible irony now in my life. I have always used food to cope with stress -- any stress. Being diagnosed with diabetes is a huge stress! But the one thing that I could count on to relieve my stress will have a negative impact on my health. Which in turn will increase my stress! And in attempting to control my eating I increase my stress further because part of my coping mechanism has been eating what I want, when I want, and how I want. So any attempt to restrict my food intake automatically results in increased stress. It is an incredibly vicious and painful cycle. How can I find a way to decrease my stress that doesn't involve food? How can I control my eating? How can I survive this?

Journal Entry: I told people I was diet controlled, at least, that is what my doctor called it! But saying I was diet controlled really meant that there was almost no control. I was not really capable of controlling my diet. And not taking pills or insulin meant that there weren't any external factors assisting in control. Basically, I was uncontrolled!

Journal Entry: I wonder why my fear of complications doesn't make me eat better? There are so many complications! Nephropathy leading to kidney failure; retinopathy leading to blindness; neuropathy leading to a multitude of problems from pain to loss of sensation to loss of bladder control to gastroparesis ...; cardiovascular disease leading to angina, myocardial infarctions and CVA's; peripheral vascular disease leading to limb amputations; sexual complications. My God! Even writing them down is overwhelming! So overwhelming that part of my mind is moved to nihilism. "Forget it! There is nothing you can do, anyway!" Another part of me knows there is something I can do. The research has demonstrated that better glycemic control leads to a decreased risk of complications. So there is something I can do. I am just having trouble doing it! I am trying, but so far I haven't been terribly successful. Maybe over time, I will.

A Feeling Of Failure

I knew for quite a while, a month maybe, that I needed to make some changes. Each morning I would conduct a blood glucose test and the results were discouraging. I would place a drop of blood on the test strip and wait, with baited breath, for the 45 seconds it took to receive a result. "8.2 mmol/l! Oh my God, 8.2 mmol/l! Oh well, tomorrow will be better." Each day I would get similar results and tell myself similar lies. Every once in a while the result would be better. "See, 6.5 mmol/l! There, I knew it would get better!" But deep inside I knew that 6.5 mmol/l was the exception, not the rule. And I also knew that even 6.5 mmol/l was bordering on high. But acknowledging this also meant acknowledging that I really did have diabetes. I would no longer be able to pretend to myself that it wasn't really true.

I had been trying to make changes to my eating habits. But it was SO hard! I just couldn't seem to make the major changes that were necessary. I was fighting habits which developed years before and were difficult to interrupt. I was used to using food as a stress reliever, the one surefire coping mechanism I had. But now, although food still decreased my stress, it increased my blood glucose. Which increased my stress and led to the need for more food. It was a vicious cycle.

Eventually, it occurred to me that something had to change. If I couldn't change my eating habits perhaps I could add an oral antidiabetes agent. At least then my blood glucose might be in better control -- and better control might lead to less stress. Finally, I had a plan of action! I saw my physician and asked for a prescription. She was supportive and encouraged me to continue trying to make dietary changes but didn't pressure me. I left her office with a strange sense of ambivalence. Although I had gotten what I wanted, a prescription for metformin, I wasn't happy. I felt I was a failure. If I had been a really good diabetic I should have been able to do it with diet alone! Shouldn't I?

Journal Entry: One of the things that I find fascinating about my diabetes is that if I didn't know, from the blood results, that I have diabetes, I probably wouldn't be able to tell, physically. I feel well and even when I wasn't on the oral antidiabetic agents, I don't think I felt significantly different.

Journal Entry: One step -- that is all I need to take -- just one step towards controlling my diabetes! But I just can't seem to stop feeling that I should already be in control! Now! Today! And Forever! And my natural inclination is to respond to my failure to be in control with a sense of nihilism -- a belief that I will never be able to be in control. Somehow I need to find a way to fight the nihilism -- to focus on small steps toward success. Small, achievable steps that might eventually lead to an overall goal of diabetes control. But somehow I can't seem to find a way to take a small, single step. It sounds so simple -- to just take one small step. What is not simple is believing that one step is enough. Trusting that one step will lead to further steps and in the long run result in the attainment of diabetic control. That is not simple at all!

It's Just a Coke!

One day I went to a restaurant with friend. It wasn't a special occasion, just an evening out. Shortly after we were seated a waitress came and asked for drink orders. "I'll have a diet Coke® ," I said. We sat there, chatting and trying to decide what we wanted to eat. I was thinking carefully about this because I was finally trying to eat in a way that would keep my blood glucose in control. Soon, the waitress reappeared with our drinks and requested our food orders. We gave them and she disappeared.

I tasted my diet Coke® . **But**, it wasn't diet Coke®. It was regular Coke®, it had been sweetened with sugar. Now came the dilemma. Thoughts raced through my mind. What should I do? Should I ask the waitress to correct her mistake? If I did, should I explain that I am diabetic? Am I just being fussy? And is it fussy to want what I ordered? Did it really matter at all? What if I just drank it? After all, I often eat or drink things that have sugar in them. Couldn't I do so tonight? But as I sat there, I realized this was important. When I asked for a diet soda, I was trying to eat "properly." Thus, to drink the sweetened Coke would be a betrayal of my choice to eat well that particular night.

As I tell this story, I am aware that the actual solution was very simple. I called the waitress over and told her that I had requested diet Coke® and this was regular. She was apologetic and immediately replaced it with diet Coke®. But I also realize that the actual experience was more important to me than a simple case of a mistaken order. Because as I sat there, I faced many of the issues of being diabetic. Suddenly, diabetes wasn't just an abstract condition that I had -- it was part of who I am. It has an impact on the choices I make and because it is a stigmatized illness it has an impact on how others see me. And that was not simple at all!

Food! Glorious Food!

Food, Glorious Food!
    It fills my mind,
        teases my senses,
            lures me in,
                and refuses to let me go.

Food, glorious food.
    Positively essential.
        But suddenly,
            dramatically different.
                The enemy!
Food, glorious food.
    How shall I consume thee?
        Knowing what I know
            How shall I decide?
                What shall I eat?
    Food? Glorious food?

Journal Entry: When I was diagnosed with diabetes, I immediately realized that I was going to have to be on a diet. There it was that dreaded word -- diet. And not only would I have to be on a diet, but I would have to be on it for the rest of my life! The thought of that was overwhelming. All my previous diet "failures" rose up to taunt me. I had never managed to maintain a diet before, how would I do it now? I think at that moment the fear was so overwhelming that I blocked it out. It was intolerable to imagine food as the enemy for the rest of my life. Based on my perceptions of how a diet worked this would mean never having any of the food I really liked for the rest of my life. I simply couldn't imagine that. And at the same time I couldn't imagine that there was any other way to view food/dieting.

The fear was if I ate even one piece of chocolate, for example, I would be unable to stop. So it was better to just have none. I had this fear because this is what had always happened to me in the past when I went on a “diet.” Like many large [or read that overweight, obese, or fat, if you like!] women I have been on and off diets for most of my adolescent and adult life. I have lost the same 10-20 kgs over and over. Each time I would begin strongly -- I would lose weight and be able to avoid the temptation to eat any “forbidden” food. But eventually, as time passed and my stress level increased, I felt more frustrated and deprived. Eventually, I would be unable to resist and one taste would lead to the binge I had feared. This was followed by feelings of anger and despair. I had failed again. Once again I had proven that I was not capable of maintaining a healthful diet. This was followed by a long period of uncontrolled eating until something triggered a shift back toward a period of control.

<u>Journal Entry</u>: There is always a little voice in my head now that forces me to acknowledge the reality of my condition. I think this is what having a chronic illness is all about. The reality that you have a disease, it is always there, and barring some medical miracle, you will have it for the rest of your life. And there is no escaping it. As McLean (1981) says, “I did not understand that it was not just a life condition, but also a life sentence” (p. 53). Sometimes, I think that, at least at the beginning, ignorance really is bliss. I know too much about diabetes. I can’t get the thought of the complications out of my mind. And I am very aware that this is a life time condition. No matter what I do it is not going to go away. All I can do is control it. And that will mean controlling what I eat for the rest of my life.

Safe, So Far

It was time to go back to my doctor. Every three months I have a hemoglobin A1c test. This is a blood test which is capable of determining the average blood glucose over a three-month period. Therefore, it is a good indicator of overall control. I hated having this test done! It felt like a test -- a test of my life as a diabetic. Was I a "good" diabetic with a low hemoglobin A1c or was I "bad?" I felt guilty when the results were not good -- sure that it was a sign of my lack of self-control and will power. When the result was good, I felt relieved that I had passed the test, but at the same time I felt I was a fraud because I knew I wasn't really good. I knew my eating was still very much out of control. In addition, I felt angry that I was subjected to this scrutiny which seemed so judgmental. The strange thing was the judgment all seemed to come from an internal place. My physician never chastised me for my results. She only encouraged me to keep trying. But I had spent much of my life feeling I was not good enough -- and this was another example of that.

On this particular visit I guessed that the results were not going to be good. I had seen the numbers on my glucometer slowly rising over the last month. When I saw the doctor she informed me that my hemoglobin A1c result was 8%. Three months earlier it had been 7.5%. This 0.5% increase in hemoglobin A1c correlates to an increase of approximately a full mmol/l in terms of average blood sugar. This is a significant increase.

However, my doctor informed me that even with this hemoglobin A1c result my risk of developing long term diabetic complications was relatively small. So even if my hemoglobin A1c, and consequently, average blood glucose, never improves, I could probably live my life without any diabetic complications. As I heard this I felt a huge wave of relief. A sense of calm came over me. I was all right. I was doing all right. Although I try not to focus on the risk of complications I'm very aware of feeling that they are just around the corner. As a nurse, I have seen people with these complications and they are/can be devastating.

This visit with my physician allowed me to shift slightly in my perspective. Now, instead of feeling guilty and chastising myself for how bad I've been I can celebrate the fact that I am all right. The sense of relief I felt was pleasant, but at the same time I'm still aware there is room for improvement. In fact, improvement would decrease the risk for longterm diabetic complications even more. But right now I'm safe and even if I never get any better I will probably be okay -- complication wise. So I'm safe, so far.

Journal Entry: I have been thinking a lot lately about how diabetes is affecting my life and I have realized a few things. My initial reaction was, "Oh My God! No! This can't be happening to me. I can't handle it!" I then went through a period while I was trying to accept the idea. I would tell people I was diabetic. But I was still not really coping with it. Lately I seem to be moving back into denial again -- it is not the same as the beginning, but I am still basically ignoring the reality of my diabetes. Sometimes I "forget" to do a blood sugar check. And yet of course, I never really forget! But I still eat what I want, even though I know I should be starting to make changes. Looking back, I was lucky to be diagnosed when I was. My fasting blood sugar was only 7.7 mmol/l and this probably means that my period of denial hasn't done any lasting damage. Many people don't have this luxury and I am intensely aware that many type 2's already have complications at the time of diagnosis.

The Ever Present String

I keep seeing television commercials about diabetes. There is one in particular that I find quite distressing. It is sponsored by Shoppers Drug Mart -- "Think of this string as your life. If you have diabetes, fluctuations in your blood sugar can affect not only how you live your life but the length of your life." I hear it and I want to scream! I want to say, "I'm trying! I'm doing the best that I can!" But the message in the ad taunts me. It seems that no matter how hard I'm trying -- it isn't enough.

What does it mean, anyway? One of the problems with type 2 diabetes is that complications are generally slow to develop. If having an elevated blood glucose level led to an immediate reaction, perhaps I would have an easier time adjusting my eating. I am motivated. I know all about the complications. I have seen them. Young people blind or in kidney failure -- on dialysis or waiting for transplant. Older people with rampant atherosclerosis -- foot and leg amputations or coronary artery bypass grafting. I have seen them all. But despite my knowledge and motivation, I can't seem to maintain a balanced diet. A voice inside of me cries out for something -- for food. All it wants to use to deal with my stress is food! I keep trying to find another answer, but nothing works. Nothing else works!

So I hear those commercials and I want to scream! I don't know what to do! All I know is that I am not doing enough. Think of this string as your life!!

Journal Entry: Isolation can be a very painful experience. Having diabetes sometimes makes me feel different and isolated which makes me feel like I am shut up in a box. The box is clear -- I can see out and others can see me -- but I am still trapped in it.

Caged?

The door to my cage is open;
I can easily fly away.
But I hesitate,
afraid to flee
this most familiar place.
Outside is the freedom I have longed for.
But suddenly, all I can remember

are the hardships,
the endless flying.
The exhausting search for food.
And the fear of the cats,
and all the other predators,
who are only trying to eat
ME!
So I stay,
no longer caged,
but not exactly free.
Caught in a web of my own construction.
Trapped by my own fears,
my own inadequacy,
my lack of trust in myself.
And the only one who can free me
-- is me.

Journal Entry: I realized as I wrote the poem, "Caged?" that once again, the cage is made by me. The process of uncaging is also up to me!

Life Goes On

Diabetes:
    fight it,
    curse it,
    learn to live with it.
And life goes on.
Chronic illnesses:
    hate them,
    learn to acknowledge them,
    make adjustments.
And life goes on.

A thesis to write:
  fear it,
  plan for it,
  will write it.
And life goes on.
There is more to life than this.
Extraneous things threaten to overwhelm me.
I can't describe them.
I just know that,
  life goes on,
    around me,
      within me,
        outside of me,
  and I can't stop it.
Because life goes on.

Writing begins.
And rewriting continues.
And life goes on!

A License To Drive

It was March and my birthday on the 19th meant it was time to renew my driver's license. So, two days before my birthday I headed off to the Motor Vehicle Branch to renew my license. I didn't anticipate any problem other than the possibly long wait in line.

I arrived at the office and there were only two people ahead of me and I was feeling pretty lucky. The last time I renewed my license I arrived to a line of at least 15 people. This seemed pretty tolerable.

Within five minutes it was my turn and I approached the counter with the necessary form and the $40 fee. Confirm my height, weight, hair colour and eye colour and I'd be out of there, I thought. And yes, all of that occurred just as I expected. But then came another question. An unexpected question. "Do you have any medical conditions?"

Without much thought I answered, "Yes, I have type 2 diabetes."

"Do you take insulin?" came the second question, rapidly, on the heels of the first.

"No, but I do take an oral antidiabetic agent," I replied.

Immediately, the clerk began typing information into her computer. Without looking at me she said, "You'll have to get this medical form completed by your physician."

I tried to explain that this really wasn't necessary. My blood sugar was really very close to normal. It was barely about the upper limit on the standard scale. I was fine. There was no need for the form. My diabetes would have no effect on my ability to drive.

Not surprisingly, my explanation had no effect. "You must get this form completed within forty-five days," she said.

I tried another tack. "My physician is on maternity leave. She won't be back for at least three months."

"That's okay," she responded, "her locum can fill in the report. You must do this."

I didn't want to hear it. I paid my fee and left the office fighting tears. Why was this happening to me? Wasn't it bad enough to have diabetes? Now I was being stigmatized because of it! Maybe I should just get rid of my driver's license. Maybe that would be the best thing to do. Then I wouldn't have to worry about it.

Worst of all, the bureaucracy now knew of my diabetes. All the way home I berated myself for my stupidity. Why didn't I just say "NO" when she asked about medical conditions. It wouldn't have been that big a lie. Who would have known the difference?

Later, when I told other people about my experience I received many suggestions that I should have just lied. But inside, despite the fact that I had thought about the possibility myself, I knew I couldn't have done that. I have to accept the reality that I have diabetes. I have tried to deny it. For a year I ignored my health completely. But it does exist. I do have diabetes. If I pretend, even to the Motor Vehicle Branch, that I don't, then I am perpetuating my own denial. And for myself, I have to accept that I do have diabetes. Yes, I wish I didn't have diabetes. Yes, I wish I didn't have to spend $25 to get the medical form completed. Yes, I wish there wasn't this assumption that having diabetes makes me no longer able-bodied -- no longer safe to drive a car without my doctor's assent. Yes, I wish diabetes wasn't a stigmatized condition. But I do have diabetes and I have to live with that. And while I can work to change the stigma, until it does change, I will have to live with that, too.

Journal Entry: Do you know there are an estimated 1.5 million Canadians with Diabetes!?! I don't even know how to comprehend that number! 1.5 million Canadians! (CDA, 1997b) According to the Canadian Diabetes Association (1997a), diabetes utilizes more health care dollars than any other single disease.

Journal Entry: Do you know that in just 5 years the estimated number of Canadians with diabetes has increased to two million? (Kalla, 2000). Is this an epidemic or what? If two million Canadians shouted, "Diabetes is an epidemic!" Would you listen then?

Journal Entry: Watching a television program I realized 1996 was the 75th anniversary of the discovery of insulin. One thing that amazed me was a gentleman who was 82 years old. He was diagnosed with diabetes when he was 6 years old -- in 1924. His physician told his mother to let him eat whatever he wanted because he was going to die anyway. But another physician he saw knew about insulin and began treatment. It is hard for me to imagine having diabetes for that many years. I would love to talk to him -- to see how he has lived with the disease

It is astounding to think that when this man was diagnosed the only way to monitor diabetes was through urine glucose testing -- inaccurate to say the least. Glucose doesn't begin to spill into the urine until the level is at least 10.0 mmol/l, higher in some people. In addition, any glucose in the urine reflects the previous 2-4 hours of blood glucose levels, not the current level.

When I was in nursing school we were still doing basic monitoring using Clinitest® tablets to check for glucose in the urine. During that time, a friend's brother, who has type 1 diabetes, purchased one of the first reflectance blood glucose meters. It was about the size of a shoe box and cost approximately $500. Hard to imagine that in just 15 years we have gone to glucose meters weighing 50 grams and costing less than $50. Hard to believe, isn't it? I wonder what will happen in the next 15 years?

Deus Ex Machina

My glucometer
fifty grams
of technology.
So simple?
Or complex?

Four times a day
    life hangs
        in the balance.
Sliding into chaos?
Thirty seconds
    of waiting
        for judgment.
Endless time?
A slave to the machine?
    To diabetes?
        To health?
Choosing life!

Journal Entry: I have been thinking about how many people would be really bothered by all this. I was never particularly bothered by the idea of poking my finger. What bothered me more was the idea of having an illness that had all these negative implications. I don't know why it didn't bother me. Because really, it isn't a very pleasant procedure. It often hurts - not a lot, but enough. It is inconvenient. Other people are often bothered by the sight of blood. It is expensive. It is tedious. So, there are many negative implications. And I am aware of all of them. And they all bother me, too. But I guess that the idea of getting complications bothers me more. If doing all this (testing regularly, exercising, eating right) will help keep me healthy, then I guess I will do it. Because the bottom line is, this is more important to me than a little inconvenience and discomfort. So, I am dependent on the technology. And that is okay with me.

However, at the same time that I say that I don't mind being dependent on the technology, what I do mind is the cost of the technology! The strips for testing blood glucose cost approximately $1.00 per strip. I test 4-5 times a day! That results in a monthly cost of approximately $120, just to test my blood sugar. And I am forced to do this because the only way to maintain good control is through frequent monitoring in order to know when changes are necessary. And as the evidence shows that better control leads to fewer complications, I guess I will choose to monitor frequently. But sometimes it doesn't feel like a choice! Luckily, I have a health plan that assists with the cost. I don't know what I would do if I didn't have the plan!

It Didn't Seem like a Big Thing

It didn't seem like a big thing. My foot was a bit sore. It hurt every time I took a step. Not a lot, but enough that I noticed it. As the days went by it didn't improve and I began to wonder what was happening.

"Here you go," he said. The emergency room physician handed me a prescription for an antibiotic. It seemed that I had a foreign body in my heel. You could see a small black mark which was the presumed puncture site. I wondered what it could it be? It still didn't seem like a big thing.

I took the antibiotic and things seemed to get better. My foot didn't seem to be so sore. Of course, I wasn't really walking much on it. I was spending three days in bed after laser eye surgery. But I didn't really worry about it because it wasn't a big thing.

One day I realized I had been on the antibiotic for six days and my foot was still painful. By then, I was out of bed and I noticed how much it hurt to walk. I went back to the emergency room. I didn't think it was a big thing but I was conscious of the fact that I am a diabetic. You have to be careful about things in your feet with diabetes! The emergency room physician decided to do an incision and examination. I did wonder if it should be done by a surgeon in the operating room but I wanted the problem solved. So I agreed. I mean, it wasn't a big thing.

After the anaesthetic wore off my foot was incredibly painful! I couldn't put any weight on it. Even when it was elevated on three pillows it throbbed continuously. But I expected that some painkillers would solve the problem. I took some acetaminophen with codeine and hoped that the pain would improve. But it didn't -- it got worse. By now I was beginning to be frightened by the intensity of the pain. I called a friend, hardly able to speak, as I cried out my fear and pain. She suggested I call my general practitioner for some advice. I did this, and she prescribed oral morphine. Surely that would be effective? I was literally stunned when the pain remained. Finally, at nine in the evening, I couldn't stand it anymore. So 12 hours after the incision and examination I went back to the emergency room. The staff in emergency didn't seem particularly worried about my pain. They did, however, give me a total of 25 milligrams of intramuscular morphine. I lay on the emergency stretcher and cried as the pain continued, unabated. Maybe this was a big thing?

After the morphine, a nurse approached me and said I could go home. Go home? Was she kidding?!? I had received 25 milligrams of morphine with NO relief! Didn't she understand this was a big thing?

I refused to go home which shocked the emergency room staff -- I sensed that they weren't quite sure what to do with me. All I knew was that I was not going home. This pain was not normal! Something was wrong!

Eventually, the emergency room physician admitted me. Mostly, I suspect, to get me out of his hair. Strangely, as soon as I was admitted my anxiety eased. It wasn't my responsibility anymore. Someone else was in charge. Maybe it was a big thing, but I could relax.

I didn't sleep that first night. Not because I was worried, but because I was in pain and nothing seemed to relieve it. Finally, morning came and with it a new staff of nurses. My nurse for the day was concerned and telephoned the doctor. "You do know this patient is a diabetic?" she said. "I think you need to come in to see her." I was pleased with this. Finally, someone was acknowledging there was a reason for concern. I relaxed, sure that I was being cared for.

That afternoon the on call physician arrived with a resident in tow. As they observed my foot I saw the look that passed between them. Suddenly, there was a spate of activity around me. Stat blood work, an intravenous, vital signs, glucometer readings, a stat surgical consult, and a bolus of a litre of saline. I realized that my relaxation had been premature! How many times had I been on the opposite side of one of those looks. The look that says, "We don't want to scare the patient but I think we might have a big problem!" Oh my God! It really was a big thing.

When the surgeon came to see me he was quick to reassure me. "I don't think we're looking at necrotizing fascitis," he said. NECROTIZING FASCITIS! Good God, the thought had never even crossed my mind! Necrotizing fascitis! If it was necrotizing fascitis I could easily lose my foot, my leg or my life! This was a big thing!

Luckily, I didn't have necrotizing fascitis. I was started on an intravenous antibiotic and 24 hours later my foot had dramatically improved and so had the pain. Three days later I was on my way home. Maybe it wasn't such a big thing? For a few moments I wondered if I had overdramatized the whole thing.

But it really was a big thing. How did I convince myself for so long that I could ignore my diabetes? That I could eat what I wanted without any impact on my body? That I was immune from the risk of complications? That an infection in my foot was nothing to worry about? I didn't want to know. Because to know would mean I would have to make changes in my life. And because I would have to really acknowledge the fact I actually do have diabetes. And it actually does have an impact on me. And I didn't want to face that. I just didn't want to believe it.

So it really was a big thing. Much bigger than a serious infection. And an infection in a diabetic's foot is a big thing! Infections increase blood sugar levels as the liver produces excess glucose. These elevated sugar levels slow healing as the bacteria multiply rapidly in an environment rich with glucose. But it was also a big thing because I can't go back to my level of denial. And I don't think I want to. Because I have made some of those necessary changes. I eat three meals a day and follow a restricted diet. I ride an exercise bike. And I check my blood glucose four times a day. And as every day goes by I get better at knowing how my body is doing.

So it was a big thing. And I guess that's a good thing.

Life

Life begins each day,
and each day
I choose how to live it.
Whether in joy or sorrow,
up or down, in or out.
On so many days
I make a choice unconsciously.
Unaware that it is a choice.

Sometimes preferring to believe
that fate
chooses my path.

Journal Entry: I never did go the diabetes education centre. When I was first diagnosed I strongly resisted the idea, partly because I wanted to deny I had diabetes and partly because I worried that receiving education about diet would stir up all my issues related to food. I feared that the end result might be more destructive than beneficial!

As I began to work on my thesis and do the research on the medical narrative, I found I was doing on own independent learning about diabetes. In many ways, I think this was more effective for me than a trip to the diabetes education centre would have been. I could approach this learning at a speed that was comfortable for me and at times when I was most ready to learn. As I began to integrate the learning into my sense of self I became interested in taking my understanding further.

Interestingly, this parallels the way in which I imagine the thesis can function. As readers are being given permission to read the thesis in whatever way is most meaningful, the focus remains on the independent learning of the reader.

The Shift to Knowledge

Suddenly, I understand --
    not just the facts,
        the numbers,
            the statistics.
Suddenly, I understand --
    inside myself.
        Being diabetic
            is part of who I am.

No longer an external --
a fact I acknowledge
but prefer
not to believe.
Suddenly, I am diabetic --
though I have been for two years.
Suddenly, I get it,
and it is me.

The Journey

I was walking through the woods one day
intent
on where I was going.
I turned to see where I had been.
A mistake.
I should have kept moving.
Suddenly I was halted,
standing still in my tracks.
Stopped by my questions and fears
Where am I going?
What is the way?
What is my purpose in life?
What am I doing?
The path I was walking
disappeared in a flash of fright.
Now I am sitting here
lost and confused.
I no longer am sure of the way.
The woods are so frightening,
shadowed and dark.
Haunted by fears and by foes.

The only way out
is through sorrow and pain.
Perhaps I should wait for some help?
That isn't the answer,
my soul knows it clearly.
Though my body quakes with the fear.
If I start the journey
where will I end up?
Will it be any better than here?
I could stay here forever,
a statue -- a shadow.
Frozen by fear or by pain
But the only way out
is through the morass.
I must climb to the site of the light.
The longer I wait here,
the harder it gets.
There must be some other way?
I must rise to my feet.
It is time to begin
with the steps that will lead the way.
Or time will run out.
To the end of my life.
No journey, no path, no trail.
So time to begin.
The choice has been made.
The journey begins today.
I don't know the route.
I don't know the way.
And I don't know where I am going.

But somehow I'll get there,
I'll find it -- I'll do it.
Whatever fate brings to my life.
There is no other option.
Life just keeps on moving,
can't stop it, don't even know how.
I must travel the path
that my life journey leads me.
That's the answer -- at least for now.

The Birthday Gift

It is six days until my thirty sixth birthday and I have given myself an early present. I don't suppose it would seem like a very good present to most people, but I'm happy with it. It is something I probably should have given myself last year! But perhaps I'm getting ahead of myself.

It was Friday morning and I was sitting in the waiting room of a specialist's office. A magazine sat on my lap but although I had it opened to an interesting article, I was really more interested in my own thoughts. "What will he be like? Will I like him? Will he do what I want? How will I feel? When is he going to be ready for me?!?" I felt very stressed -- I knew what my values and beliefs were, but I knew nothing about him. I hadn't met this physician before. As a nurse I'm used to knowing the physicians that I see as a patient. But this was a new physician in town. So now I have to depend on the opinion of my general practitioner and it feels strange to not be able to make up my own mind about whom I should see.

I had known for a while that something had to change. I was finally accepting that I really am diabetic. And I was finally ready to make some dramatic changes in my life.

My blood glucose just kept creeping ever upward. I felt very frustrated ... and very scared. I knew I wasn't eating perfectly but I wasn't eating any differently than three months ago. And yet, my sugars were much higher. And the higher my sugars got the more frustrated I became and the more I wanted to eat to relieve the stress I was feeling. It was a vicious cycle. In addition, I was beginning to feel more and more frightened about the risk of complications. I knew that as blood glucose levels increase so do the likelihood of complications. I would read the numbers on my glucometer and realize that I was in a danger zone. The problems could begin at any time. Something had to be done. So far there hadn't been any signs of complications and I wanted to keep it that way. So I told my general practitioner I thought I needed to see an endocrinologist. And now, here I was.

"Sue Taylor," came the call from his office staff. I was weighed [thank goodness, I haven't gained any weight!] and measured and then I went in to meet him. He was so young. It seems strange to see a specialist who is so close to my own age. He reviewed my medical history and then came to the crux of the matter. "So, you were controlled with diet for while, then metformin and acarbose, then glyburide, but now your blood sugar is out of control. Have you tried a combination of glyburide and metformin?"

"No!" I said. "And I don't want to!"

"Wait a minute," he said. "Your average blood glucose is..."

"I know," I interrupted. "It's not that I don't want to be in control. I just think it's time to move to insulin. I'm tired of screwing around trying different drugs that work for while and then quit working. I want to get in control and stay in control. And I think that means insulin."

A look of surprise came over his face. "Well," he said. "I certainly don't hear that very often. Most people want to avoid insulin at all costs."

"Well, I want to avoid complications at all costs. I know too much about the risks. And besides, I think I'll be on insulin eventually, regardless. I mean, I am only 35, it isn't likely I'll be able to stay on oral antidiabetes agents forever, anyway."

"Yes, you're probably right. Especially given how young you are. So, how would you like to go about this?"

We spent the better part of an hour in a technical discussion of the benefits of each of the possible options. Finally we made a decision. I would begin with two injections a day. This was the most simple option. I can always change to a more intensive regime later, if necessary.

What felt really good was his trust that I could manipulate my insulin dose, according to my blood glucose, as necessary to get into control. This allows me to be a "nurse" for myself. So often, I have felt powerless within my disease but now I have been given permission to use all the knowledge, skill, and judgment I have gained in my years as a nurse. And yet, I can have support and assistance as needed. As he said, "If you need help occasionally, give me a call."

So I left the office with what I had been wanting. A prescription for insulin. And I had a smile on my face. Why was I smiling? Well I kept thinking about how I felt when I first started on metformin. That was about two years ago and at that time I felt I was a failure. That I had failed in maintaining control without medication. Now I knew differently. This time I had made a choice. A good choice. A choice for health. This time I was taking control of my health rather than letting it take control of me.

So, the birthday gift I gave myself was two vials of insulin and a box of syringes. And it was the best gift I ever received.

Journal Entry: " Compulsive eating is a very, very painful activity. Behind the self-deprecating jokes is a person who suffers enormously. Much of her is centered on food, what she can and cannot eat, what she will or will not eat, what she has or has not eaten and when she will or will not eat next" (Orbach, 1998, p.34-35). This notion of compulsive eating is, in many ways, similar to the focus that diabetics, especially those of us using insulin, place on eating. This is one of the things that makes diabetes so difficult for me. Even now, when my eating is in relatively good control, there's still a great emphasis in my life on eating. This creates a terrible, painful schism for me. I have to eat, but not too much and not too little. I have to eat at the right time, not too early or too late. And the problem is although the outward act is control, the inward activity/emotion is still one of compulsion. There is still emphasis on food. There is still compulsion to eat -- only now in just the right way. And so, the compulsion is still there, it is just focused at a slightly different angle. In managing my diabetes I must find a way to be rigid enough to be in control while avoiding compulsive rigidity which would almost certainly end in rebellion. I have to find a way to eat what I want without compromising my health. I move backwards and forwards, always trying to stay on that highwire. It is not an easy thing to do day after day.

The Great Date Square Mystery

The woman sat, staring at her glucometer. "9.1 mmol/l!" she said out loud. "9.1 mmol/l! Where did that come from?" It was a mystery and she felt compelled to solve it.

She thought back over her evening, what could be the cause of the high reading. She hadn't been under any particular stress, so that wasn't the culprit. She hadn't exercised as much as usual, but it wasn't significant enough to account for the high result. She had definitely taken her insulin. The only thing left was what she had eaten. What she had eaten was a date square. They had looked so good. They had been the snack in class and she just couldn't resist having one. What a treat. She hadn't had one in such a long time. She decided it would be okay-- she didn't eat her orange, or her muffin -- together they had about 25 grams of carbohydrate. How much could the date squares have? She took the smallest one there was and figured it would be okay. Well, she was wrong.

This experience had actually happened to her before. On that occasion she had managed to convince herself that she must have failed to dial in the correct amount of insulin on her pen. This incident proved that the problem had not been with her insulin. And also proved that even a small dietary indiscretion would raise her blood sugar significantly.

It isn't that 9.1 mmol/l is so terrible, once in a while. What bothered her was that this episode of hyperglycemia was so unexpected. Obviously, she had misjudged the amount of carbohydrate in the date square quite grievously. She had thought she was getting very good at estimating carbohydrate. Being so wrong scared her. She didn't like being fallible. And she didn't like the unpredictable nature of her diabetes. She has gotten used to having diabetes, and most of the time she can live with having to limit what she eats, and when. She is happy her diabetes is in good control and she knows the occasional 9.1 mmol/l is not a serious problem. But she wishes she could eat a date square occasionally without having hyperglycemia. Damn it, once in a while she should be able to eat a date square!

Journal Entry: It is fascinating for me to look back at some of the things I wrote several years ago. When I wrote Safe, So Far, it seemed so impossible to maintain good blood glucose control. At the time, a hemoglobin A1c of 7.5% seemed like a marvelous achievement. But for the past year I have maintained a hemoglobin A1c in the range of 5-6% and I do that without much difficulty. It is amazing to me to realize how much things have changed! I never imagined that I would get to this level!

Food, Medicine, Food

I eat food.
Every day.
Four times a day.
At prescribed times,
in prescribed amounts.
        Is it food?
        Or medicine?
        Or food?
My blood sugar drops.
I eat candy
and feel better.
        Is it food?
        Or medicine?
        Or food?
I want a chocolate bar.
I can have one.
But only by calculating
how many grams
        of carbohydrate

it contains.
Then I must reduce
the carbohydrate in the rest of the meal.
It is food!
And medicine!
But it is food!

Journal Entry: I was rereading The Lord of the Rings and came across the following quotation which made me think about my diet:

> The lembas had a virtue without which they would long ago have lain down to die. It did not satisfy desire, and at times Sam's mind was filled with the memories of food, and the longing for simple bread and meat. And yet, this waybread of the Elves had a potency that increased as travellers relied on it alone and did not mingle it with other foods. It fed the will, and it gave strength to endure, and to master sinew and limb beyond the measure of mortal kind. (Tolkien, 1966c, p. 213)

It seems to me that following a relatively strict diabetic diet has an extremely positive effect on me, much as the effect of the lembas is described. It strengthens me, both physically and emotionally. Physically, because it keeps my diabetes in control. Emotionally, because as my diabetes remains in control I can make a conscious choice to keep my eating in control which increases my sense of internal strength. But at the same time, my diet doesn't always satisfy my desires and I often have memories of food which fill my mind with images of food I would like to eat. But this new internal strength allows me to choose not to eat this food, but instead to maintain my diet and keep my diabetes in control.

The Many Faces of Diabetes?

I am reaching the end of my research into my thesis and yet new questions about living with diabetes continue to arise. The most recent is perhaps one of the most interesting and one that I never expected to be asking. That is, am I really a type 2? A recent visit with my endocrinologist confirmed that he is not certain of my type 2 diagnosis. There are a number of reasons for this lack of conciseness. Primarily the fact that I have characteristics of both diseases. For example: I am obese, over 30, have never experienced diabetic ketoacidosis, and responded [moderately well] to oral antidiabetic agents. All of these are characteristics of type 2. At the same time, I have other autoimmune diseases -- type 1 diabetes is based on autoimmune destruction of the beta cells. I lost, rather than gained weight, when I began using insulin. And I use a relatively small dose of insulin indicating that I don't have a high degree of insulin resistance. All of these characteristics would tend to suggest that I could be type 1. So what am I? It would probably be possible to get an answer. We could test for islet cell antibodies -- the presence of these would mean that the pancreas is being destroyed by autoimmunity -- an indication of type 1 diabetes. We could also do a c-peptide test -- c-peptide is the precursor of insulin and a high level would tend to indicate type 2 because the pancreas is attempting to produce enough insulin to overcome the resistance. I haven't had these tests done because the results are not necessarily conclusive and they are expensive. And I have to ask myself whether they really matter. What difference does it make? My treatment would remain the same, as would my lifestyle. But as I continue to reflect on this question, I realize that psychologically, there is importance in knowing. The importance is not so much in knowing whether I am type 1 or type 2, but knowing for a certainty. I find this a fascinating realization because I have always said that I dislike categorizations. In fact, one of the reasons I chose to use narrative methodology was to avoid the themes and categorizations that are common in some other types of interpretive research. But at the same time that I dislike being categorized I find I feel a need to have a category. I suppose there are a number of reasons for this. One is that in meeting other diabetics one of the first questions is always, "Which type are you?" I now find myself having difficulty responding to these questions. Do I say, "type 2?" This is how I see myself. Or at least, this is how I have learned to categorize myself within my own mind and to externally describe myself. But at the same time that I write that, I hear a voice saying, "but you know that you see yourself as different from other type 2's!" Or at least, as different from any type 2's that I have met personally. Most of the type 2's that I have met seem to have a laissez-faire attitude towards controlling their diabetes. However, I must admit that my experience on the Internet is beginning to shift my views. I am beginning to connect with many type 2's who are as concerned as I am about keeping their diabetes in control. But I now have a problem with saying I'm type 2 because I have this niggling doubt that I am misrepresenting myself. And I guess that is where the issue comes from. The label/title of type 1 OR type 2 has a role in my construction of myself as a diabetic. The language that I use to describe myself has an impact on who I am/become. At this time, I'm not exactly sure how I would be constructed differently if I called myself a type 1. But I sense that it would be different. I wish I could articulate what the difference is, but at the moment I am unable to do so. Perhaps later.

Currently, I tend to call myself a type 1 1/2. My endocrinologist uses this terminology and I have heard other people use it as well, but I have never seen it in a book describing the classifications of diabetes. Always, the subject is addressed as if there is a definite delineation between the two types. And I suppose, that medically/scientifically speaking, there is. If the islet cells are being destroyed by antibodies leading to decreased [and eventually no] insulin production than you are type 1. If you still have endogenous insulin production you are type 2. But psychologically, there is more to it. At least, I think so. Calling myself type 1 1/2 gives me some satisfaction because it allows me to accurately characterize myself. But it dissatisfies me because many people are not familiar with the term and it doesn't actually fit the defined classifications. So there is some internal conflict and a need to know which type I am. At the same time, there is a fear about knowing because I don't know how to be a type 1. I have spent all this time learning to be a type 2. As I write this, I think it sounds silly. The learning I did is still valuable. There really isn't much more to be learned about being type 1. I'm already on insulin, so I've already learned that. But these are all cognitive learnings. What I haven't learned is how psychologically to be a type 1. Does it matter? I don't know. My intellect tells me there is no difference but my gut is not so sure. And so I struggle on.

Journal Entry: I was rereading The Little Prince and I found the following quote. The Fox says to the Little Prince, "And now here is my secret, a very simple secret: It is only with the heart that one can see rightly; what is essential is invisible to the eye" (St. Exupery, 1943/1982, p. 70). My diabetes is an essential part of me, and yet it is invisible. I have been trying to make it visible. So that people can see this essential part of myself.

Liberty

The woman sits,
thoughtful,
as her energy
flows
through her,

and around her.
Is it given?
Taken?
Stolen?
A gift?
The light of the energy speaks,
brings hope,
brings life.
In the past, the energy faded.
But now
the woman sees
an internal source
deep within --
which she can access
and which provides
liberty from her fears!

AFTERWORD: THE JOURNEY ITSELF, HOME

Each day is a journey, and the journey itself, home. (Basho, cited in Tremmel, 1993, p. 456)

And so, the journey of my thesis comes to an end. And yet, as I reread the narratives of my participants and my own narratives, I continue to make new meanings. And as I do so, I change my life and in changing my life my stories become richer (Widdershoven, 1993). But wherever I am in my journey, that is home. And so it shall be for you.

And so, dear reader, I ask of you only two things: The first is that you remember that while the thesis journey is complete, finalized in these concrete pages, the journey of my life and the journeys of my participants' lives, continue. The second is that you remember the power of the story:

> When the Baal Shem had a difficult task before him, he would go to a certain place in the woods, light a fire and meditate in prayer -- and what he set out to perform was done. When a generation later the Maggid of Meseritz was faced with the same task, he would go to the same place in the woods and say: 'we can no longer light the fire, but we can still speak the prayers' -- and what he wanted done became a reality. Again, a generation later, when Rabbi Moishe Lieb of Sassov had to perform this task, he went to the woods and said: 'we can no longer light a fire, nor do we know the secret meditations belonging to the prayer, but we do know the place in the woods to which it belongs -- and that must be sufficient.' And sufficient it was. But when another generation had passed and Rabbi Israel of Rishin was called upon to perform the task, he sat down on his golden chair in the castle and said: 'We cannot light a fire, we cannot speak the prayers, we do not know the place, but we can tell the story of how it was done.' And the story which he told had the same effect as the actions of the other three. (Jong, 1997, p. 327-328)

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Appendix A

Advertisement to Attract Participants

I am a graduate student at the University of Victoria. I am studying the experiences of people living with type 2 diabetes to broaden understanding of the impact diabetes has on one's life.

If you are an adult with type 2 diabetes controlled by oral hypoglycemics (pills) and/or diet and are interested in participating in this study, please contact Sue E. Taylor at 595-3784 or via email at suetay@islandnet.com.

Appendix B

Consent Form for Participation in a Study Entitled Always and Forever: Toward an Understanding of Type 2 Diabetes Through Narrative

Researcher: Sue E. Taylor (250-595-3784)
Faculty Supervisor: Dr. Laurie Rae Baxter (250-721-7777)

In this research project I am studying the experiences of people with type 2 diabetes in order to broaden understanding of the impact of diabetes on one's life. As part of my graduate studies at the University of Victoria I would like to talk with you. I am particularly interested in your personal experiences of living with diabetes. Topics to be discussed include:

1. How you learned you had diabetes and how you felt about the diagnosis.
2. Your experience with making changes in diet and lifestyle.
3. Any times in which you have felt labeled or stigmatized as a "diabetic."
4. How you feel about having a chronic illness.
5. How your family and friends have reacted to your condition.
6. Any fear of complications from diabetes.

The information obtained in the interview will be written into the form of a story describing your experiences. You will be given a copy of this story so that you can make corrections, additions, or deletions. The final story will be published as part of my Master's thesis.

Your participation is voluntary and you may withdraw from the study at any time without any explanation. If you choose to withdraw, all information collected will be immediately destroyed.

You will be requested to participate in a minimum of two interviews with an estimated length of 60-90 minutes each. You have the right to refuse to answer any questions which you do not wish to answer.

Your participation and the information collected will remain confidential. Your anonymity will be protected by the use of code names on the interview results of individual participants. Interview results will be maintained in a locked filing cabinet and only I will have access to this information. Once the thesis is complete all interview results will be destroyed. Your last name will not be attached to any published results.

Your interview will be audiotaped and tape will be destroyed immediately after your responses have been reproduced in written form with code names to protect anonymity. If you wish, you may refuse to have the interviews audiotaped.

Your signature below indicates that you have read and understood the foregoing and that you agree to participate in this study.

Name of Participant (please print) ________________________
Signature of Participant ________________________________
Date ______________________
Researcher: Sue E. Taylor (250-595-3784)

VITA

Surname: Taylor   Given Names: Sue Ellen

Place of Birth: Edmonton, Alberta, Canada

Educational Institutions Attended:

University of Victoria	1990-2000
Royal Alexandra Hospital School of Nursing	1980-1983

Degrees Awarded:

Diploma in Nursing	Royal Alexandra Hospital School of Nursing	1983
B.Sc.N.	University of Victoria	1994

Publications:

Oberg, A., Taylor, S., Harvey, C.M., & Murray, P. (1995). Reading a tango: Multiple interpretations of text. Connections '95, 38-44.

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Title of Thesis:

And I Will Leave a Trail: Learning to Live with Type 2 Diabetes: A Narrative Curriculum

Author [redacted]

Sue Ellen Taylor

November 14, 2000