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Dietitian and Diabetic: Thoughts on Working and Living with Diabetes

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I have been invited to share with you some of my thoughts and experiences on working in and living with diabetes, so that you may gain another perspective in diabetes care. Through my professional knowledge and personal experience I hope to give you a greater insight into this condition, that will aid you in the education and support of people with diabetes. I have included various topics, not just food and nutrition, to emphasise the importance of taking a holistic approach to diabetes management, regardless of your specific role. These are my thoughts and experiences and I do not imply they are those of all people who live with diabetes. I start by telling you a little of my story.

I was diagnosed with insulin-dependent diabetes 20 years ago. Back then, I didn't know anything about diabetes, nor how much it would influence my life and ultimately determine my future career. My only understanding of diabetes then was that my great uncle injected himself daily, was not allowed sweet foods and was certainly not a picture of health. I can still remember how scared and anxious I felt, waiting for those final blood tests to confirm my, and my parents', worst fears. Injections frightened me, I didn't know what I was allowed to eat and I seriously thought I might die. Perhaps many people with diabetes share these feelings when they are first diagnosed.

- *Because of the well-intended advice given by family and friends, some of us may have preconceived ideas about what having diabetes means. Please clarify any misconceptions by ensuring you give us all the necessary information, regardless of how knowledgeable we may appear. This is*

Nutritional Management of Diabetes Mellitus. Edited by G. Frost, A. Dornhorst and R. Moses
ISBN 0 471 49751 7

- *particularly important when it comes to nutrition. Many believe people with diabetes should* never *eat sugar and this perception could mean we are unnecessarily restricting our diet.*
- *For young children newly diagnosed with diabetes, what you don't say can be just as frightening as what you do say. We usually need reassurance about all aspects of diabetes, including what we can and cannot eat.*
- *Be very careful how you word things and remember to talk to the children too, not just the parents.*

Following my diagnosis, I spent two weeks in hospital (how things have changed), getting better, but more importantly learning how to manage my diabetes. I realised that insulin injections were not that bad, there were still some things I *could* eat (more about this later) and that I wasn't going to die. When my blood sugars had finally returned to normal levels, I no longer felt lethargic and thirsty and I began to 'help' the nurses. Whether I was helping or not is questionable, I was probably more of a hindrance than a help. None the less, I diligently filled water jugs for patients, and felt an extremely important nine-year-old, handing patients their drugs with a glass of water during the drug rounds. For the most part I loved being in hospital and had lots of fun. The care and support I received from staff was invaluable in helping me to adjust to life with diabetes and planted a seed that would later grow into a passion and subsequent career in health care. Of course the love and support from friends and family was also extremely important and I would not have got through it without them. Meeting someone else who had diabetes while I was in hospital gave me hope and reassurance that I would be OK.

But it was not always smooth sailing during my hospital stay. I shed tears every night when Mum left the hospital, and the death of the elderly lady opposite me did nothing to reassure me. I was scared and worried. Although I seemed to handle my diagnosis with ease, perhaps I was putting on a brave face during an obviously traumatic time. Others must have done the same for me.

- *Support from family and friends helps us to cope with the transition of living with diabetes, but please do not underestimate the importance of having health professionals nearby. Your support can make all the difference.*
- *If possible, introduce us to other people who have diabetes, because this gives us a sense of normality and proof that there are other people successfully coping with diabetes. They may also be able to give us some practical tips on how they manage on a day-to-day basis.*

During my hospital stay health professionals taught me everything they thought I should know about living with diabetes. They were fantastic at demonstrating insulin injections, blood glucose monitoring and what I could and couldn't eat. They also taught me to fear the never-ending list of complications that would inevitably result if I didn't follow their never-ending list of advice. As a child, I had no idea what insulin injections, glucose monitoring and avoiding sugar had to do with my eyes, heart and kidneys, let alone my feet! All I knew was that from that point on my life would need to revolve around injecting, testing and eating.

- *Teach us how to manage our diabetes independently and encourage us to take responsibility for our* own *health.*
- *Don't underestimate our fear of diabetic complications, even when our behaviours don't reflect it.*
- But*, sometimes we need reminding of the complications that can result from poor lifestyle habits!*

What health professionals didn't prepare me for was the frustration I would experience in trying to achieve what I sometimes felt was the impossible: normal blood glucose levels. It sounded so easy in hospital, inject this, eat this, don't eat that, but in reality it became harder the older I got. Life became a choice between being different with normal blood sugars or sacrificing my health to fit in. The two rarely coincided. Occasionally I would do what was best for my diabetes, but more often than not I would ignore it and carry on regardless. Nobody prepared me for the emotional aspects of living with diabetes. Whether this was dealing with the guilt of missing blood sugar tests, eating things I was told not to or feeling like a failure when, despite following all the 'rules', my blood sugars seemed to have a mind of their own. What was the matter with me and *my* diabetes?

- *Diabetes does not always take first priority in our lives, just as looking after your own health is not always your first priority. We need your support and encouragement to help keep diabetes on our agenda.*
- *Often our inability to achieve normal blood sugars can make us feel like failures. Try not to reinforce this with your body language and the words you use. For example, referring to abnormal blood glucose results as 'bad' is often interpreted as 'I am bad because I cannot achieve normal sugar levels'.*
- *Most people with diabetes wouldn't mind performing blood glucose tests and injections every day, as long as they were guaranteed normal blood glucose results. If only diabetes was this simple!*
- *When you are frustrated with our blood glucose results, try to imagine how frustrated we may feel.*

Like life, living with diabetes has its ups and downs. Often, our lifestyle habits and those of our family are better than most, because of the information we have received from health professionals, particularly on diet and exercise. On a more serious note, the personal responsibility for blood glucose control can bring a rare level of maturity and dependability early on in life. Conversely, there are no holidays from diabetes and sometimes the juggling act of insulin, food, exercise and stress can feel draining, time-consuming and often difficult.

- *Occasionally we need reminding of the positive aspects of living with diabetes.*
- *Sometimes, living with diabetes can feel very serious – try to laugh with us once in a while.*
- *Try not to make assumptions about us – we may all have diabetes, but we may cope and manage things in very different ways.*

Since getting diabetes I have been privileged to meet some very talented health professionals. Sadly, I have also been disappointed by professionals who did little to help me. My first paediatrician literally jumped for joy and seemed more pleased than I was when my HbA_{1c}'s were near-normal. Occasionally I was lucky enough to see Joan, a paediatrician living some distance away, who I saw on and off into adulthood. She was very good at identifying the gaps in my diabetes management that other doctors never seemed to notice. For example, falsifying my blood glucose results when I didn't want anyone to know how 'bad' they were or when I simply wanted to pretend that I didn't have diabetes. Other doctors and dietitians appeared to be far removed from what it was like to live with diabetes, and I just couldn't connect with them. I don't doubt that they were fine professionals, but they seemed to operate to their own agenda without asking what was concerning me.

- *We like you to share our enthusiasm when we achieve our goals but we also need your understanding and empathy when things aren't going so well.*
- *If you feel you are not getting anywhere with us, put the ball in our court by asking us where we need you to help.*
- *Just because we don't ask for help doesn't mean we don't need it.*
- *It may sound obvious, but remember to keep probing and asking questions until we find the best solutions to our diabetes-related problems.*
- *With your help, managing our diabetes can feel achievable.*

Having diabetes and regular exposure to health professionals over the years has certainly fuelled my interest in nutrition and dietetics. From an early age, I learnt much about how my body worked and this fascinated me. I was amazed at how directly food could affect my blood glucose levels and overall feeling of well-being on a daily basis. I was sure that food and nutrition must also affect people without diabetes, perhaps in a less obvious way, and I wanted to learn more. My frustration with the ever-changing dietary advice given to people with diabetes was also instrumental in my decision to become a dietitian.

When I was diagnosed (with diabetes), I was told to totally exclude sugar from my diet and follow very strict carbohydrate exchanges, which was the advice given by dietitians at that time. I can remember drinking gallons of fruit juice at mealtimes to ‘make up’ my set exchanges because I couldn’t fit another mouthful in. I was repeatedly forced to snack when not hungry to avoid hypos, often unable to eat with everyone else because it wasn’t the right time for my set diabetes regime. Cakes, chocolates, biscuits, etc. were of course strictly forbidden, as was any food containing added sugar, including baked beans! This made parties, sleepovers and canteen lunches difficult and, although allowed the indulgence of ice cream, it was only once a week and *if* my blood glucose levels were well controlled. Thankfully things have now changed.

As a dietitian I have lived and worked in Australia, the USA and the UK and have noted variations in the nutritional recommendations given by dietitians and diabetes specialist nurses in their everyday practice. Essentially, the same dietary information is given, but the emphasis varies considerably. Speaking in very general terms, the nutritional focus in the UK is on very good but quite general ‘healthy eating’ advice using the plate model, such as reducing saturated fats, increasing fruit and vegetable intake, increasing fibre, moderating refined sugar and salt, and so on. Only small consideration is given to the carbohydrate content of foods, at least from the patient’s perspective. In Australia, similar approaches are taken to healthy eating using the food pyramid, but with a much greater emphasis on glycaemic index. In many centres in the USA, more time is devoted to estimating the carbohydrate content of foods/carbohydrate exchanges and how this relates to the need for varying insulin doses at meal times. Although ‘healthy eating’ concepts are discussed, there is a much smaller emphasis given to the glycaemic index.

Although we are all clear on many aspects of diabetes nutrition guidelines, such as the need to reduce fat intake in relation to heart disease, there are still many aspects upon which the jury is still deliberating. For example, should we be teaching patients in depth about how to estimate the carbohydrate content of foods and hence deliver variable amounts of insulin based on what and how much is eaten. Here in the UK, the development of new insulins and insulin delivery systems such as pens and infusion pumps is fuelling a returned interest in the need to teach patients about the carbohydrate content of foods. An ongoing interest in the glycaemic index is also being seen, and how it can be applied in a practical way to the nutritional management of all types of diabetes. Further discussion of these issues is included elsewhere in this book.

The best way of course to achieve consistency in diabetes nutrition recommendations is to carry out research. I believe it is important to remember that demonstrating the effectiveness of nutritional advice by assessing improvements in diabetes outcomes is not enough. We need to go further and ask ourselves whether or not people with diabetes are willing and able to follow our recommendations in the long term. This is a subject which continues to fascinate me, as I know that I did not always follow the advice given to me when I was growing up with diabetes. Why? A scientifically proven approach may well deliver the desired outcomes in a controlled clinical environment, but is it simple to apply in the real world and does it make a notable difference to diabetes control and perhaps more importantly quality of life? Assuming that you do not have either the time or resources to carry out your own clinical research, the time-tested approach of talking and listening to your patients can provide you with valuable information. The point here is that dietary advice is not a 'one size fits all' approach. The type and complexity of information given, how and when it is delivered will depend on the individual, the resources available to you and your professional judgement.

- *Don't rattle off the same piece of information to all of us, based on your own agenda. Make sure it is relevant to us, otherwise we see little point in following your advice or returning to see you.*
- *Dietitians are often not very realistic or practical. Talk to us about our everyday foods and how we can still eat the things we enjoy every now and again while maintaining our diabetes control.*
- *Remember to listen.*
- *Question tradition.*

As a dietitian who also has diabetes, what nutritional guidelines do I now use to manage my own diabetes? I believe I have taken the best from all I have learnt about food and diabetes over the years. I have not always followed 'current thinking' on nutritional guidelines, but rather I have used what works for me. I started insulin pump therapy five years ago to improve my glycaemic control and introduce greater flexibility to my daily life. I have therefore moved away from the strict 'sugar-free' diet that I followed on diagnosis, to what I think is a much more healthy and balanced approach to food and nutrition. I generally follow 'healthy eating' guidelines but occasionally have a sugar and fat-loaded treat. I estimate the carbohydrate content of foods, which allows me to adjust my insulin doses according to what and how much I feel like eating. I also use the glycaemic index to fine tune the way I deliver my food bolus, such as split or extended boluses and during exercise.

I remember very clearly during my dietetic training an eight-year-old boy, Josh, who was admitted to the children's ward with ketoacidosis. I spoke in great detail with Josh and his mum about juggling diet and insulin doses and answered their many questions about what he would be able to eat. After spending some time with them, his mum became quite upset. I told her that I had diabetes and her attitude seemed to change. The next day, I returned to the ward to review what we had spoken about. As I walked onto the ward, I remember hearing Josh's mum say to her friend, proudly and with enthusiasm, 'There is Josh's dietitian – she also has diabetes'. I don't routinely tell all the patients I see that I have diabetes, but for many patients it can be beneficial. Having diabetes has allowed me to:

- Gain a greater understanding and acceptance of patients when they do not follow the advice I give them, e.g. testing blood sugars or following dietary advice. This makes it less frustrating for me, and the patient usually feels less judged and better understood.
- Recognise in patients what they do not always recognise in themselves, e.g. denial, fear, anger, etc.
- Empower and inspire patients, 'If you can do it, then I can too' (you don't need diabetes to prove this, try following your own dietary guidelines coupled with saline injections for a week).
- Address, in small and subtle ways when appropriate, the emotional aspects of living with diabetes.
- Do not forget that there are many aspects involved in managing diabetes and that for many patients food and nutrition is not always the first priority.
- Realise that patients not only need information, they also need support, even if they don't admit or show it.

I firmly believe that all health professionals without diabetes can achieve this kind of empathy by working towards understanding their patients and believing that they can make a valuable contribution to the quality of life of people with diabetes.

As someone who has lived with and cared for people with diabetes, I would encourage you to teach them the necessary knowledge and skills to manage their own diabetes on a day-to-day basis, so that they take responsibility for their own health. Consider all aspects of diabetes not just the nutritional issues, so that you give your patients the best possible care. Ask questions and listen. I have tried to share with you some of my ideas and I realise that my experience is not that of all people with diabetes, but I hope this has enhanced your understanding and inspired you to give your patients the information and care they need to live a long and healthy life with, not despite, their diabetes.

I wish you all the best in educating and caring for people with diabetes.