

## Complications: What If?

**All the diabetes books, pamphlets and internet sites talk about “prevention” but there is a taboo on discussing what it’s like to experience complications.** This article aims to expose some of the myths surrounding complications and share the insights of some of the young adults who have not only coped but have conquered and transcended complications.

Unless you’ve been living under a rock for the last twenty years, you will know that research has shown that lowering your HBA1c will reduce the risk of developing complications (1). This is great news but unfortunately the studies are often misinterpreted. Complications do not arise only as a result of poor control. Diabetes, even when well controlled can eventually impact on the body, after 15 years with type 1 diabetes, 80% of people will have evidence of changes to the blood vessels at the back of their eyes and the rate is even higher after 20 years. So encountering a complication shouldn’t be a reason for despair, nor should you feel as though you have failed to prevent it.

Given long enough with diabetes the odds are that you will have some sort of encounter with a diabetes complication. In most cases the complication will remain in the background, sometimes it will need treatment; in very few cases will it permanently impact on your life. The onset of a complication can be scary, however, as you suddenly have to face the uncertainty that comes with a new health problem.

In analysing how to cope with stressful and difficult situations of which being diagnosed with a complication is obviously one, self-help and counselling texts borrow from work

done by Dr Elizabeth Kubler-Ross in the 1960s (2) and describe stages of grief; these are denial, anger, bargaining, depression and acceptance. Whilst it seems simplistic to expect everyone’s reactions to follow a defined path, and it may deny the uniqueness of each person’s personality, coping mechanisms and support networks, it can be useful to realise that you will experience a range of emotions. It is OK to feel angry or depressed, anxious or disbelieving. You don’t need to feel compelled to justify your feelings nor be obliged to progress from stage to stage in an orderly, sequential fashion. The people I interviewed had a range of reactions and ways of coping with a diagnosis of complications.

**Tony**, an incredibly energetic and optimistic twenty-something guy who has had diabetes since infancy said his diagnosis of early kidney damage didn’t seem real and he was able to convince himself that it didn’t really matter until, hot on the heels of that diagnosis came retinopathy and he started to calculate how long he thought he would “have” until he went blind. He felt compelled to start securing his future by frantically pursuing his career and doing further study. **Andrea** describes trying to “hold herself together” in the eye clinic; waiting until she got outside to cry tears of grief and fear when she was told that hemorrhages near her reading area meant that she needed urgent laser treatment. **Vicki** described a sense of hopelessness and frustration, that despite working really hard to control her diabetes over the past few years her retinopathy still progressed and she felt she was being punished for a misspent youth. Although each of these people are at a different stage of treatment, it is extremely unlikely that any of them will lose their sight and their eye doctors are optimistic that treatment will ensure that they retain their vision.

Some other people I interviewed described feeling despair when protein was detected in their urine, only to find that this sign of early kidney damage was reversed in subsequent tests, either through improved control, blood-pressure medications, a combination of both or in one example none of the above. Even in those whose kidney function has declined, **Jenny** like many others is still doing fine 15 to 20 years on. Other people I have spoken with have had several false alarms – assuming that a pain in the leg plus 20 years of diabetes is automatically neuropathy when, after many sleepless nights, it turned out to be entirely unrelated.

**David** had his first experience of laser treatment in 1985 at the age of 24 and after 10 years of diabetes. He has had treatment on and off in the twenty years following. Despite a very slight decline in his peripheral vision, he has no other complications and he continues to lead a very full life. He and his wife toured around Australia on motorbikes, take regular holidays overseas and developed a passion for skiing in middle age. David is refreshingly matter-of-fact about his son's type 1 diabetes, telling us "...he copes pretty well although a bottle of test strips would last him half a year. What can I say? I was a teenage diabetic once!"

In some cases, the complication has a permanent impact on your lifestyle that requires adjusting to.

**Tony** went on to develop painful neuropathy and it is this, rather than eye or kidney problems that he feels has had a significant impact on his life, making jogging, running and being on his feet for long periods of time painful. He accepts this philosophically though, and refuses to let it hinder his enjoyment of life, finding ways to minimise the impact of the pain and refusing pharmaceutical pain relief for as long as he can. After a period of adjustment, most people realise that life does go on in much the same way as before. The complication is just another challenge and as with the initial diagnosis of diabetes, you cope. I read of one man who did end up requiring a kidney and pancreas transplant, but during the wait for the transplant, he worked in a busy full-time job that required travel and undertook a postgraduate degree. When he did have a successful kidney and pancreas transplant he went on working and enjoying his life diabetes-free.

**The following points summarise some of the wisdom offered by the inspirational and generous people who shared their experiences of complications:**

- **It really helps to speak to people who have been through the same thing.** You think you are the only one, but you go online for example and discover other people who are also going through or have been through the same thing. Support groups either in person or via the internet are a great way of finding people in similar circumstances. I found emails with a couple of people also undergoing laser therapy made me feel less isolated.
- **It can be useful to take a friend, relative or partner with you to doctor's appointments.** Vicki relates "When my ophthalmologist told me I needed laser, he was completely lacking in compassion and empathy and virtually told me it was my fault. I was in such shock and so upset I didn't know what to say or ask, so the next week my Mum went with me and we asked lots of questions and the doctor was much nicer." Ask your doctor lots of questions and be assertive-it's your health and you deserve to know what's going on.
- **Your health professionals should not make you feel upset or depressed;** this is not going to help your health. If you are unlucky enough to strike one of the minority of doctors who are less than psychologically supportive then you should consider seeking a second opinion or if you feel able to, tell them what it is about their behaviour or comments that makes you uncomfortable or upset. Be aware that you have every right to seek a second opinion and/or change doctors.

An ophthalmologist told me that one of his patients had a less than ideal outcome because she had earlier withdrawn from treatment for her retinopathy for a lengthy period of time; the doctor volunteered in a professional way that he thought the fact that her previous ophthalmologist "was not a good communicator...probably had something to do with it". I think that is the saddest thing I have ever heard: somebody suffering permanent eye damage that may have been preventable and all because her doctor had the bedside manner of an emotionally stunted ferret.

- **All the research shows that early detection and treatment can significantly minimise the impact of almost all complications.** It is never too late to take proactive steps towards managing complications.

Nobody puts their hand up and says “yeah I’d like to have diabetes and I’ll take complications with that thanks”. People do the best they can in the circumstances they find themselves in. If you have complications, it’s destructive to worry about whether or not they could have been prevented and besides you’ll never know anyway. All you can do is play the hand with the cards you’ve got now. Frances says that whilst not wishing diabetic retinopathy on her worst enemy, being forced to face her greatest fear has given her a sense of peace and inner strength that she never knew she had.

“I can’t change the past. I try to manage my health as well as I am able and I do what little I can to make the world a little better than it was when I found it. Nothing in my everyday life seems like much of a drama after coping with fearing I would lose my sight. Surprisingly, the laser and operation required to preserve my vision weren’t that bad - it was coping with the fear of the future that was really hard.”

- **Don’t assume the worst. Try to deal with one day at a time and rely on good medical advice.** Many people have treatment for a complication and they go back to their perfectly normal life again. Try to view the glass as half-full and focus on what is good about life, not on the setbacks. This doesn’t mean that you won’t have bad days, just be kind to yourself, pick yourself up, dust yourself off and try to find something positive and fun to do. It is amazing how effective diverting yourself even for a short while can be.

Your health, not to mention your life gets complicated the moment your first islet is destroyed by whatever diabolical process starts type 1 diabetes. Whether or not it gets more complicated depends on a whole lot of circumstances. Nobody can be sure of what the future holds, but spoiling enjoyment of the present by worrying about potential future problems doesn’t make sense. We should view each day well lived as a victory. Should a complication arise, the practice you have had in living positively will help you to conquer this new challenge.

#### Footnotes:

1. The definitive study is The Diabetes Control and Complications Trial Research Group: The effect of intensive treatment on the development and progression of long-term complications in insulin-dependant diabetes mellitus. (DCCT) *N Engl J Med.* 329:977-986, 1993. See also Klein R, Klein BE, Moss SE, et al, "Glycosylated Hemoglobin Predicts the Incidence and Progression of Diabetic Retinopathy," *JAMA*, 1988, 260(19):2864-71.
2. Kubler-Ross, E. *On Death and Dying.* Touchstone 1997

#### Some Books You May Find Useful

- Juliano, J. *When Diabetes Complicates Your Life: Controlling Diabetes and Related Complications.* (1998) Wiley.
- Butterfield, D. *Showdown with Diabetes,* W. W. Norton
- Edelwich, J. Brodsky, A. *Diabetes Caring for your emotions as well as your health* Perseus Books
- Kushner, H.S. *When Bad things happen to Good People*

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