

# **Living With HIV & Diabetes: The Perfect Storm**

## **Introduction**

My name is George Rodgers I'm 55 years old, I'm HIV and I have type II diabetes which was triggered of by antivirals in 2000. I'm also the founder of the first HIV and diabetes support group H.A.D.

## **How Little They Know**

I attended a group meeting at Metro in Greenwich a couple of months ago and it left me cold at just how little understanding those involved in mental health care understand what it's like living with diabetes and the implications it has on a person's life when things go wrong, especially as it's come to light recently that HIV consultants here in the UK have known about the link between antivirals and diabetes since the late 90's if not earlier but ignored it.

## **When CBT Didn't Help**

Two years ago I went for Connotative Behavioural Therapy because I was still getting angry about what I've been through over the past fourteen years because those involved in my care wouldn't take the effects the medication was having on my diabetes seriously and when I ran into trouble I was accused it was physiological.

Another part of wanting to go for counselling was to help me to get those closest to me to understand why I needed to make life style changes because of my diabetes and the response was similar to what I got last week. Why do people need to know, you can't change people's attitude and there lies the problem.

## **My Rollercoaster Ride**

In 200 I started taking a combination regime which triggered of pancreatitis, the pain was that bad I stopped taking my medication but the damage had already been done it triggered of my diabetes.

I was given a lecture a week later by a consultant about stopping and starting medication but a week later after seeing a dietitian at the diabetic clinic who told me it was a good job I stopped taking my medication when I did as I would have ended up dead.

This left me with no option but to ask the question "How are antivirals going to affect my diabetes?" This led me to have battles with various consultants (seven in total) because they wouldn't accept the fact that the antivirals were having an effect on my diabetes and I ended up stopping my medication completely.

At times if felt like I was playing Russian roulette and I wasn't the one holding the gun.

During those thirteen years I only had 18 months where everything went all right. That was between 2004 and 2006. That's because I thought I had found a consultant who understood my situation as he reassured me that if my antivirals started interfering with my sugar levels there was a tablet he could give me.

So I went of and did my bit I went to the gym regularly, I was eating better basically I was looking after myself because I thought I had a safety net in place, I didn't have to worry about my antivirals having an effect on my diabetes.

Eighteen months later things changed for some reason I became resistant to one of the tablets and everything went downhill from there. I got accused of not taking my medication properly despite being on it for eighteen months without any problem.

The consultant changed my medication three times within a month without waiting for results to come back. One of the tablets he gave me caused my sugar levels to go into double figures and despite being reassured eighteen months earlier that I could be given a tablet if the medication started to affect my sugar levels I got told it can't be the medication it must be my life style.

The consultant after that wasn't much better she couldn't understand what the problem was either so I ended up staying of medication for 18 months and after a long discussion with my partner at the time I changed hospitals and started seeing the same consultant as him and ran into the same problems there.

Despite the consultant knowing my medical back ground she still ignored my question in regards to how will the antivirals effect my diabetes especially as she was going to give a tablet similar to the one that triggered of my pancreatitis but she totally blanked my question and I ended up staying of my mediation for another eighteen months.

It was in that eighteen months that my CD 4 count dropped to 29 and I had no choice but to go back on medication once again I was reassured that I ran into any problems I should ring the hospital.

Two days after being on the medication I became violently sick, I was literally bring up acid. My metabolism was going so fast that two minutes after eating I wanted something else, my sugar levels were going into double figures and I was crying for no reason at all. I put up with it for three days and when I finally rang the adherence nurse the response I got was unbelievable "that doesn't happen to other patients, it must be psychological and she put the phone down on me. I even had one consultant tell me I had to keep my diabetes separate from my HIV and my GP would have to deal with it. The trouble there is GP's don't know enough about HIV.

## **Diabetes Is A PERVASIVE Disease**

Being diabetic isn't like being HIV where you can just take a tablet and forget about it. Diabetes is a life changer and a pervasive one at that. It is one of the most pervasive changes an afflicted person will ever have to face.

Diabetes might not seem much in the beginning (especially for type II, and often a "honeymoon phase" for type I) but with time an individual will soon become painfully aware just how much diabetes will demand of them.

Diabetes demands that we (and our loved ones) learn a lot of information in a short space of time, and often more than those involved in our care, we have to completely change how we view our eating habits and what we consider healthy. We have to throw away the information that made sense for a new and obscure world and hope we can get help and support from those that have already been through it.

Being diabetic puts us on alert to protect ourselves from harm of careless outsiders, or clueless third parties. Being diabetic forces us to think how meals will affect us and like it or not diabetes demands family unity and outside support. Diabetes is a thief of spontaneity; it demands you plan almost every minute of your life.

Unlike a job that's sent you over the edge or a relationship that isn't right for you diabetes is with you for the long term and there are times when you do need help and reaching out for support from friends and family is essential.

### ***Diabetes makes us feel judged...***

Just like being diagnosed with HIV diabetes, in itself, can be anger inducing. We often feel like we have failed somehow. Whether its type 1 or type 2, people often feel a big burden of guilt over past habits or parenting, or perceived flaws (however erroneous those might be.) Often, people who are diagnosed with type 2 diabetes may have been fighting, or struggling with weight and eating habits for years, before feeling like they were given a 'death' sentence for 'failing' to make the grade at these tasks. To top it off, few medical professionals discuss how BIG the role of our genetic makeup is when it comes to diagnosis, and how even peoples who are thin, or otherwise in relatively good health, can end up with a diabetes diagnosis.

Instead, diabetes is portrayed as the disease of the obese and inactive, and not simply a disease in which our immune systems are more sensitive to unhealthy triggers, thanks to our genetic makeup. Many things like alcohol, smoking, other medications and illnesses, as well as pollutants or pesticides, may trigger a diabetes diagnosis. Some of those triggers, we may work at reducing their influence; some, we may not. One works at REDUCING the risk of getting

diabetes, but the use of the word "prevention" is a potentially judgment inducing misnomer.

### **Diabetes Is Poorly Understood**

Just like HIV diabetes doesn't just bring with it a lot of self-blame it often brings with it the blame of outsiders who poorly understand this disease. This is in part the fault of our current medical professionals and in part the fault of our media who see diabetes as a course of obesity.

You would think that for such a deadly disease there would be many prepared and able medical professionals and there are some great ones out there, who would be better educated and not so misguided. Many patients' particularly type II are left in the dark with what they have and how to proceed. We are often kept from access to specialists, educators, testing tools and insulin so managing this diseases and learning how to do so in what would be in a safe environment are often huge and frustrating hurdles and are left not understanding why they can't make strides and worse being judged and labelled for not being non complacent.

The amount of new information we are learning about HIV and diabetes is far out pacing the amount of continuous HIV and diabetic education many medical professionals are receiving. This leaves us with antiquated guidelines leaving many patients out there clueless and confused.

It follows that because diabetes is such a pervasive disease and such a complicated and misunderstood disease that diabetics themselves are misunderstood and at times seen as an inconvenience.

If a family member had a deadly nut allergy then the family would keep the home free of nuts but when it comes to diabetes few people can understand what it's like to have to completely re-structure a life after a disease and require the support of the whole family.

Often, family and friends think that diabetes is the person's problem and that they don't need to contribute or support in any way. They don't want us to "cramp" their style, or to change on our account, in anyway. Often if a person with diabetes does the cooking they end up cooking two different meals for their family or loved ones, or may get little understanding of why they want a healthier food cupboard in the home.

Feelings of frustration, anger or resentment are met with snide comments of disbelief: "What's the big deal? You can eat that...", "Just diet and exercise and your diabetes will go away," "Just stop eating sugar," "I don't see why you feel so sick, you don't look sick, you must be faking it," "You brought this on

yourself, anyway....It's your fault, I'm not the one with diabetes," "Please don't bore me with your disease, at least it's not cancer,"

For the diabetic it's often a lonely world, especially if there's no support group to vent your anger or concerns in. It's even lonelier if you are a gay man and even lonelier if you are HIV and diabetic. Our struggles often go unacknowledged and we can be viewed as drama queens, hypochondriacs "obsessed" with our disease. It is a nuisance for others to change especially if that change is indirectly related to them. Diabetics are often feel left out of activities involving food, particularly if the items are challenging and no longer doable for them.

### ***Diabetes is PERVASIVE in ignorance...***

I wish diabetes was JUST a misunderstood disease; the problem is people will make decisions BASED on that ignorance, and misinformation just like HIV. Doctors choose to not educate themselves because it's a disease that can be 'avoided' and it's the person's fault; employers choose to not respect diabetic's needs because they see them as 'making stuff up' because according to many poor doctors, it's 'no big deal,' and it could have been 'avoided,' and it's the person's fault... and it keeps snowballing and snowballing.

It's the same when you go for counselling especially Cognitive Behavioural Therapy. "Why do you need to tell people about you're diabetes," "But you are an inconvenience," "You are focusing too much on your diabetes, I want to know the person before you became diabetic!"

You get the idea.

For diabetics, proving themselves as worthy patients, employees, friends, and family members, is often a daunting task. We face the same accusations people living with HIV do, you brought it on yourself and get chastised for it, this is often the bread and butter of diabetes as well... Especially, type 2 diabetes and small children with type 1 whose parents often get accused of having given them 'too much sugar' as babies. I mean, who thinks that? Do you know any mums out there who filled their baby's bottles with pixie dust sticks? I don't...

### ***Mental Health***

A recent survey found that out of 2,741 people living with diabetes who needed emotional support 2,072 didn't receive it. The survey doesn't include people living with HIV and diabetes.

The implication is clear: the emotional impact of living with HIV and diabetes isn't considered important.

### ***Why is it Important to get emotional Support?***

The emotional impact of living with HIV and diabetes can be severe. People living with HIV and diabetes are more likely to experience depression. In many cases help is surely needed.

Then there's the impact of emotional health and physical wellbeing. Living with HIV and diabetes requires frequent attention over a long period of time. Motivation is the key. Psychological problems like diabetes burnout in which people essentially submit to the condition, having temporarily lost the ability to keep going which leads to uncontrolled blood glucose levels which leads to complications.

### ***Living with Diabetes BRINGS mood swings...***

Anger, depression, loneliness, you name it. When our blood glucose levels get either too high, or too low, our moods WILL swing back and forth. Mood swings can vary between just general grouchiness, irritability, to violence (especially, during low blood sugars, when we may have little control over who we are.)

It's bad enough dealing with this scenario, but often friends just make us feel 'belittled' when they ask "Can you check your blood sugar?," if we share our emotions, or our frustrations. I admit, it's sometimes not so easy to tell... but if you're in the middle of a rational argument with someone, do not stop to ask them this; it's quite the same as asking a woman if she's on her period. I don't condone violence, but I can't say violence WON'T happen if you happen to reduce someone's honest views or emotions to a blood glucose episode.

### ***How can I help?***

Be an active "reader", and consider your friend or loved one with diabetes, as an open book; that is, listen more, and talk less. Read more, and assume less. Seek to learn, and seek ways in which you can be of help. Instead of suggesting actual tasks to 'police' your diabetic's behaviour, you may ask an open ended question, such as "Is there anything I can help you with?" Or, "I have noticed you struggle with x, y, and z... is there anything I can do to make that easier?"

We can help our diabetics by "dividing and conquering" tasks, like bringing back up glucose supplies, or calling ahead to find out what meals will be served at events, or friends' places. We can even help by making a favourite diabetic's dish to bring. I don't know why, but these small things that take away my 'spontaneity,' are the ones that peeve me the most. If I have someone else as a backup for my forgetful mind, I don't have to feel so vulnerable at those times.

Invest your life alongside your diabetic friend or loved one's life -- I mean, you want them around for a lot longer, right? Why not go to their support groups with them, or their diabetes educator sessions...? Ask thoughtful questions that do not put a person on the spot; you can ask about what a hypoglycaemic event is, and feels like, when the person is NOT in the middle of one, for example.

Embrace a HEALTHIER life. Do not treat the diabetic's new life changes like they are a death sentence, but as a wakeup call to the entire family that they need to be a bit more conscientious of what they eat, portion, and manage. If they are related to you by blood, it might benefit you ENORMOUSLY to follow their eating regimen and lifestyle, and get used to it now... while you don't have the strong pressure of complications looming over your head.

If your loved one, or friend, is greatly struggling with uncontrolled anger, and depression, remind them that it is OKAY to feel that way, and that it is OKAY to need some help sometimes with the overwhelming burden of managing a controlling, and demanding illness. Diabetes is as much a psycho-social disease, as it is a physical disease, and it WILL require outside support, and often require therapy.

### ***And Finally....***

Finally, we need better support not just from the medical profession but from the various HIV support groups.

Those of us that are now living with both HIV and diabetes feel like we've just been left to get on with it.

Yes we get plenty of support around diet and the importance of living a healthier life style but there's more to living with diabetes than diet and it's easier said than done.

We need better support around other issues as well like issues around stigma problems diabetes brings like erectile dysfunction and the mental effect it has on us.

How many people living with HIV and diabetes are going to go to a Diabetes support group and talk openly about living with both conditions?

We may be in a minority but that minority has a nasty habit of becoming a majority, we need better support.

