

Birchgrove

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to tell....

In this issue of the Birchgrove newsletter we aim to explore peoples experiences around disclosure. Should you tell people about your HIV, your Hepatitis C, or even your Haemophilia/Bleeding disorder? What are your experiences of telling people about your health status? What are your experiences of not telling people about any of them? How do people react when you tell them about your HIV? Are there any tips for Birchgrove readers about telling friends and family? What happens after you have told certain people? Has this changed your relationship for the better or worse? Is there a right time to tell and if so when? How do you do it and how does it make you feel? Do you feel that certain people should know? What do they do when they are told and how do they handle that information? How do you tell partners or children? Does your status affect your employment and do you tell employers or fellow colleagues?

Obviously we can't answer all your questions and everyone approaches this issue differently but hopefully some of the articles will give some food for thought.

stopping the secrets...

My husband is an HIV+ HCV+ haemophiliac. He was diagnosed with HIV at the age of 11. We met at University in 1998, and on our third date he told me he was HIV and HCV+. I was very upset, partly as I already knew that this was the person I wanted to spend my life with and it was very upsetting to believe that would be cut short so early in our relationship. At the time he asked me not to tell anyone else, as he was not sure about how other friends would manage.

Shortly after our wedding in 2001 it seemed more appropriate to stop keeping his medical status a secret, particularly from my family and our closest friends. My family reacted extremely well, my mother wasn't surprised or upset even though we had both been lying about it for 3 years. She has been extremely supportive since. We are still close friends with those who have been told - ***the most difficult part of telling them is trying to explain that neither of us are about to die and that it is best just to get on with life and enjoy what there is.***

HIV is more difficult to disclose than HCV simply because of the stigma. In particular as my husband became HIV+ through a blood transfusion there seems to be a certain degree of people taking the disclosure well because it is "good AIDS." However, we have generally had the experience that we are underestimating our friends by the way we have expected them to react, and everybody has coped very well.

The author of this article asked to remain anonymous.

...Or not to tell

contents...

Page 2
Disclosing to new partners
Page 3
Putting a Stop to the Lies
Page 4
Disclosure in the workplace
Page 5
Information that may help with Disclosure
Page 6
Haemophiliacs can't be gay
Page 7
The Peg-Interferon Diary- The Story Continues
Page 8 - 9
The Macfarlane Trust
Page 10
Partnership Group
US Legal Action
Page 11
Campaign News
Page 12 - 13
Recombinant Factor VIII- An Update
Page 14
Bob The Bleeder - Can He Fix It?
Page 15
Resources and Information

Timing is everything

So you meet someone at a party, you like each other, sexual tension is high, you're horny and up for it. You've both had a lot to drink and you invite her/him back to your place. The sofa becomes a hot bed of passion and before you know it you're naked with this gorgeous person. There's something you've forgotten...HIV.

You know you're not going to do it without a condom but you feel you ought to tell her/him. She/he seems cool about it and hasn't lost her/his enthusiasm. You spend the next few hours in wild abandon.

The next morning when you wake she/he doesn't seem as keen and in fact she/he's very quiet. You part with a kiss and a promise that you'll call but she/he never seems to be in when you do.

To tell or not to tell?

If you're really just out for a good time and a one night stand of fun and passion you may want to consider whether or not to tell. If you're going to use a condom anyway perhaps you don't need to face the disclosure issue?

On the other hand - what if the one night stand turns into a relationship? If you've been having sex with your new partner for weeks she/he may feel betrayed when you do tell her/him. Sometimes people can get into this situation and end up living a lie with their partner for years and years.

Desperately seeking...

If all you want is a loving relationship with someone who cares for you, the hardest thing in our busy lives is of course meeting that person. But once you've cracked that, when do you tell? On the first date? After a week? A month? Three months?

The main thing is to give her/him a chance to get to know you and how long that takes will depend on how often you get to see each other and how much talking you do.

Location, location, location

So now you've decided to break the news but where's the best place? Here's a few things to consider:

1. If you do it at your place you can't leave if you need time alone afterwards
2. If you do it at her/his place, she/he can't leave and may not feel comfortable asking you to go if time is needed to think things over

3. If you're in a pub people may overhear your conversation
4. If you're in a restaurant you can guarantee the waiter will interrupt just at the crucial moment

A top tip!

Go for a walk in the park.
The advantages of this are...

1. You can be side by side and won't have to look her/him in the eye when you reveal your status
2. You won't be overheard
3. She/he will be able to hug and reassure you
4. Embarrassing silences or thinking time are easier when you keep strolling along
5. You can end your date and make arrangements to meet again without either of you feeling pressurised
6. There's usually a cafe in the park for when you're both ready to sit across a table

Be prepared for the questions

Once you've disclosed your HIV status there may be lots of things to ask you about. Maybe straight away or over the next few weeks.

Get your answers ready for some of the common ones:

How did you get it?

How long have you had it?

Are you OK?

They'll be a cure soon won't there?

And afterwards...

Many people living with HIV have gone through this process and ended up in long-term relationships with a partner that cares for and loves them

What if it doesn't work out?

Firstly, it may not be anything to do with HIV. People enter into and end relationships all the time. If it is to do with an attitude about the virus, this is HER/HIS problem, not yours. It's really scary to take the risk of disclosing to someone and congratulate yourself for doing it. Next time it will be easier.

Disclosing to new partners

...what if the one night stand turns into a relationship?

Putting a stop to the lies...

Over the years the secrecy surrounding my HIV diagnosis has consumed me. In the early days especially as the stigma and fear was immense. Having this virus has changed me in many ways but I never expected it would turn me into a liar. I have lied to my family and friends and people very close to me for years and I became extremely good at it. Developing tactics and quick responses to any questions, alibi's and cover-ups so that no one would suspect. Why? Because I didn't want anyone to know. Why? Because I thought it would change my relationships with people for ever, I would lose any control I had over the situation, It was my problem not theirs and mostly I feared that people wouldn't understand and treat me differently.

So what has changed to make me think any different? I suppose the fact that there is some hope of a future with today's drugs, and I don't want to spend the rest of my life lying to people that I care about and spend my life with.

Having spent a lot of time talking to other people with Haemophilia and HIV has helped me get my head around talking about HIV as I would any other aspect of my life.

I told one friend shortly after my diagnosis and I regretted it as looking back it freaked him out almost as much as it did me.

I told 2 friends 6 years ago as they were going to live abroad for a few years. I told them because I didn't think I would be alive when they got back. Looking back it was heavy load to dump on them, they were very supportive although shaken by my news, but urged me to share this with others. So over the last 5 years I have been telling my friends, very slowly, one at a time. Its never easy and however many times I played over the scenarios in my mind it never worked out as planned. There is a never a right time. There are plenty of wrong times to do it but never a right time. I could always think of an excuse not to tell them. One by one though it does get easier. I am getting used to now seeing my friends look at me in disbelief, see the sadness on their faces, the hugs that follow, that silence as they try to make sense of it, the endless questions that follow, the reassurances that I have to give, the anger they take on and then when it all sinks in and again disbelief that I have carried this secret without telling them, without sharing it.

So how has it gone so far? I feel better in myself. I feel happier being honest with my friends for the first time in a long time. I do not have to keep up the pretence and it makes life easier for me. I am lucky in that the people I have chosen to tell so far have been very supportive and understanding. But what impact has it had on them? I would like to think it has made our friendships stronger overall but individually

there have been similar reactions. Everyone I have told has reported lying awake all night unable to sleep as they have tried to make sense of it. Everyone has come back with endless questions after they have thought about it. I think they have all needed support from me in trying to help them get through it. Every occasion has been emotionally draining for all parties. One friend had to take the next day off work, as he was so upset and angry. One friend phoned me the next day to tell me he had been awake all night remembering a memory he had. In 1986 when a government "don't die of ignorance" advert came on the TV, when we were with a crowd of mates, he remembered kicking me and saying pay attention this adverts for you. I didn't even remember myself as I think I blocked a lot of things out in those early days of HIV. We have laughed about it now.

One friend said to me some months after I had told him that he it really depressed him, he said he felt like I had died the moment I told him and he went through some weird mourning period. Another said that he was so pleased I had told him now and not years ago, as he didn't think he could have handled the news when the prognosis was an imminent mortality.

Everyone has needed support themselves and I have tried to help this process by telling them the people that know and don't know. They have been able to go and talk to someone else about it that has gone through the disclosure period and the thought process that goes with it. I have given them reading material as most of them have gone through an initial quest for knowledge as so many of them knew very little about HIV. I have given them phone numbers of HIV phone lines where they can phone for support and information themselves. I have always, where possible told friends 2 at a time, i.e. couples, as I realise that it is a heavy load to drop on somebody if they haven't got someone to talk about it with and human nature is that they will want to talk about it.

The common question everybody has asked me, once they are assured I am not going to drop dead in the next few weeks, is why haven't you told me before? My answer is that they never asked me. I have never lied about having Haemophilia and have worn a red ribbon for years and still nobody ever asked me. I always assumed it was because they didn't want to risk asking me if they couldn't handle the answer they didn't want.

The journey is far from over and I have a few more on my list to tell but it does get easier with practice and I haven't regretted it once so far. After all what are friends for?

by Paul

Disclosure in the workplace

Telling your boss or work colleagues about your HIV status can be a daunting prospect. As someone living with HIV who has changed jobs since my diagnosis I have had to face the dilemma of who to tell and when to tell them on a number of occasions. Sometimes this has been a positive experience and at other times a negative one.

When I was diagnosed with AIDS in the early nineties I was working for a small Housing Association as a Supported Housing Officer. In common with many people who are newly diagnosed I was terrified of people finding out. For the first year there were only two people who knew, my partner and a close friend who lived many miles away, so it was a big secret.

My job involved me living on site and working very closely with one colleague. Before I found out I had AIDS we were very close and talked about everything but I didn't feel able to tell her about my status. I found it very stressful to maintain the friendship we had developed and it was difficult to tell the lies that I needed to in order to cover up my activities and fears. On my days off I would sometimes go to Positively Women or have a hospital appointment and I hated having to lie the next day when my colleague asked how I'd spent my free time.

As I found out more about AIDS and HIV, as I learnt to call it, I started to worry about where I would die and what would happen. I was given a flat to live in with my job and was concerned that when I got ill and was no longer able to work I would also be homeless.

I started to look for jobs with local authorities as I thought I would be treated fairly when I got ill. However, I was very worried about what the situation was with regard to my status. I found out that I didn't have to tell future employers that I had HIV and in 1994 I got a job as an emergency officer and moved out to my own flat.

In my new workplace nobody knew I had HIV and I was quite reserved compared to my colleagues who talked openly about their lives. Some of our clients had AIDS and one day I had a blazing row

with another worker who felt we had a right to be told if someone had HIV. When questioned he said it was so he could wear gloves whenever he visited. To me it was as if he was saying "I wouldn't touch you without a pair of gloves on". Over the next year or so I got more and more tired and struggled to do my job. I did everything I could to avoid going out on emergency calls and would persuade my colleagues to go instead. I got a reputation for being lazy. One day I was out with a colleague and we were going on a routine visit to someone who was dying of AIDS. I had been to this man many times before but on this particular day I just couldn't face him. I asked my colleague whether she minded going alone and I wonder whether she thought it was because I was prejudiced against people with AIDS!

Towards the end of 1995 I developed a chest infection and was off work for three weeks. Our service was 24 hour and so people had to work over Christmas and New Year. I was due to work on Christmas Day but despite the antibiotics I'd been given the infection got worse and I got weaker and weaker. My colleagues knew I didn't want to work at Christmas and started making comments about a 'fake' illness. I tried to combat this and continued to go to work but a few days before Christmas I could barely get out of bed. I went to hospital and suspected PCP was diagnosed. I refused to be admitted and my family collected me with the medication I'd been given and took me home. I recovered and eventually returned to work but it was obvious that my colleagues didn't think I had been seriously ill.

In 1996 I was a member of the speakers team at PW and we increasingly had requests from the media. As my family and close friends knew I had HIV by this time I agreed to do an interview for a monthly women's magazine. It was to be published in two months and I began to worry about how it would effect me at work. My main concern was that our clients would panic and phone the council, particularly those who I had administered First Aid to, even though I was always extremely careful to cover up any cuts and sores on my hands and wear gloves. I went to see my boss and told him I had HIV and that it may

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