



Birchgrove

THE BIRCHGROVE GROUP, P.O. BOX 313, CANTERBURY, KENT CT1 1GL. TEL: 0345 697231

the sex issue...

Sexuality should be a huge concern for the haemophilia community. Even before the advent of HIV, we were counselled about the risks of men passing on the gene for haemophilia to their daughters; or, for women who are carriers, giving birth to a son who was a haemophiliac.

Establishing a relationship and starting a family has always been a loaded issue. Accepting the realities of a genetic condition which not only affects the sufferer but can also affect the children is a responsibility which we have always been made to face. Many of us have consequently been made to feel guilty even about deciding to have children.

What effects have these pressures had on our feelings of self worth, our desire to be sexual, and in the establishment of intimate relationships? Having haemophilia also affects one's body image and therefore one's consciousness as a sexual being. Joint damage, limited movement, and altered physical appearance all play a significant role in how people with severe haemophilia see themselves and how they function sexually. For all of us with haemophilia what are our attitudes about our bodies? Do we have fears of acceptance by actual or potential sex partners?

Facing up to being infected with HIV and being infectious has served to reinforce an already negative self-image. Sex and sexuality are issues that many people with haemophilia are reluctant to examine, subjects that we are all too quick to push back into the closet.

Haemophilia centres have always played a major part in the lives of haemophiliacs and their families. Although some professionals recognise that many haemophiliacs can be empowered consumers of health care, many have played a very paternalistic role; or for nurses and/or social

workers, a great percentage of whom are women, a maternalistic role. Many haemophiliacs say that it is terribly embarrassing to have the women who provided their haemophilia care to them as children, then trying to talk with them about their sexuality. This has become especially significant since the advent of HIV. Many haemophiliacs say that they still feel as if they are children in the eyes of the haemophilia centre staff. The underlying culture of paternalism which pervades many doctor - patient relationships (not just those related to haemophilia) often contributes to this atmosphere.

In the early years of the HIV epidemic, there was intense denial about this disease both in families, and amongst the medical care providers. Prevention of sexual transmission was just not discussed very openly. Certainly, whatever discussion did occur was shrouded with embarrassment and secrecy. Unfortunately, much of the early risk reduction messages equated sex with death. "Use condoms every time or you'll kill your partner." It didn't help that a number of women were already infected before anyone knew about risk reduction. Sadly, there are too many wives and partners who have already died.

THE SEX ISSUE continues on page 3

WARNING • WARNING • WARNING

This newsletter contains sexually explicit language. We hope that many of the articles are offensive or at the very least positively smutty. We believe that the repeated use of rude words will help to broaden peoples vocabulary and may even broaden their minds!

Sex, drugs and rock 'n roll are issues that are very close to the heart of the Birchgrove. So it will come as no surprise that we have chosen to cover these important themes in our forthcoming issues. (Any comments or contributions are always gratefully received.) This issue we are taking the opportunity to re-examine the concerns surrounding sex and sexuality.

Some of you may remember in the dim and distant past that our medical professionals made two simultaneous decisions. They not only decided to tell us that we were infected with HIV but they also took the opportunity to (perhaps for the first time) discuss our sex lives and/or our sexual proclivities. This double shock was not easy to come to terms with.

At least not many of us have had to bother with any more of those irritating little "safe sex" talks or any more of those intimate "counselling sessions" with embarrassed professionals who seem more awkward about what we get up to in bed than most of us did. I suspect that this embarrassment factor has made SEX a subject that most haemophilia centres no longer feel eager to tackle. But we are still HIV positive and we still have sex.

Where is the safe sex literature? Where is the support for our partners? Where is the support for people who are establishing new relationships? It is an increasing concern that many who at one time practiced strict "safe-sex" procedures no longer feel the same sense of urgency. Do you still wear a safety-belt? There are some who never bothered to start!

This surprising lack of energy and effort going into information for people who are positive cannot help the rest of the community. There are many anecdotal examples of positive men who are not willing to take on the responsibilities of being HIV positive. It is perhaps a little ironic that the health promotion authorities put such efforts into persuading people who may not be positive to "take care" and little or nothing into those people who are a guaranteed risk to the rest of society.

What about a safe sex campaign for those living with the virus? Not, "this is how to avoid AIDS" but "this is how to face another bloody condom after ten years!". What about risk reduction for those who have become sick and tired with the whole concept of HIV, "safe sex for the terminally bored."

SAFE SEX - WITH A COW!

Phobias have made the national headlines in Zimbabwe and in the United States. In Zimbabwe, Israel Zinbange was convicted for having sexual relations with his cow. His defence was based on nosmaphobia, which in this case includes the fear of contracting HIV from a human sexual partner.

In a similar story from Washington DC, uniformed CIA officers wore latex gloves when a delegation of lesbian and gay officials attended a meeting at the White House. While nosmaphobia may have been a factor in this action, other psychiatric terms describing the Secret Service's behaviour include homophobia, auto-mysophobia, katagelophobia, and spermophobia.

At least, the Zimbabweans' HIV/AIDS education programs are effective. Zimbabweans understand how HIV disease is transmitted, which is more than can be said for US federal employees. Israel Zinbange was sentenced to jail as a consequence of his nosmaphobia. The Secret Service officers will probably only be ordered to attend a hastily constructed and useless HIV seminar. Justice might be better served if they were sent to work on a Zimbabwean cattle ranch for a few months.

The next issue of the "Birchgrove" newsletter will be on the theme of Drugs. We would be pleased to publish peoples views and experiences both of using prescribed medicines and recreational drugs such as marijuana, ecstasy and alcohol etc.

The views expressed in each of the articles are those of the individual authors, and not necessarily those of the Birchgrove Group. The Birchgrove is a forum for discussion and seeks to encourage debate on the issues that affect people with haemophilia and HIV. We would encourage anyone who may have strong views regarding any of the items published in this newsletter to write to the Editor. We are keen to publish any thoughts or views which help promote a healthy debate. No assumptions should be made regarding the health status of any individual whose name appears in this publication.

"BIRCHGROVE" is published by:
The Birchgrove Group, PO Box 313,
Canterbury, Kent CT1 1GL
Tel: (0345) 697231(Lo Call)

Editorial Board: Michael O'Driscoll (Editor),
Paul Jenkins, Cady Khudabux, Paul Kimberley.

I've heard stories from around the country about the risk reduction advice offered through haemophilia centres. Some spoke about sensitive, confidential assistance. But others told of counselling sessions in the clinic waiting room, or in public hallways. Of how couples were split up and given divisive messages. There were many versions of the same punitive message "do it right or die".

The family splitting and punishing messages offered, either overtly or covertly, were responsible for adding insult to injury. One message was that we shouldn't get pregnant, because we could die and kill our child as well. Another was that our men weren't keeping us safe enough, so it was up to us to make sure that we were responsible for safe sex; instead of communicating that it was a shared responsibility to be safe. The unspoken (and semi-spoken) messages formed a powerful undertow:

Sex=HIV, HIV=Death; Therefore, Sex=Death.

I sometimes feel that we are in the process of incest recovery here. Many health care professionals have chosen to treat us in a very paternalistic manner. In essence, they have said to us, "Believe in us, and give us your trust. You can't know what's best for you unless we tell you. Don't worry, we'll take care of you, and everything will be all right." They were our daddy.

Unfortunately, a dependence on this paternalistic health-care system has not helped us to deal with a disease that was injected into us by the doctors who said they had our best interests at heart. We need to realise that decisions were and are often made on financial grounds rather than purely medical grounds. We need to see our health care as part of a larger economic and political picture. Not simply a relationship between an injured child and a caring parent.

During the early to mid-1980s, there were few organised attempts to even acknowledge the epidemic, let alone respond to it. The medical world had difficulty in confronting the realities of the situation. How could the freeze dried concentrates that they recommended be contaminated? How could best practice be so wrong?

An analogy can be drawn between the silence that surrounds our haemophilia-related HIV epidemic and silence that surrounds incest. Some haemophiliacs are only now waking up to this abuse. They can hardly believe that their "father" would have done those things to them, but the effects of HIV on their bodies is evidence that does not lie. Others deny that this "father" could

ever or would ever, abuse the family like these dangerous siblings say he did.

But for many of us, it feels crucial that we get something from "daddy" around this "incest" process. We need to be listened to in a very deep way. We need to speak of our pain and anguish. We need the depths of our hurt validated, and to have acknowledged that what happened to us was, and still is, very, very wrong. Perhaps we need to hear someone say that they are sorry.

I'm not saying that they should publicly admit wrongdoing, but that they should openly recognise our suffering in a way that allows us to feel seen and to feel heard. That this should be done without defensiveness and denial. For those of us who still have a strong emotional connection to the medical profession, this validation and recognition would be a good beginning for a healing process.

Ultimately we need to heal ourselves as individuals, and not leave it up to "daddy" to make everything OK. One way to begin the healing process is through activism. This process can help us demonstrate that we are children no longer. You're reading it right now.

Another way is to try and heal our own individual lives. It is necessary to learn new concepts in order to become a healthy and functional adult after surviving life threatening abuse when dealing with sexuality and/or health care. Some of these things include; setting appropriate limits and boundaries around what each party is allowed to do, and/or is responsible for. Learning to insist on having full, informed consent to any procedures or any decisions, and being aware of the freedom to choose the appropriate people to support and advise us.

I have struggled with many of these things for years, and I know that it can take tremendous amounts of energy and courage to become responsible for one's own healing. Each individual's contribution to this fight for independence can help the health of the haemophilia community. We must strive to create better communication channels between health care professionals and patients and we must learn to speak openly about what is important to any, or all of us.

This article is based on ideas of Beth Weinstein who writes for The Common Factor, the US forum of The Committee of Ten Thousand.