ISSUE N° 7

Birchgrove

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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.

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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!

EDITORIAL

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, automysophobia, 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, ecstacy and alcohol etc.

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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 individuals 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.

Days Before Condoms

Remember when fucking was fun? Remember when just about anything went? When the exploration of each others' bodies meant both the giving and receiving of pleasure, and was an expression of love? When you didn't have to worry about STD's because there were drugs to sort them out?

Those were halcyon days, the Days Before Condoms (DBC). It all ended for me in the Summer of 1985, when I was diagnosed as being HIV positive. I was informed by Centre Director, a man who, though not lacking in empathy, seemed acutely uncomfortable with what he had to tell me. It took quite a while for all the ramifications of the diagnosis to sink in - hardly surprising given the conflicting information I received on each separate visit to the hospital.

The first visit it was, "Don't worry too much because only 10% of HIV positive haemophiliacs go on to develop full blown AIDS," but by the second visit it had risen to 50%. Shortly after the message was, "You'd better make a will, son, because 90% of you will be dead within three years."

There was however, one constant: "Don't, whatever you do, have sex." Just to complicate matters further, at the time of the diagnosis, my wife was five months pregnant. Of course she was offered really helpful advice like, did she want a termination? Given that she hadn't contracted the virus, and that this might be our only chance for a child, we politely told them what they could do with their termination. On second thoughts, perhaps we weren't so polite after all.

This great big "No" of sex lasted throughout the Summer and on into Winter. My daughter was born in November of that year and I was becoming somewhat demented from this prolonged spell of unwanted celibacy. The rationale as it was explained to us was, "You just can't take the risk of infecting your wife and child; condoms aren't reliable; just abstain till we think of something; what did God give you hands for, anyway?" My wife gave birth by a Caesarean section, which meant that our period of abstinence was further prolonged, till we were finally informed by the centre Social Worker, that there was some light at the end of the tunnel.

This light was called "Safe Sex." Suddenly condoms were okay; not only were they okay, they were cool, they were hip, they were sexy. Suddenly, every bastard seemed to be wearing them, they became a fashion accessory. They were even advertising the damn things on TV. The thing was that I could still remember the DBC. And while condoms might look cool hanging out the arse-pocket of faded Levi 501's, given the choice, I think most HIV positive people would rather not have to use them. Most of the good looking, healthy actors used to sell the condom concept, actually had a choice - they weren't infected with the virus. If you're given a choice about something - anything - then you're free to experiment; if something is imposed on you, then it becomes a drag.

But in those days, just being allowed to fuck again was a joy. As long as you could bury the fear and worry of infecting your partner through some accident with a condom. As long as you could cope with sex that was gentle to the point of passivity; as long as the missionary position was all you needed to get by.

But what if these things weren't enough? What if you weren't happy to consult a checklist each time you jumped into the sack with your partner? A checklist that said, "Don't come in (or on!) your partner; don't stick your tongues down each others' throats; don't bite, scratch, lick or suck; don't get carried away; don't stick it anywhere other than where nature intended; and don't do oral sex."

Picture the scene, the lights are turned down low, the two of you are kissing and cuddling, feeling yourselves getting aroused, the juices starting to flow. Clothes are abandoned, limbs get tangled up, you're thinking about only one thing, when that internal alarm goes off. Uh-Oh. Out comes the mental checklist; you run down it, asking can we do this? No. That? No. How about this then? Yes, but only when the moon is in Scorpio, and only then if it's a leap year and the month has an "O" in it. Jeez, I can hardly wait!

I guess this is about something that was stolen from me, and not just from me, but from my wife. Call it the innocent pleasure of sex, for want of a better term. The freedom to enjoy sex without having to worry that I might kill my wife as a result of my sexual drives. This is a major part of my life that's been limited; not only has my immune system been compromised, so has my sexuality. I miss all the things I can't do, and sometimes I feel bitter and angry. I resent the fact that we can't take the risk of unprotected sex to try and have another child. This issue, has perhaps, been the bitterest pill to swallow.

And yet somehow, we've adapted; we've adapted because we've had to. The first thing we did was to give up on the safe sex manuals and

rely on common sense. Then we started experimenting with different types of condoms. There are so many on the market now, you can feel bewildered by the choice. But trying all the varieties can add to the fun. You can get your plain, run of the mill type Johnny; Superfine for extra sensitivity; ribbed; coloured; flavoured - try Lemon and Lime, that's a favourite of ours - extra-strong for the paranoid, extra large for the liars; you can even get Johnnies that glow in the dark!

And then of course there's foreplay, which, with a bit of imagination and experimentation, can often be the most exciting part of love making. We've discovered that foreplay isn't necessarily merely a prelude to penetrative sex. In fact, the pleasure that can be derived from touching, stroking, caressing and licking, can lead to an orgasm as intense and as satisfying as the orgasm from actual intercourse. The only limit is the imagination, and as my wife keep telling me, "sex is as much in your mind as it is in your genitals".

Honesty is crucial to any good relationship and especially when it comes to sex. But if one of you is HIV positive then it becomes absolutely essential to work out how you discuss things between the sheets. If all the issues aren't discussed, then fear and ignorance can create an insurmountable barrier to a full and happy sex life.

But, if both partners are fully aware of the issues, are honest with each other, open about what they want from their sexual relationship, and they both give their consent, then there are numerous ways in which they can give each other pleasure with minimal risk.

In regaining control of our sex life, we have found the confidence to take control of other aspects in our lives. HIV and AIDS has ceased to be the defining characteristic of who, and what we are. I have been forced to become more intensely aware of sexual issues in our relationship and I have had to develop the confidence to take responsibility for those decisions that effect the health of me and my wife.

The most important thing to me is no longer the state of my HIV or which new prophylactic drug to take, (the only prophylactic that I'm interested in these days is the kind that you wear on your dick!). But watching our daughter grow up, my wife's career, finishing my degree, friends, holidays, a glass of red wine and a good movie.

Oh yes, and fucking with someone I love.

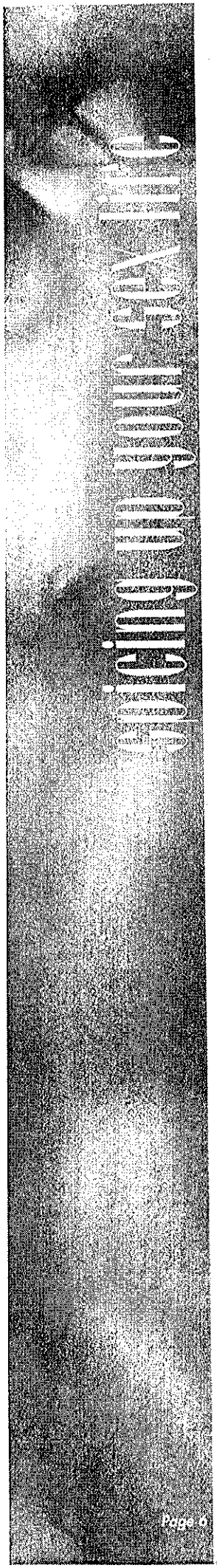
HAND JOBS

The Canadian AIDS Society Guidelines state that there is a "theoretical risk only" (this is a category lower in risk than "low risk") of infection to the person receiving mutual masturbation of the vagina or penis because semen or vaginal fluids may be present on the partner's hand. These fluids may get into the bloodstream through a cut or perhaps directly through the mucosal lining of the urethra or vaginal opening if semen or vaginal fluids are used as a lubricant. However, there is no empirical evidence of HIV transmission by this route. There is "no risk" if a water based lubricant is used instead of semen or vaginal fluids.

Usually, there is "no risk" of transmission to the partner giving the mutual masturbation. Risk can be increased to "theoretical risk" if there are cuts or sores on the hand and there are vaginal fluids or semen that can come into contact with those sores. Again, no documented risk of infection has ever been demonstrated for this activity. Using latex or polyurethane gloves for this activity decreases the risk but is also considered "theoretical risk only" since there is always the possibility of tears or rips in the glove.

Most of my reading has cautiously presented the fact that there is some risk of communicating HIV (and probably some other organisms) if there are breaks in the skin of either partner. For instance, a bad hangnail or cuts on the hand of the stroker could provide an avenue for infection if contact is made with semen, blood or vaginal fluids of the strokee. If the strokee has sores on the penis or in the vagina, the sores can provide both a source of infection for the partner and a means of infecting the person with the sores. On the other hand (no pun intended, but take it for what it's worth), my partner is HIV-negative after more than 10 years of giving me great hand jobs.

(The editorial board would like make it clear that despite an endless amount of regular experimentation it does not seem to be possible to re-infect yourself through masturbation!)



BY MARK WEISNER, PH.D.

Passion? What passion? It's only a faint glimmer on a far off horizon. You've been with the same partner forever, and you wonder what happened. The romance, the intrigue, the innuendo, those nights of racing over to meet each other, the passionate kisses, the sex... gone. You stand in the bathroom and wonder if its worth the trouble to even get something started.

Once you've ruled out physical or emotional causes, and if you have had a relatively problem-free sexual appetite in the past, try some of the following suggestions:

Arrange intimate times together. Sexual play can start with innuendo in the morning for activity in the evening. A lot of sexual pleasure is created by anticipation. A midday phone call, flowers sent to the office, a love note expressing your eagerness to be together - all increase your sexual energy level.

Make "sex dates," stop waiting for spontaneity. The reality is that people who are newly sexual usually "plan" having sex. As they dress for the evening, and plan their time, they allow for, and even arrange situations for sexual contact. Do you remember the days when you changed the sheets on the bed because you knew you'd be having sex?

Think about activities that lead to sex. You can arrange to have sex now, just as you did back then. Perhaps a romantic prelude is in order...a quiet dinner for two, or a walk on the beach. Having a large meal before sex can take the fun out of it. Think ahead.

Use your imagination. Fantasise freely. If you are bold, share your fantasies with your partner, either before going to bed or during love making. Ask directly for what you want, either in a note or in person. Experiment and watch your desire grow.

Make a list of sexual preferences in the form of a menu. Include appetisers (foreplay), main course (intercourse or acts leading to orgasm) and dessert (afterplay). Exchange filled-out menus with your partner. Completing a sexual menu makes it easier to communicate verbally with your partner later.

Experiment. Plan something new with your partner every now and then. Carry it through even if it makes you a little uncomfortable. This will increase your repertoire and appetite.

Play with one another. Have sexual play leading to orgasm without intercourse. Learn to focus on other aspects of intimacy - using all five senses. Practice touching each other differently. Ask what kinds of touching, and where your partner prefers to be touched. Slower, faster, lighter, harder, more to the right, more to the left - these are the kinds of directions that can be helpful.

Be generous. If you are receiving directions, don't expect that tomorrow your partner will want the exact same kind of stimulation. Just as people change from day to day in their intensity of orgasm, it is quite normal to be more or less sensitive from one day to the next. Gently ask for directions if you aren't getting the kind of response you expect.

Notice your reactions. Focus on your own feelings and share them with your partner, so you won't lose the focus of your own body. If you are both concentrating on what you are "doing to" the other, your efforts will cancel each other out. Focus on what creates positive sensations for you. Tell your partner exactly what to do to make it increase.

Do some research together. Sit down together and leaf through a sexual manual that presents different sexual activities and positions. Sharing this input becomes a catalyst for discussion. If you can communicate sexually, you will be able to communicate on any level.

Be flexible. Orgasms are not mandatory; the goal of making love is mutual pleasure. Whatever gives you pleasure is enough. If one of you is not well or too tired for an orgasm, stop. If being held is your idea of pleasure, ask for it. If your partner insists that you give him or her an orgasm, and you don't feel up to it, ask them to take care of themselves. If you keep turning your partner down, take the time to look at the problem seriously.

Get the big picture. Understand that what happens in your relationship is a generally reflected in the bedroom. If your partner avoids having heart-to-heart talks with you in the relationship; you might find yourself feeling a lack of his/her presence during lovemaking. You might end up feeling like you just had sex when you wanted to make love. Talk about the difference and see what happens.

Get help. If you can't make these suggestions work, seek out a therapist who works with sexual issues. Most sex therapy only requires a few sessions if you don't have a problem history. Having a rich sexual life is healthy, and worth the effort it takes to create.

Author Mark Weisner, Ph.D. is a Psychologist and a trained sex therapist, lecturer and author.