

The Birchgrove

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Partners or Carers....

ARE INFORMAL CAREGIVERS IMPORTANT IN AIDS CARE?

What do caregivers do?

Informal caregivers of people with AIDS provide practical help and nursing care at home. They are often the lovers, spouses, friends, or family of someone with AIDS and are not professional care providers. The service they provide is essential to the scope of AIDS care services and saves society great expense.

AIDS care services in the US have shifted from hospital-based care to community-based and in-home care. Rising health care costs and many people's preference to receive health care, and, when possible, to die at home, have driven this trend. The percentage of AIDS deaths in hospitals decreased from 92% in 1983 to 57% in 1991. Informal caregivers have helped make this shift possible.

Caregivers provide practical support such as shopping, housekeeping, and transportation to clinics, as well as more basic assistance such as help with bathing, going to the bathroom, and feeding. As symptoms worsen, caregivers are also likely to take on more clinical roles such as keeping track of medications, giving injections, inserting catheters, and cleaning wounds. Caregivers often provide front-line medical and mental assessment, being the first to note changes in health and to decide when to go for help. One study found the value of personal care tasks and housework performed by caregivers equalled a per capita value of over £25,000 a year for caregiving.

Who are AIDS caregivers?

A national survey found that 3.2% of the entire US adult population have provided care to a friend, spouse, relative, or lover with AIDS. Almost 3/4 of caregivers were under 40 years old. Caregiving was equally distributed across gender, race and ethnic groups among the general population.

Traditionally, parents, spouses and adult daughters have been the caregivers of people with terminal illnesses. With AIDS, family

members still provide care in many cases. However, with gay men, it is more often the partners and friends who provide care. A study of 265 British men with AIDS found that 87% had a close friend or partner as primary caregiver.

What are caregiver burdens?

AIDS is prevalent in young and middle-aged people; one in every four new HIV infections occurs in young people under the age of 22. Caregivers, also, are often in their 20s, 30s and 40s. At that age most people are traditionally building relationships and developing careers, not caring for sick people or preparing for the loss of their partner. The stress involved in this "off-time" caregiving can be enormous.

Unlike professional care providers, informal caregivers are often on call 24-hours a day and are not protected by a limited work day or professional distance. Many informal caregivers have never cared for a seriously ill person, nor have they seen someone die. Also, caregivers must learn skills such as how to give shots or insert catheters, often under extremely stressful circumstances.

Many caregivers of AIDS patients are also their sexual partners. This

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In this newsletter, we look at the subjects of Partners and Carers. These are topics which, for those of us who are directly affected by HIV and AIDS, tend to be put on the backburner. We hope you can relate to what is being said, but we had very little feedback from partners and carers when we mentioned this issue in the last copy of Birchgrove.

COMMENTARY

OK, Where do I start.

This will be the first newsletter that has been produced without the guidance of our guru Paul Jenkins who died on January 9th 1997

How can I, a lad from the streets, step into the shoes of a man that had so much talent, when it came to setting out the newsletter.

I'm also finding it very difficult to force myself into the office to get on with the work.

But knowing that Paul would kick my Ass if he thought I was giving up on Birchgrove.

I will do my best to keep this publication to the high standards, that were set by Paul.

There is a Birchgrove Wales special edition which celebrates the life of this man. Copies are available from the office.

This Issue is on the very important and often forgotten subject of **Partners & Carers**.

A subject we as positive Haemophiliacs tend to take for granted, **Partners & Carers** are the people who, in lots of cases, (mine included) keep us on an even keel as we navigate our lives in the company of HIV & AIDS.

We have tried to include a broad spectrum of thoughts relating to this subject, but we had very little feedback from the mailshot, asking for articles from you out there.

(I thank those who wrote)

So I have found myself looking through bits and pieces and trying to put them all together.

I would like to thank the National Carers Association and NAM for the information they supplied.

And will finish this with a hope that your all well and you enjoy this issue of Birchgrove.

Any articles thoughts or views you may have on the subject of Haemophilia HIV/AIDS, please send them in for the next issue. Any Funnies from the women's weekend in Oxford would be good. Or even an article on this weekend as none of us boring men were allowed to attend.

The Next Issue will be on "Safer Sex" for the Heterosexual Couple.

National Birchgrove
Dogsbody, Sofa, Secretary, Collator, Editor, and
Convener.

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puts them at risk for HIV infection. For HIV-positive caregivers, disease progression symbolises the loss of their partner as well as their own changing health status. Caregiving also raises the question of who will care for them when they become ill.

Informal caregivers may experience numbness, compassion fatigue, or burnout from losing multiple friends and loved ones to AIDS, or from caring for someone who has been ill for a very long time.

In some communities there is still fear and stigma surrounding HIV disease. In addition, people greatly affected by AIDS are often already stigmatised populations: gay men, injection drug users. Caregivers may fear social rejection, loss of job and/or housing and may thus conceal their caregiving status from family, friends, and co-workers.

For women with HIV, having responsibility for children at home may pose a barrier to obtaining caregiving support for themselves. A study of HIV-infected mothers across the US found 46% were the sole caretakers of children. Only 30% knew about child care assistance services, and only 8% had contacted those services. Caregiving for mothers with HIV must include the children as well as the sick mother, and address the welfare of the children after a parent dies. According to one estimate, there could be over 80,000 AIDS orphans in the US by the year 2000.

What can be done to help?

Helping caregivers benefits both the caregiver and the patient. Professional clinicians can include the caregiver in the "triad of care"-doctor, patient, caregiver-and train them in simple medical procedures to help improve patient care. Caregivers can benefit from psychological help (like support groups) to help them cope with the emotional roller coaster involved in caring for a terminally ill person. Caregivers may also need support in grieving the death of a loved one.

Some people may be unsure how to act around a person with AIDS, or confused about the best way to show love and support. A study of PWAs identified what they see as helpful and unhelpful actions in caregiving. Helpful actions included expressing love or concern, acting naturally, providing an opportunity for reciprocity and providing encouragement. Unhelpful actions included avoiding interaction, acting embarrassed or ashamed, breaking confidentiality, and criticising their medical care decisions. Doctors and clinical staff have an excellent opportunity for primary and secondary prevention with caregivers during medical appointments or home visits. Informal caregivers may benefit from prevention education and assistance in staying HIV-negative. HIV-positive caregivers need information on early treatment of HIV in order to stay healthier longer.

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The UCSF Coping Project, in San Francisco, CA, has been studying the physical and psychological well-being of gay male caregivers for over five years. The project found that while caregivers experience stress and depression, they also experience positive feelings associated with loving, caring and comforting. To sustain this positive well-being, the Coping Project suggests three techniques: define what is personally meaningful and valued by the caregiver; facilitate intimacy and conversation between caregivers and their partners; and help caregivers tune in to "brief human moments" that create positive feelings.

Well son, once upon a time the white man was getting on with his deforestation and his pillaging of the jungle resources, as is his wont. When out of the chaos ran a green monkey. No I don't know why he was green, perhaps he'd gone mouldy. Anyway, up jumped a hungry African who thought, yum, yum, monkeys bum, that looks tasty. So he grabbed two bread fruit stuck, them on either side of the monkey and took a bite, he'd made a monkey burger, just like the burgers he'd seen on his satellite TV. The only thing was he'd forgotten to cook it, come to think of it, it was exactly like the ones he'd seen on TV.

Well, the African went home and pretty soon, he had sex with his wife, and then he had sex with a couple of other peoples wives. Well, it took a few years, but the African eventually began to get sick with a strange wasting disease. And it was about this time, that along came a V.S.O. worker and he had sex with the African's wife and he had sex with the other wives. I don't think he did use the missionary position either! In his spare time, not that he got a lot, the V.S.O. would hang out in a bar in Harare. And one fateful day, he was lolling on his high stool, drinking his seventh daiquiri, when into his life flew "patient zero" - the man most likely to. Outside, behind the bins, wham bam, thank you mam! Well, it seems that patient zero was an airline steward. So he climbed backed onto his jumbo and took off for distant parts. He wandered up and down the aisle, serving out the duty frees, the complementaries and his little packet of chopped nuts. In fact, he wandered around most of the gay bars in the world, a little bit here, a little bit there and quite a bit in the middle. It took some time, but eventually the junkies and the addicts began to share it round.

Son, lifes got a filter system, if you pour muck in at the top, it can take a very long time for it to reach the bottom.

Now patient zero began to get very sick and nobody knew what it was Then someone thought, hang on he's not the only gay bloke to get all these weird diseases, perhaps there's a connection ???

ARE YOU NEW TO CARING ?

Whether you are suddenly thrust into a caring role because of an accident or sudden illness, or whether you have been looking after someone for a number of years, it can be hard to know where to start getting the help that you need. This Article gives a very brief outline of the kind of issues that you may like to think about.

Help from social services

You have the right to ask for help for your relative or friend if they are sick or disabled. This help could include a place at a day centre, home help, adaptations to the home to make it more suitable, meals or temporary care at a residential or nursing home. The social worker must take account of your ability to continue caring when they assess what help is needed. If you cannot manage any more, they can arrange for a permanent place in a residential or nursing home.

A sitter to look after your relative or friend every so often

Many areas of the country now have sitting schemes to look after your relative or friend, so that you can have a regular break, some time to yourself. These are run by social services/work departments, but often they are run by voluntary organisations.

Benefits

Most disabled people who need a lot of help or supervision can get either Attendance Allowance if they are over 65 or Disability Living Allowance if they are younger. It doesn't matter about their other income or savings.

If they get one of these allowances, you may be able to claim a benefit called Invalid Care Allowance for looking after them. You must be between 16 and 65 years old and not earning more than £50 per week.

Even if you can not get Invalid Care Allowance, perhaps because you are over 65, there may be other benefits you can get. If you are on a low income, you could get Income Support, or Housing Benefit to help with the rent. Some carers and disabled people can get money off their Council Tax, regardless of their income or savings. If they are on a low income, they may not have to pay anything at all.

Income Tax

Married men with dependent children whose wives are severely disabled can get an additional personal tax allowance on top of their Married Couples Allowance. CNA is lobbying to extend

CARERS ASSOCIATION

this tax allowance to married women in similar situations.

Speak to your tax office to see if you qualify.

There are carers support groups and Carers National Association (CNA) branches in many parts of the country, where carers can get together to discuss their concerns and meet others in a similar position.

Some parts of the country have Carers Workers whose job it is to support and help you get the services you need.

Get in touch with Carers National Association to find out what's happening in your area. These are just some of the things that might be available to help you with your caring role. You may have other questions that you want to ask. We're here to try and answer them! Advice & Information CNA runs an advice and information line for carers on weekday afternoons between 1 pm-4pm.

You could consider joining Carers National Association. If you join CNA you will be adding your voice to the thousands of carers who already support our work.

For a membership fee of £5 a year you:

Will receive information about caring.

Will be sent our magazine The Carer every other month - to make sure you don't miss out on anything new which you might benefit from. Get a free Carers Emergency Card to carry with you - it alerts the emergency services that there is someone at home who needs looking after if you have an accident or are taken ill. Can join a branch for support and information.

Join a national charity campaigning effectively for your rights. Most recently CNA steered a private members bill through Parliament which gives carers legal rights under the Community Care system. This is known as the Carers Recognition & Services Act.

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There are over 7 million carers in Britain, saving the Government about £30 billion a year. The Carers Bill would mean that local authorities would be obliged to provide those services. Carers are entitled to receive an assessment by Social Services of what they need to support them to carry out their unpaid work as carers.

"Disabled in Britain: Behind Closed Doors"

A new report published by Scope reveals the grim situation for many carers. It shows that Britain's unpaid carers are over stretched and unsupported, having to fight for the most basic things they need to carry out their role. They often endure financial hardship, social isolation, emotional and physical health problems and strain on family relationships.

Over 1,300 parents and carers contributed to the Scope report:

- * 57% faced financial hardship. Many had used up savings, gone without holidays and major new purchases. Three quarters said their health had suffered. Over three quarters felt tired or frustrated and suffered emotional stress, a quarter had felt despair.

- * 67% felt that caring put a strain on their marriage.

- * 64% said that their caring responsibilities meant that they sometimes neglected other family members.

Nearly two thirds said they did not get enough help from the state. Only 13% had had a formal assessment of their needs from the Local Authority. Again and again, carers say that they have to fight for any help for themselves or the person they care for. Scope wants the work carers do to receive greater recognition.

As a starting point, the Carers (Recognition and Services) Bill should become law. And Scope believes that comprehensive Civil Rights legislation for all disabled people would have a beneficial effect on carers lives. Working with other carers' organisations and groups, Scope will continue the campaign at both national and local level to secure a better deal for carers.

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FINDING SOMEONE, WHO CARES ?

It's been three years since my diagnosis and for most of that time I have had to cope with illness of one sort or another. My partner has been a vital source of support even though I'm rarely disabled for 24 hours a day I never know when I will need help and he has been there for me whenever I have needed him.

The care and support I have got from elsewhere has not always been so reliable. I have had to deal with all sorts of professionals and volunteers and although some have done more than I could have hoped, others have let me down.

Finding the right people to support me has not been easy but it has certainly been worth the trouble. It's extraordinary how some people will go out of their way to help you whilst others will consistently fail to do what they promise. When I first became ill the doctors decided that because I had a past history of drug use my problems were psychological and so ended up treating me like an idiot! Fortunately I quickly found help elsewhere at the local body positive group where I was made to feel very welcome - it was absolutely bloody wonderful to meet another human being infected with this awful virus. I have always been able to ring up or turn up in whatever kind of mess and be sure of a caring, reassuring voice.

The body positive group didn't just respond when I needed help, they thought ahead and made vitamins and information available for me on a regular basis. Unfortunately the other local voluntary group has not always treated me well. At first there was always someone to say hello and maybe offer a cup of tea. I used to call in on my way home from consultations at the hospital, with my head full of questions and worries. But after a while everyone was always too busy to talk. At one stage the skin split around my ankle and walking became almost impossible. I phoned up to ask for help in getting a pair of crutches, but they gave the phone number of the Red Cross and told me that I would have to pick them up myself and leave a deposit. Of course I couldn't get there myself and I didn't have the money for the deposit. A number of times I have been searching for medical information on AIDS. Most people at this organisation seemed to have very basic knowledge of the medical side of things and weren't interested in finding out even when I asked for their help. Knowledge is empowering the more we know the easier it becomes to talk to doctors and to understand and cope with living with the virus.

However, one good thing definitely came out of this organisation - my buddy. The first volunteer

I was to be befriended by was totally unsuitable. I had nothing in common with him, at all and could not understand why he had been picked to be my buddy. After this uncomfortable start I was introduced to Shamsher.

Shamsher is a very, caring non-judgmental and understanding person and my life in the last year or so would have been impossibly difficult without her help. We have a lot in common so we naturally became good friends.

It is important to feel that your buddy is helping because they want to help and not simply because they want to be a volunteer and very careful consideration must be taken when volunteers and service users are matched up. Not only is Shamsher around to give me lifts to the hospital (even arranging her work hours to do so, at the displeasure of her boss) but she helps me organise prescriptions, fill in all the ridiculous forms, and do all the things which may not ordinarily seem like much, but having to remember and organise them when you are ill can be a big hassle.

Shamsher calls me regularly, at least four times a week, to make sure things are OK. It's a nice feeling knowing that within a day or so I will see her and that if I do have problems, no matter what they are, she will try to help, all in all making my life a lot easier.

Shamsher has always believed in me, which is very important to me, and helped me fight the prejudice I have encountered from various health professionals in the statutory and voluntary sector. She lends me any literature she comes across and is like a partner in my quest to obtain information about the virus.

I was totally independent before I became ill with HIV. Since that time I have been constantly asking for help which I find very demeaning, so having someone there to act as my advocate has made a lot of difference and I spend much less time worrying about having HIV and more time learning (in my own rather slow way) about how to live with it. So one good thing about having HIV is that it led to my meeting Shamsher. I don't think I have ever met anyone so selflessly caring for others. I'm so proud to have Shamsher as my Friend and very lucky to have her as my buddy.

HEALTHY LITTLE BOYS...

ELISABETH 'S STORY

My family doesn't fit any of the stereotypes often associated with HIV. Our risk factor was having boys with haemophilia who got HIV from their treatment. They were small when we found out, and they were happy, healthy little boys who went to school like everyone else.

I felt numb to start with, and then depressed. Helping them to feel good about themselves in spite of severe haemophilia was hard enough, but the additional energy I needed to keep positive with such a death sentence hanging over us seemed almost impossible. My partner and I found it difficult to talk about, probably because we were both hurting too much.

I got most support from other mothers in the same position, although at first we were all very wary of burdening each other. When we found that it was safe to talk openly we explored the pain of anticipating suffering with losing, and burying our sons. There were lots of tears, lots of heartache and every day we had them became more precious and important. But there was no support group for my partner - he had nowhere to go to unburden his feelings. And that created difficulties for our relationship, because we were always at different stages of the adjustment process.

I have come to regard living with HIV as a challenge and I do everything I can to keep them healthy and to enable them to feel positive; to really believe that there may be a normal life ahead. I cope by keeping myself very well informed and by getting support from a wide range of friends. I worry about burdening any individual too much. Twelve years on we are doing well.

But doing well doesn't stop the anxiety when blood-test time comes round again, or when the cough won't respond to medicines, or now that they start showing interest in girls. And I often feel incredibly lonely.

Because the boys were small when we first found that they were positive the information seemed to belong to us and we told a lot of people - close family, friends and the grown-ups in our church. Everyone was sad, but very supportive and they have loved and cared for all of us in the same way as they had always done. But there were people I couldn't tell, and so I've

found it impossible to keep a secret.

We told the boys that they had HIV when they were 10 years old. They already knew what HIV was and how it is passed on. Although it was a surprise they were more interested in how it would affect their lives immediately than in anything longer-term. Now they are older it is difficult for us to own up to the fact that we told a lot of people. They just want to keep it a secret so that their friends will continue to treat them the same as everyone else. It will be very hard for them to decide when to tell a girlfriend - should they do it early on so that they don't get involved with someone who can't handle it? Or should they leave it till later and risk being rejected by someone they care about deeply?

In some ways HIV has brought us closer - as a family, and with the friends who have shared our darker moments. There is a poignancy and tenderness about sharing difficult experiences which makes relationships sweeter and life worthwhile. We talk honestly about our fears and the things which make us feel vulnerable and we always know that we can expect love, commitment and respect from each other. We can, together, cope with things that seem impossible alone. And there are so many wonderful memories, more and more as each day goes by. As Gibran says 'The deeper sorrow has carved into your being, the more joy you can contain.'

DISCLAIMER

As usual, the views expressed in each of the articles are those of the individual authors, and not necessarily those of the Birchgrove Group.

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Editor, Gareth Lewis,

HOW ?????

If you do have children, it is important to think about the many ways in which their lives could be affected by your diagnosis. Even if you are completely healthy, it is best to plan early for any possible changes in your health or circumstances.

There may be times when your children need emergency care, but you also need to think about respite care (i.e. when you need a rest), short term care and long term care. You may have support from family or friends to plan for these times without professional help, but getting the input of a specialist child worker can be useful in thinking through all the implications. Whenever possible and appropriate the child should also be involved in the process of planning for times of special need.

Many people want a strong relationship to develop between the carer and their children so that if the carer does need to take over it is less traumatic for the children. The choices you have of possible carers for your children include the rest of your family at home, other family or friends, local authority carers and adoption. Many people turn first to the help which is closest to them amongst their family and friends. This will normally be the best choice for the children as it reduces the disruption and change in their lives. The carer may be able to get extra support from Social Services .

Many parents are worried that approaching Social Services will result in their child being taken away, whereas in fact the legal duty of social workers is to 'promote the upbringing of children within their own family, by providing a range and level of services appropriate to those children's needs.' Social services may be essential to you in providing foster carers for short or long periods. Planning ahead and thinking about the needs of your children in the long term gives you the opportunity to get advice which is appropriate to your needs. As well as social services you may find that there are other local or national organisations - such as Barnardos - which can help.

Pregnancy

If you're thinking of getting pregnant you may encounter attitudes suggesting this is wrong. However, the choice of whether or not to have children is an individual one and should always be made by the woman (and her partner) based on up-to-date information.

Having a child is a life-changing decision, whether or not you have HIV. So take time to think about all the advantages and disadvantages. You need to consider whether you will have the the strength and resources to care for a child.

Minimising the risk

If you decide to have a baby there is on average a 6 in

7 chance that the child will not be infected with HIV. It is not clear how a child becomes infected. Remember that a foetus begins as a single cell and develops a completely independent blood circulation from its mother.

However if you have been ill or your CD4 count is low, the risk of the child being infected is higher and a pregnancy can damage your health.

If you want to conceive with a male partner who is negative one option is artificial insemination: getting your partner to produce some sperm which you then insert. If you are the male partner and your partner is negative, you could consider artificial insemination by donor. If you are going to fuck, you should do this during ovulation. Your health during pregnancy is very important and you may need to take extra supplements such as vitamin A. Get advice from a dietitian first.

Childbirth itself is a likely time for infection to happen and because of this your doctor may suggest that the baby be delivered by caesarean section. Although there is always a danger in taking a general anaesthetic this is a relatively safe procedure. Nonetheless it is a difficult choice whatever you decide, your choice should be respected.

There is also a risk of infection during breast-feeding so this should be avoided if possible. This may be difficult if breast feeding is important to you for cultural reasons. Research has shown that taking AZT before, during and after pregnancy can significantly reduce the risk of your child getting infected. However this is still not well understood and there are many potential problems in doing this. In particular, taking AZT early may seriously affect your own treatment options should you get ill

The other main problem is side effects. Because the use of the drug during pregnancy is relatively new, we do not know if there are any long term side effects to your baby. However there is no evidence that the drug causes abnormalities during pregnancy - the number of birth defects found in children whose mothers took AZT is no different from the general population.

After a child is born it may have HIV antibodies from its mother. It may take many months before you will know whether or not she or he also has HIV. Decisions about parenting are always complex, but they are far more so when HIV is involved. One of the best places to seek advice in the first place may be the health adviser at your clinic. If you don't get a good response, contact an HIV/AIDS organisation which provides services for women

COPING

What to Expect Now that Your Friend Is Sick

There are some events and experiences that almost all carer share, some characteristics and attitudes that you, too, will most likely develop. These are part of the definition of a carer or caring friend.

A Feeling of Urgency

As a carer, your sense of time and urgency will undoubtedly speed up. Often, when this is all very new, you may feel that you have put your life on hold for the duration of your friend's illness. This may be troubling to you for a variety of reasons. You may actually feel that you are waiting for the day when you can begin to live your own life again. Then one day it will probably occur to you, as it has to many others, "What am I waiting for? If I am waiting for something, then I must be waiting for my friend to die." This is a normal response, and the guilt you may feel is natural, too.

Once the initial crisis of an AIDS diagnosis or opportunistic infection has passed, you'll come to realise that your friend may live for quite some time, and may go months, if not years, between serious illnesses. Although not a cure, the use of AZT and other medications has been clearly shown to delay the onset of symptoms in many individuals. People with AIDS are living longer and better lives than was the case earlier in the epidemic. Most likely, you will find yourself working to turn the time you spend with your friend into a positive and fulfilling experience. Once you get past the attitude of "I am doing all I can to help you live, but I will never be free until you die," you'll find yourself and your friend very much alive.

Still, you should each acknowledge the enormous stress that faces you and begin to learn to "live for each day." Although it may sound simplistic, a slogan like that can be helpful.

Tom explains how he and his longtime lover, Mart, who is infected with HIV, learned to look beyond the immediate future. "Because Mart and I both had been so sure it was going to be a quick, dismal, dreary end, each day that we had each good thing that happened to us—we became aware of. It was a gift. Each additional day and joyful experience was a bonus that we hadn't expected to have. Therefore, we valued it even more. And do you know what? We were wrong. We had a lot of time."

Giving Basic Care

As a carer, you will find yourself providing practical as well as emotional and spiritual support. You will run errands, wash clothes, cook meals, change sheets, take temperatures, dress sores, keep company, and wake up in the night to give medicine. The list is truly endless. Usually, you will do all this while you continue with your own life: going to work, paying the bills, taking care of the children.

Hugh and John, both in their late thirties, went through drastic changes as John became sicker, first with chronic diarrhoea, then with other infections. Hugh, John's lover, a contractor, describes his life this way: "The first few months that John was sick, I just didn't believe it. I mean, what do you do? It was like every conceivable problem in the world was there. I got a big job renovating a kitchen, and I was trying to do all the work myself so I could make more money. Meanwhile, I got up at six and made breakfast every morning for the both of us, then went to work, ran home to make John lunch, and ran back to work. So naturally, everything got all screwed up and I lost the job. At one point, John owed two months' back rent. I owed a month's rent. I told John everything was taken care of."

Suzanne, meanwhile, went from "zero to sixty" in no time when it came to taking care of her daughter Michelle. But there was a price to pay. "I don't know how much of it was that I didn't want to think. I was constantly running.

Anything she wanted, I ran for. Even when I was visiting her in the hospital, I was running to Sixth Avenue, Seventh Avenue. 'So you want a grape, no problem.' Somehow, I think running that fast is also running away from what's happening. It's too large a problem to really digest."

Why Taking Care of Someone with AIDS Is Different

Being a carer of someone with AIDS is a vastly different experience from being the primary carer of someone with any other devastating illness, such as cancer or Alzheimer's disease. Carer and friends of people with AIDS encounter a great many painful and difficult circumstances that make this illness unique.

PREGNANCY TESTING FOR WOMEN

A seminar was held on November 11th 1996 by the women and HIV/AIDS Network at which Wendy Simpson and Fiona Boyd presented details of the research study now in progress at Simpson's Memorial Pavilion Edinburgh.

The study has been set up in response to Department of Health Guidelines which recommend that HIV testing should be offered on a voluntary named basis to all women in areas of high HIV prevalence. Edinburgh is one such area, where the incidence of HIV infection in pregnant women, although now falling, has been on average 1 in 660 between 1990 and 1994. This recommendation has arisen from recent developments in the understanding of HIV and the effectiveness of therapies available to reduce the risk of mother to child transmission.

However, there are no clear answers from previous research as to how we should offer the HIV test in a way which allows women to make an informed choice about testing without causing undue anxiety. This study, which is funded by the NHS Executive, is preparing different methods of offering HIV testing to 3,000 pregnant women with the aim of finding the most acceptable method.

The study is addressing the following questions:

- 1 What is the effect of different ways of testing on :
 - ◆ uptake rates
 - ◆ psychological impact after booking
 - ◆ longer term psychological impact
- 2 Are pregnant women in favour of HIV testing in pregnancy ?
- 3 How do pregnant women think HIV testing should be offered ?
- 4 Does the midwife have an effect on uptake and psychological impact ?
- 5 Do age and socio-economic variables have an effect on uptake ?
- 6 What is the detection rate of HIV positive women for each of the methods ?

All women booking in the hospital are randomly allocated to one of five intervention groups. They are sent one of two different types of leaflet - a special leaflet about HIV testing in pregnancy or a leaflet containing information about HIV testing amongst the other antenatal blood tests. At the clinic~ they are given one of two different levels of pre-test counselling by the midwife - minimal or comprehensive. One group are not offered the test directly by the midwife, but are informed that the test is available if they want to ask for it. It is made clear to all women that they do not have to participate in the study if they do not want to, but if they do participate, they have a choice about whether to take the HIV test or not. The information leaflets were developed over some period of time, getting feedback from many relevant professionals including health promotion officers, midwives and health psychologists and were tested with a group of pregnant women. The counselling protocols were also developed with professional help and were modified on the basis of the midwives' experience.

Data on whether women accept HIV testing is being collected and self-complete questionnaires for the pregnant women are being used to collect data on anxiety, satisfaction, knowledge and attitudes towards testing. Home interviews are also being carried out to explore the women's feelings in more depth. Using all the data collected on uptake of testing and the various aspects of women's feelings, the results will be able to inform future policy on how testing should be offered. The study is due to finish in February 1997.

For further information about the study contact either Wendy Simpson or Fiona Boyd,

Department of Obstetrics and Gynaecology, Centre for Reproductive Biology, the university of Edinburgh, 37 Chalmers Street, Edinburgh EH3 9EW (tel: 0131 536 3213)

I read that word—saw it in print. It was the most devastating moment of my life. The tears came. I screamed. I cried. I prayed. I was in pain and I was alone. Waves of nausea came over me. Sleep did not come until much, much later.

I would have gladly exchanged my life for his, but that was not to be. My son was dying. Every emotion known came through me. I was angry and frightened, feeling guilty and trapped and betrayed. I have heard that some parents directed these feelings toward their son. That I don't understand; My love for Daniel was the one constant emotion I could rely on at that time.

I did not stop loving my son; I drew closer to him. While he was still in the hospital, he asked his two brothers and me to come in to have the doctor talk to us about this disease: We knew so little about AIDS. It was heartbreaking for all of us, but his brothers were extremely supportive as were their wives and grown children. Rather than causing the family to run, the disease caused us to love Daniel and each other even more.

On his return home, we worked together on his diet and general health care. We had received instructions from the hospital before Daniel was discharged, as well as information about the various agencies we could tap, social workers, legal matters, and so on.

So my son came home to the room he had had since he was six years old, here to live for the short time he had left in this life. I thanked God each day that I was able to care for him, for in this time we got reacquainted.

I got to know Daniel as an adult and not the little boy that I sent off to school every morning. That is not to say that there were not rough spots: Each of us had a period of adjusting.

Daniel had been living independently in another city for several years: Being dependent on Mom, again, wasn't easy for him. In the meantime, I had been living alone in my own home and had become independent as well: Living with my son again wasn't easy for me!

We cooperated with each other in every respect as far as his illness was concerned. However, we would have a little spat every now and then and pout around for an hour or so; then things would start flowing in the normal manner. I think we were normal in this.

When he came home from the hospital, he was frail and weak, but as time passed he grew stronger and gained weight. In fact, he looked

better than he had in years! It was easy to forget that he had AIDS; it was a relief to have hope. As the months passed, Daniel grew weaker. He spent more time at home and we had more time together.

Though there were stretches of grief and pain, I do not think of our time together as negative. My son had a unique sense of humour and a way of expressing himself that rubbed off on all of us, even his dog, who keeps my spirits up today with her comedy. We laughed a lot over small things.

Then one day, he was hurting so very much. And he looked up and said, "I'll tell you one thing: I'll never go through this again." He thought about what he had said, and then added wryly, "Guess I'll never have the chance!"

We had much time to talk; we grew close as mother and son and confidant. He became more spiritual as time went by. He openly talked of this and I was glad.

I did not press my beliefs on him for fear that it would hold him back or make him think that I was making some sort of judgment. I loved him too much to judge and, oh God, he was dying!

There are times in the middle of the pain when the only thing to do is laugh. Sometimes it seems like black humour; but it was a choice of laughing or crying, and I cried enough as it was. Toward the very end, when his health started to deteriorate rapidly, Daniel was unable to lift himself from the bed.

He had always taken care of his own medication, but he was also becoming forgetful. I asked him whether he would like me to count it out for him.

Daniel half-lifted one hand and pointed a weak, shaky finger at me and said, "Don't you start treating me like an invalid!" He had great pride and was concerned about losing his faculties.

My heart went out to him. About this time, he could hardly swallow his food: Sometimes it took two hours to eat a meal. How I suffered for him and with him!

I wasn't ready for this kind of thing to happen and it was heartrending for me. But, all through the illness the most unexpected things happened. At the beginning, a young woman had been sent out by one of the agencies on a temporary assignment.

She was wonderful and she and Daniel grew to like each other a lot. Even after her assignment was over, she came by daily. But at some point,

continued from Page 10

it got out of hand: She fell in love with Daniel, knowing that he was dying and knowing his lifestyle! That created a lot of problems that no one knew how to handle. Also unexpected was the fact that Daniel's two closest, life long friends absolutely deserted him when they learned he had AIDS. Daniel was crushed and there was nothing I could do.

Whether it was their fear of getting the disease or some other reason, I don't know. But the pain it caused was almost unforgivable. If there is one lesson you learn from reading this, let it be here: Don't desert the people who love you when they need you !

There were times when he was in the very depths of despair, especially at night. He would play very soft music and listen for hours with his lights dimmed. He would sit with his knees up and with his head resting on his arms, almost in a fetal position. When I went in and saw him, I would quietly walk out. This was a time of prayer and meditation for him, but it was a heartbreaking picture for me.

My last conversation with Daniel is a memory I will treasure forever. He was in pain, he was hurting, but he wanted to talk. I sat in the chair beside his bed.

We talked about many things.

He wanted me to know how much he appreciated and thanked me for caring for him. His one great concern was how I was going to make it after he was gone. I tried to let him know that caring for him at this time was a privilege for me, that I would not have it any other way.

I tried to tell him that my life would change and have new meaning for me—and it has! He gave me so much. It seems as if we covered every facet of his life that night.

Through this part of it, three months after Daniel's death, my one consolation is that one sentence, "Mother, I'll be waiting for you."

A TO Z OF COMPLEMENTARY THERAPIES

Many people with HIV have used complementary and alternative therapies to help them improve their well-being, relieve symptoms and stress, and stay healthy. Yet if you were to ask all the doctors treating people living with HIV what alternative or complementary therapies they would recommend, you would get as many answers as there are doctors. Although complementary and alternative therapies are widely used by people with HIV there remains a lot of misunderstanding about how useful they are. It's worth finding out as much as you can about any therapy you are interested in. For most people, other therapies are complementary to conventional medicine - i.e. they may be helpful additions but do not replace their clinical care. However many therapies claim to be completely alternative ways of understanding our health and illness, and the language used reflects this.

Choosing and using a therapy

There are many possible benefits that different therapies may offer: Stress reduction and improved mental health many forms of complementary therapy are excellent ways of reducing stress and often have knock-on benefits such as increased sense of well-being and a greater sense of control over your life.

No single therapy is going to do all of this for you. And you may find that you get very little benefit from any therapy.

Starting some therapies may mean that you have to make big changes in your life.

Finding a practitioner

Most practitioners of complementary or alternative therapy will not see many people with HIV. So it can be hard finding someone who you are confident understands your situation well. It's worth asking the following questions: What is the treatment you offer and how can it benefit me? Different practitioners may approach the same therapy in very different ways. Amazing claims should make you very wary.

What is your experience of treating people with HIV or AIDS? Get an independent reference if you can.

How much do you charge and do you have a concessionary scheme? You shouldn't be charged more than a maximum of £50-£60 for an initial consultation.

Acupuncture

This is part of Traditional Chinese Medicine (see below). It involves the insertion of fine needles into different points in the body to improve the flow of energy. This is normally a painless process. It is a good way of coping with fatigue and stress and for a short while after the treatment you may feel very sleepy. It is also widely used to reduce pain.

Continued on Page 14

A PARTNERS THOUGHTS

May I start by thanking you all for providing an interesting, relevant and very informative journal. It is one of very few things which provides support and the knowledge that other people are out there who understand and who are prepared to speak out. In response to your request for an article from carers, I fall into that category and therefore am writing to you with my experiences. Please feel free to transcript it as i'm unsure if the finished product will be article worthy, but know one has asked me to write down how I feel and it seemed to good an opportunity to pass on ! I would prefer my name and address not to be used if you wish to use any of my letter.

I met my partner seven years ago whilst still a student and found out about his HIV status from a mutual friend. I started seeing him six years ago. Moved in five and a half years ago and we married in June 1992. I think it is fair to say we have been happily married ever since !

We recently learnt my partner had been infected around 1981/82 but My partner was not told until 1995, and only then because he asked to know. There reasoning was he was to young to cope, yet he was 18 years old and in a relationship. Being one of the first has never been easy as no one had any answers or experience. Our first contact with a counsellor told us that, "My partner might be around in two years but I'd be very surprised if I saw him in ten years time." Not very supportive and wholly devoid of empathy. the same person also told us we would be quite safe to have unprotected sex for a year before I became infected. Fortunately we knew different. The one time we did via a condom splitting turned me a funny colour yellow with Hep B. and thank goodness that was all. It is difficult to not list lots of negative comments, but I will reach the positive ones at the end.

Since support has improved. My partner's first admission was dreadful, with our two nearest hospitals refusing to tread on each others toes by admitting him. One deals with the HIV problems and the other with Haemophilia, and after two weeks of nursing at home My partner ended up in the Haemophilia one, as i'm sure you can imagine brought it's share of problems. Apparently this had never arisen before - the trials of being the first. Our Consultant on the HIV side is super, as are the whole team including the only counsellor who has ever helped me, a health visitor there. She sits and listens and occasionally makes constructive remarks, or tells me I'm not mad which is most comforting.

At present, My partner is (fairly) well but has a rip roaring bad cough which sends us both loopy. This is one of my largest areas of guilt at present as I know full well the cough is not My partner's fault. It does

not stop it being annoying. He has gone through phases of night sweats, no appetite, bizarre fungal growths, bizarre chest infections, equally bizarre sinus and ear infections but keeps smiling. Due to good home management he has been out of hospital (touch wood) for two years. He has recently changed medication (shame we can't use the new protease medication) which seems to have helped, and now has 3TC with AZT. he also takes 1000 mg Vitamin C a day in reference to an earlier Birchgrove article. We're not sure which is helping the most ! I hate the high toxicity of these drugs but we've never looked into full blown alternatives. Why is HIV so different in Haemophiliacs ?- there's another question. Why can't we drink our tap water without worrying ? was one of my more recent questions. This came at a difficult time for us and seemed the final insult until we forgot anyone had ever told us and coped that way.

Two other things I rarely look directly in the eye because it hurts are religion and children. I am not religious and have no firm beliefs in much other than I love my life when My partner is well. I wish I had sometimes. And, I do want children, and I have not yet found a strategy for coping with that. So I get overwhelmed, angry, bitter, guilty and occasionally hysterical. But there are positive's. My partner is happy on the whole, except when Forest lose, immensely happy against lots of odds and my priorities have changed. I like now appreciate now, and I do not think "I miss that now it's gone." Every day is appreciated for what it is, a day together which we invariably fill with fun things and giggle. We have wonderful friends, people who support us through thick and thin, which certainly keeps me going. And we have wonderful family. My parents have rallied and are there when I thought they would disappear when I told them two years ago. It has changed our relationship for the better. And, since My partner finished work we've got a small scruffy dog who is brill . My perspective of life has changed for the better.

I could go on forever ! but the main points and observations are here, not as deep or individual as they might be but that would take chapters. And it is hard to put your innermost feelings onto paper, I rarely do that in my own head.

Thank you for calling me a very special category !

Keep up the good work as they say,

Yours,

A Partner

HE DESERVED BETTER THAN THAT.

HISTORY OF LOVE

I was 21 years old when we met, he was older than me. He told me that he had Haemophilia and, being a nurse I understood what that meant. You don't really" he said. He was reluctant to get married until I understood all the implications . It wouldn't be a 'normal'. ordinary life. He was right!

When we married there was no getting away - no break from being a full-time carer. I was a carer at work and a carer at home. He wasn't ill or incapacitated all the time but there were lots of jobs he just couldn't physically do. Little things like moving furniture or getting down on the floor caused a knee or elbow bleed. He got frustrated at himself, I always had to lend a hand or two. I could never get on with my own jobs. I moved paving stones, bricks, built fences, walls, and terraced a garden. He was angry and frustrated that he had to wait for me to come home from work before he could start jobs. Me I was just knackered! He was helpful though - he would iron and cook but unfortunately the washing machine always remained a mystery to him.

Despite all the problems we were happy and felt we had a good life. Haemophilia however, dominated both our lives. Social events and outings were often cancelled at short notice due to a bleed. Whenever we booked a holiday he was always ill or immobile. In the end we stopped booking and just went on the spur of the moment, if he was fit enough. Often we had to come home after one or two days the longest we managed was five days - we never travelled abroad One spring we went to the Lake District we had only been there an hour when I had to ring friends to bring us home - a knee bleed that required a weeks bed rest. Thank God for understanding friends. A lot of friends however, didn't know he had Haemophilia The lies we told, the excuses we made. It was hard work living with the lies, remembering who we had told what!

We managed, we got through the visits to the hospital - three or four times a week before home treatment. We got through the hospital admissions for elbow bleeds, knee bleeds, ankle bleeds, muscle bleeds and an internal bleed that nearly killed him. We lived through the days confined to the house, the days spent in bed or on the settee immobile due to a bleed or arthritis. We coped with his frustration and boredom, of being stuck indoors for days on end We were doing all right then along came HIV.

Thinking back I can't remember the date when we found out that he was HIV positive. He was not best pleased! ! Not as much was known about HIV in those early days - it even had different initials! We went along to all the meetings to find out as much as we could. We weren't worried at first, things weren't that bad. "It doesn't affect Haemophiliacs like it has affected homosexuals" we were told. Its safe to continue to have sex!! Suddenly that changed " Don't have sex at all" we were told "Wash his clothes and crockery separately - disinfect!" "Stuff that" he said I washed our clothes and crockery together, we used condoms. He no longer allowed me to give him treatment when he couldn't manage to do it himself - we went along to the hospital.

He didn't want any treatment for HIV which at the time

LETTERS PART TWO !!!!

Dear Birchgrove,

I wrote to you a few days ago with some of my views and experiences as a partner of someone who is HIV positive. I felt I must write again as there was a huge admission in my first letter. I realise this is rather out of context but I felt it too important to leave.

I wrote the letter on a good day and somehow overlooked how frightening it all can be, and I think this emotion is the strongest and hardest to deal with. We both are frightened and scared a good deal of the time, and it is difficult to put exactly why into words. Communication about this is so difficult because were so scared of hurting the other person - the trouble is, the less you communicate the more it hurts! This is a constant area of difficulty. My mind throws up the most difficult questions at the oddest times. Most commonly, things like - what's going to happen when Ian gets really poorly, how am I going to cope, what about work and me on my own? I don't want that. It's lots of issues. I know, around control and choices and talking about it all. We all have good times and bad times.

Thanks again for your work and time.

A partner

Aromatherapy

This uses essential oils which have been extracted from plants. Each oil is supposed to have a different healing effect on the mind or body, and can be directly inhaled or used with massage or in baths. Aromatherapy can be an excellent way of treating stress and tension pains and encouraging relaxation. Some oils can be toxic if used wrongly, so seeing a qualified aromatherapist is recommended.

Bach flower remedies

These are harmless, inexpensive remedies available from many wholefood shops. They are derived from wild flowers and claim a wide range of calming and restoring powers.

Dietary therapies

Diet is important in most complementary and alternative therapies, but there are specific diets which claim to improve health and immunity. These include macrobiotic diets, anti-candida diets and organic, raw and whole food diets. All may have advantages, but changing your whole diet at once can be very difficult, and if you are ill it may not be wise as you will need extra calories and proteins. See a dietitian before making any major changes.

Exercise and movement

T'ai chi, yoga and alexander technique are examples of disciplines which may help calm your mind, body and spirit. However, any form of exercise is worth doing as maintaining your muscle mass will help you fight infection.

Healing and therapeutic touch

There are many forms of healing through touch including spiritualist traditions, secular therapeutic touch and Reiki. All seek to encourage healing through one person acting as a channel for energy to flow into another. The results may include improvements in mental and physical health and greater relaxation.

Herbalism

This is an ancient form of medicine which uses plants and herbs to maintain health, treat illness and promote healing. Herbal treatments are often used effectively for less serious illnesses, such as tea tree oil or garlic for some fungal infections, sage for night sweats, slippery elm for relieving diarrhoea and thuya for warts. Bad reactions can occur, so you should try and see a qualified herbalist.

Homoeopathy

In homoeopathy, minute traces of a substance that would normally cause illness are used to treat the same illness. Symptoms are not repressed but encouraged as they are seen as the body's way of healing itself, and homoeopathic remedies are highly tuned to each individual. Homoeopaths understand AIDS in different ways: some aim to treat particular illnesses in the way just described, others think that the

causes of the immune damage need to be treated. However, all homoeopaths will be as interested in your emotional symptoms as in your physical symptoms.

Hypnotherapy

The trance-like state created by a hypnotist opens the mind to suggestion which can reduce symptoms and help with psychological treatment. By reducing stress and pain it can be helpful in improving all-round quality of life. However this is a therapy where getting a reputable practitioner is essential.

Massage

This is one of the simplest and most popular therapies, widely available to people with HIV through HIV organisations and drop-in centres. It is an excellent way of reducing stress and increasing well-being. There are many different sorts of massage, some of which give more emphasis to the emotional healing involved.

Reflexology

Reflexologists treat the bottom of your feet as a map of your body, and by massaging specific areas can improve the health of other parts of your body. Reflexology may offer relief for specific problems as well as reducing stress and even strengthening immune function.

Shiatsu

This is a combination of massage and acupuncture, where pressure is applied to healing points on the body, improving the flow of blood and energy and increasing vitality. It is an effective treatment for stress, anxiety and related conditions such as insomnia. It has also been used in treating nausea and other common symptoms.

Traditional Chinese medicine (TCM)

This is a whole world of medicine in itself which uses concepts, language and methods which are completely different from Western medicine. The main elements are qi gong, acupuncture (see above), and herbal remedies. Qi gong and acupuncture both focus on the balance of energies, 'qi', in the body. Chinese herbal medicines are thousands of years old, and they work by strengthening the body's immunity rather than by attacking an infection. Many people living with HIV have benefited from TCM, but if you are interested you should see a good practitioner as side-effects are possible.

Visualisation

This uses mental imagery to fight illness and has been known to improve symptoms and increase personal energy.

*With Thanks to National Aids Manual.
Publication : (Living with HIV & AIDS)
And printed in memory of Simon Mansfield*

HISTORY OF LOVE

was AZT every four hours - even through the night. Our life was messed about enough, he didn't want it messed about even more. Illness became more and more frequent I was now a carer of someone with HIV as well as Haemophilia. Trying to keep cheerful, trying not to let things get us down got harder. He complained to me, he complained to the hospital. I had no one to complain or moan to. I felt very isolated. I was trying to support him emotionally and having to support myself at the same time. No time to feel sorry for myself, no time for self pity. Our life was dominated by the effects of HIV. The rash on his face which meant he wouldn't go out as he felt he wasn't presentable. The thrush which meant he couldn't eat properly or swallow. The shingles, the diarrhoea and the weight loss. All these meant he wouldn't leave the house, except to go to the hospital. The PCP that meant two weeks in hospital and nearly killed him. The lies I told grew bigger and harder to tell. My family didn't know he was HIV positive - I hardly saw them. I was on my guard all the time - I didn't want to say the wrong thing. I was exhausted mentally and physically. We coped with it all, we were managing.

He was always kind considerate, caring and fun loving. He enjoyed a laugh and a joke. In 1990 that changed He took on a whole new personality, he became a totally different person. He became paranoid people were talking about him, laughing at him. "What the F-- are you looking at?" he asked a woman in the street. I wanted the ground to open up and swallow me.

His short term memory became very poor, he forgot things that had been said or done only moments before. This became a source of disagreement between us. I told him something, he forgot. I got the blame for not telling him. Then he became convinced I was doing it deliberately to make him think he was going mad. I was the one going mad!

He'd fall asleep at the drop of a hat - in the middle of a sentence. I was putting sleeping tablets in his drinks he told friends. Unfortunately he never seemed to fall asleep at night. He would spend all night telling me what a nasty, awful and cruel person I was. We argued he screamed and shouted. Nothing I did was right I had to agree with everything he said and did and if I didn't do it quick enough I wasn't allowed any tea! I became frightened to say or do anything, I couldn't think for myself or make any decisions. I couldn't go anywhere, do anything or speak to anyone without his approval. I wasn't allowed to use the phone unless he was in the room. Who knows what I might tell people!

Life wasn't worth living, I hated him and myself. He hated me and himself. I knew it was AIDS doing this to him but I still blamed him. I didn't know this new person, he certainly wasn't the one I had married. I was frightened of him and frightened for him. I wanted to help but didn't know how. He wouldn't let me talk to anyone, he wouldn't see or talk to anyone about how he was behaving, according to him I was the one with the problem! Oh! I had problems all right. I went to work exhausted through lack of sleep and constant arguing but pleased to be able to get away from him, even though he would ring up to check up on me. I felt that I had escaped for a while but he

couldn't escape from it. He had brief moments of insight into his behaviour when he would get upset - "What's happening to me, this is not really me." They didn't last long. He didn't care about anyone, he was nasty and aggressive to anyone he came into contact with. I began to wish that he were dead - the only way out as far as I could see. I couldn't leave him, he wouldn't have managed on his own, I couldn't do that to him. After all I was a carer.

Two years later it ended as suddenly as it had started. He had a massive cerebral bleed. He was in theatre for over seven hours unfortunately the damage was already done. This wasn't apparent until two weeks later. The first two weeks he was only semi-conscious unaware of his surroundings, not speaking, not eating and not drinking. The first night he developed a severe chest infection - the antibiotics gave him diarrhoea. How he survived I'll never know. He did survive but he couldn't do things for himself. He needed help to feed himself - he didn't know what to do with food. He had to be washed~ dressed and changed, turned and lifted in and out of bed. He got his words mixed up - he was just like a little child that had to be looked after all the time. He didn't know who I was. I visited him six days a week for eleven months whilst continuing to work full time. I cared for him, feeding him, helping to wash him, turn him, get him in and out of bed I talked to him and read to him. I shopped, washed and ironed for him. It was hard and tiring but I found it easier to cope with than the previous two years. He didn't frighten me anymore and for that I was grateful. I was frightened for him, what would happen to him. I had always promised that I would never let him linger - I broke that promise but could do nothing about it.

He developed one infection after another with me wishing each one would be his last. He recovered from each but deteriorated a little more after each one. I managed with the fourteen hours a day six days a week. I managed with his mother blaming me for his condition, saying that I didn't care, I'd never cared. That was a doddle compared to the last two years. I knew I would never be able to care for him at home and much as I was against him going into a nursing home I had no choice. After much searching I found a suitable place where I felt they would care for him. We would manage. We didn't need to manage, he died two days after I found the nursing home. Did he know? I hope not. He died peacefully and I was with him. I was very sad but happy that it was all over for him - no more suffering for him. My suffering was also over. I was no longer a carer. I wanted him back - the man I married. The funeral went well - everything that he wanted, even the Scottish piper. Friends remarked that I was coping well. Of course I was, the person that I loved had been lost to me for the past three years. The person that had just died was an entirely different person one I didn't know, one I couldn't love.

Even now almost four years after his death my most vivid memories are of him as he was the last three years of his life. I find it difficult to remember the person I married. When I remember, I remember the person he became - the person AIDS made him. I try to remember the kind considerate and loving person he was but those memories are clouded by AIDS. Those memories became sad. He deserved better than that.

BIRCHGROVE IS A FORUM FOR:

- The treatments of haemophilia and HIV
- Taking care of ourselves; through informed debate and argument
- Staying healthy with Haemophilia HIV & AIDS and HEP C
- Ways in which HIV affects love and sexuality
- The social and psychological aspects of haemophilia and HIV

PEOPLE WITH HAEMOPHILIA AND HIV

- Can be empowered and enabled to deal with HIV/AIDS through relevant information and mutual support
- Can improve their health and extend their lives by expressing feelings and confronting the issues directly
- Should be heard and have their needs recognised and not suffer in fear and isolation
- Have a role in the work of the HIV/AIDS community to inform and challenge the ignorance that exists about HIV

Available from the Birchgrove Group, free of charge to those directly affected by Haemophilia /HIV or registrants, are the following information leaflets and back issues of the Birchgrove Newsletter.

Birchgrove Newsletter Back Issues

- BIRCHGROVE newsletter Issue 3
- BIRCHGROVE newsletter Issue 4
- BIRCHGROVE newsletter Issue 5
- BIRCHGROVE newsletter Issue 6
- BIRCHGROVE newsletter Issue 7
- BIRCHGROVE newsletter Issue 8
- BIRCHGROVE newsletter Issue 9

Birchgrove Information Leaflets

- Hepatitis C - Special Edition
- HIV and Itchy skin
- An A-Z of Hepatitis
- Liver Disease and HIV
- HIV and Multiple Myeloma
- Glossary of terms

Leaflets
currently being
updated

We can also supply the following items.

- | | |
|--|-------|
| <input type="checkbox"/> "Living with Haemophilia and HIV" | £2.50 |
| <input type="checkbox"/> Red Ribbons (Cloth) | 50 |
| <input type="checkbox"/> Red Ribbon Badges (Enamel) | £2.50 |
| <input type="checkbox"/> Birchgrove Red Ribbons (Enamel) | £2.50 |

Name:

.....

Address:

.....

.....

Send to:

The Birchgrove Group,
PO Box 9, Abertillery, NP3 1YD.
or Phone Lo-Call 0345 697231 Helpline
01222 387960 Admin

DEATH NEVER OVERCOMES LOVE

My life is over:

It has come to an end.

It was not my wish to leave you.

I had no choice.

I did not ask to die.

God is the giver of life,

So he has the right to call

It back

I felt your warm loving presence.

I knew you too were having A difficult time.

I sensed you were not ready

To let me go.

I felt much pain in my suffering,

But it was not all bad.

It helped us prepare for

This separation.

It made it easier for us

To say our goodbyes.

Think about our life together.

Remember the times we shared.

We enjoyed many happy times,

But don't forget, we had

Some difficult ones as well.

We know life is not always rosy.

I want you now to set these thoughts aside.

You must begin to concentrate on today.

My life is over.

You still have your life to live,

Don't let the clock stop.

There is much for you to do.

Time is a healer. You will need it

In order to sort out your feelings.

Don't expect miracles.

It won't happen overnight.

When you become more sure of yourself,

I am pleading with you, please

Don't hold on;

Let me go.

I loved you in life.

Now that it is over for me does not change things.

I will go on loving you

For all eternity.

I have no more suffering,

I have no more pain.

I will be completely at peace

When you find yours.

Death is only a separation,

We will be reunited one day.

That is a gift to hold onto,

But don't wait for it.

Life is for the living.

Find new discoveries, fulfill your dreams.

You still have time.

You have your life ahead of you.

Live it and you will make my dreams come true for you.

God bless you.