

The Birchgrove

THE BIRCHGROVE GROUP, P.O. BOX 9, ABERTILLERY, WALES NP3 1YD. TEL: 0345 697231

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

cont on page 2

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.

continued from front page

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.

Cont on Page 3

continued from page 2

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