

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

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

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.