

No. 74 March 1997

# Talkabout

The Newsletter of People Living With HIV/AIDS NSW Inc.

◆ Where We Speak for Ourselves ◆



## who cares?

# Convenor's Report



MARDI GRAS – surprise, surprise – has been occupying much of PLWH/A's attention during February.

We kicked off with a joint fund-raiser with the PLWHA Luncheon Club at the Mardi Gras launch on February 1. Thanks to all the volunteers who sold our special Mardi Gras stickers – we raised over \$5,000. We sold more stickers at Fair Day and raffled fabby prizes at the Swimming Carnival – no cash totals yet, however.

*Talkabout* was promoted at the PLWH/A Fair Day stall (See picture page 7). To complement the fruity themes of Mardi Gras and *Talkabout*, we handed out colourful flavoured condoms and dams.

Our Parade float, designed by Brendan Williamson, featured the theme "Hope" and the fabulous Queen of Hearts, Whisky Warburton (can't wait for the pix!). And of course, as usual, we organised Time Out Rooms at the Party and Parade viewing for PLWHA in the BGF Reserved Seating. Thanks to Mardi Gras and BGF for making this seating available.

Community Development Officer Greg Allen has put a great deal of effort into our Mardi Gras activities – applause please for Greg and the volunteers and staff members who supported him through this hectic month!

PLWH/A also plans to have a stall at the Sydney Women's Festival on March 2 – staffed by the handful of people who didn't go to "that" party.

The PLWH/A Complementary Therapies Working Group, convened by John Trigg, had its first meeting on February 17. The

group discussed the possible directions it could take and resolved to set goals and time-frames for achieving them at the next meeting. It was also decided to seek out an experienced HIV GP with an interest in complementary therapies and invite him/her to join the group.

The Treatments Working Group has been busy planning another Treatments Forum for April (see Treatments Bites, page 8, for details).

In March a new staff member will join us, Robert Rogers, who will be acting as Research Administrative Assistant until the position is advertised and filled. Robert has been assisting Research Officer Jo Watson as a volunteer for several months.

The Committee had its second Strategy Day in mid-February and is still working on a final report from the two days. We'll keep you posted.

– Phillip Medcalf

## Treatment Information

You Name It,  
We'll Help You Find It

New drugs and treatments, how to keep up with the latest advances and announcements

Information access can be tailored to your personal needs

Contact Jo Watson, the Research Officer at PLWH/A  
on (02) 9361 6011,  
Freecall 1800 245 677  
Fax (02) 9360 3504  
Email on [plwha@rainbow.net.au](mailto:plwha@rainbow.net.au)



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Ed Moreno, Rolf Petherbridge, John Trigg,

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### This month's cover

by **Karen Vance**. Who cares? We all care. In different ways, in different situations, for different reasons. Carers are often invisible, sometimes put down but deeply appreciated by most of us, even when we don't always notice what they're doing, or agree with how they do it. Turn to page 12 for some carers' sides of the story.

## Talkabout

is published every month by People Living With HIV/AIDS (NSW) Inc. All views expressed are the opinions of the respective authors and not necessarily those of PLWH/A, its management or members. *Talkabout* is produced by the Newsletter Working Group of PLWH/A (NSW) Inc. Copyright for all material in *Talkabout* – text, graphics and photos – resides with the respective contributor. Contact Jill Sergeant, the editorial co-ordinator, for information on reproducing articles or illustrations.

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Letters submitted to *Talkabout* or its editorial co-ordinator are assumed to be for publication in whole or in part unless specified otherwise.

If you would like to be involved with *Talkabout* call Jill on 9361 6750 for the date and time of the next Newsletter Working Group meeting.

*Talkabout* is made possible by subscriptions, donations and a grant under the State/Commonwealth AIDS Program. *Talkabout* is also grateful for the assistance of the AIDS Council of NSW and thanks the many volunteers without whom its publication would not be possible.

Printed on recycled paper by Breakout Printing tel: 9281 5100.

Layout & Design: Alex Zinzi, Sandra Thompson.

**ISSN 1034 0866**



In a panel discussion at the World Economic Forum in Davos, Switzerland on February 3, Peter Piot, executive director of the Joint United Nations Programme on HIV/AIDS (UNAIDS), warned of the ruinous effect the worldwide AIDS epidemic could have on the global economy, and called upon the private sector to initiate aggressive efforts to fight AIDS.

● Piot and his co-panelists discussed the continuing spread of HIV/AIDS and how corporations have taken action to stem the tide. For example, Levi Strauss is working on a major AIDS education program for supplier communities in Southeast Asia, and Shell Oil is a funder of Botswana's national HIV/AIDS education campaign.

● "It is more than basic humanitarian concerns that should drive the private sector to get involved in the global fight against AIDS. Any company that operates in affected areas, sells its goods to overseas markets, or imports goods from those markets, must take action now to reduce the spread of HIV. Because today, with nearly 23 million people infected, AIDS is increasingly a threat to the global market economy," Dr. Piot said.

● Piot explained that in Kenya, economic growth has already slowed down: because of AIDS, it has been estimated that Kenya's GDP will be 15% less than it would otherwise have been by the year 2005. But the AIDS epidemic started in Africa fully 10 years before HIV was found in Asia. Many of the most promising emerging markets, such as China, India, and Thailand, are therefore likely to replicate the experience of sub-Saharan Africa in a few years' time.

● UNAIDS is developing several initiatives for co-operating with the private sector in the global response to HIV/AIDS: developing prevention technologies, making treatment and medicines more accessible to the 90% of people infected with HIV who live in developing countries, and mobilising resources in support of community-based AIDS programs. "With governments around the world straining under the pressure of massive economic and social change, the hope of solving many problems lies in the development of public/private partnerships", concluded Piot.

● UNAIDS is the leading advocate for global action on HIV/AIDS. It brings together six UN agencies in a common effort to lead and assist an expansion of the international response to HIV on all fronts: medical, public health, social, economic, cultural, political and human rights.

(UNAIDS Web page: <http://www.unaids.org> [press release])

## New Research

A NEW HEALTH DEPARTMENT proposal would allow access to your confidential medical files for approved medical research. The AIDS Council of NSW (ACON) and PLWH/A (NSW) Inc. want to know your views on the proposal.

Of course, PLWHA value their right to confidentiality. But when useful medical research needs access to confidential files, what do you think is more important?

In 1995, researchers from the National Centre in HIV Epidemiological & Clinical Research wanted to do a study to see whether people with HIV got cancer more often than people who are HIV negative. The study needed mass checks on the records of people with cancer and PLWHA to match them up. The research was useful but the individual researcher who saw the records would have breached confidentiality.

Asked for its stance on the study, ACON had to oppose it. "We couldn't approve it because it technically breached the special laws protecting confidential HIV information", said ACON Deputy Director Paul Kinder. "The HIV community campaigned hard to get those laws, so we could not agree to a breach, even if this particular study was likely to result in useful information."

The HIV laws are very similar to the general laws making all medical information confidential. The difference is that the general laws have an exception, allowing approved medical research. The proposal would put this exception into the law protecting HIV confidentiality.

If the proposal went ahead, then any research would need to satisfy the NSW Health Department's ethics committee that the confidential HIV information would:

1. only be seen by properly qualified people;
2. not disadvantage the owner of that information or anyone else;
3. only be used for the approved research;
4. be stored as securely as in the original records;

5. be anonymous in any published research results.

These are good safeguards which work well for non-HIV medical research. There would be an extra safeguard for PLWHA: that an HIV community member would be part of the approval process.

The Health Department has assured us that they will not go ahead without the support of ACON and PLWH/A. These organisations will only support this proposal if HIV positive people feel comfortable with it.

Please send your views (anonymously if you wish) by April 1 to me at PO Box 350, Darlinghurst 2010.

- Geoffrey Bloom, ACON Policy Officer (with Phillip Medcalf, PLWH/A Convenor)

## Dementia

THE AIDS DEMENTIA AND HIV Psychiatry Team (ADAHPT) is a new State-wide service that has just started taking referrals. It is a multidisciplinary outreach team consisting of two nurses, a social worker, occupational therapist and psychologist, with medical support.

ADAHPT is one of four components of the new AIDS Dementia and HIV Psychiatry Service (ADAHPS). ADHAPS is funded by NSW Health as a State-wide service for people with AIDS dementia and HIV-related psychiatric conditions, and the services involved with these clients. The service is being developed and implemented by Central and Southeast Sydney Area Health Services.

ADAHPT is the first part of the service to accept referrals. The other components - a residential facility, a sub-acute treatment unit, and psychiatric support services - will be opened this year.

ADHAPS was developed because of a widely perceived need across NSW for better ways of dealing with the complex issues related to AIDS dementia and HIV psychiatric conditions. It depends

on a combination of medical, psychiatric, palliative and community care skills within two small specialist units and an outreach team. It is not meant to 'take over' the treatment and support of everyone with AIDS dementia or an HIV-related psychiatric condition, but to enhance the capacity of existing services, carers and clients to make the most positive response possible to frequently complex situations.

ADAHPT is based at Darlinghurst Community Health Centre. Team members will be visiting services and organisations around NSW in February and March to promote its role. A carer and volunteer education forum is planned for May. For more info call 9339 2011 or fax 9360 2247.

— Dr Rosemary McGuckin,  
Service Co-ordinator

## Facts for women

A NEW RESOURCE FOR WOMEN about HIV and AIDS has been produced by Family Planning NSW (FPA) and ACON. The series of fact sheets was launched by the Minister for Women, the Hon. Faye Lo Po on March 2 at the Sydney Women's Festival.

The resource answers many of the questions women have about HIV and also provides women who are HIV positive with the most up to date information about medical services and treatments.

There is a fact sheet on each of the following topics: HIV testing, new diagnosis, HIV symptoms for women, treatments, pregnancy and parenting.

The fact sheets are available from FPA (9716 6099) or ACON (9206 2000).

— Brigid Inder, Women & AIDS  
Educator, FPA

## Quilt display

THE AUSTRALIAN AIDS MEMORIAL Quilt Project, Sydney Branch, will be holding a full display of the Quilt at the Darling Harbour



*A gorgeous portrait of gracious comperes Jamie and Vanessa by Steven Brunner sold for \$650 at the gala opening on February 14 of the exhibition What is Love? Proceeds from the exhibition go to the AIDS Trust of Australia.*

PHOTO: MAZZ IMAGES

Exhibition Centre on Saturday and Sunday April 5 and 6. The unfolding ceremony and presentation of new panels will start at 11.00 am on Saturday only.

The project will be holding workshops prior to the display for people wishing to get assistance with making or completing their panels. Volunteers are required over the weekend – if you would like to be involved in set-up/closure, or be a name reader, unfold or assisting with the sale and distribution of merchandise and information, please contact the Quilt Office for further information on 9360 7669 or fax on 9331 7628.

## Mid-North Coast options

TO THOSE OF YOU WHO HAVE been wondering what was ever done about the closure of ACON's Mid-North Coast Branch last year, there is a light at the end of the tunnel! In late January/early February, PLWH/A Convenor Phillip Medcalf and ACON Peer Education Manager Aldo Spina facilitated meetings with people who were concerned

about the provision of services in their area.

The meetings, at Taree, Port Macquarie, Kempsey and Coffs Harbour, were generally well attended. They discussed difficulties with services in the area and what people expected from ACON.

People spoke of a number of concerns they had about the Area Health Service and some hospitals and health services. Many people do not use local services because there have been incidents where confidentiality has been breached, or people have been treated rudely or refused services. In some hospital pharmacies HIV drugs are not readily available.

"I was shocked by what's happening in the area", said Phillip Medcalf. "I thought that kind of discrimination had gone out the window now that we have laws regarding confidentiality and discrimination. But I think there's also the issue that people in that area are not very aware of what their rights are, and that must be addressed".

ACON and PLWH/A have taken up some of these complaints with the appropriate authorities. However they recommend that

## Briefs



New *Contacts* out now! The resource guide for PLWHA, *Contacts* lists all relevant HIV/AIDS services and groups in NSW. Pick up a copy now at a service or venue near you!

● Congratulations to the Multicultural HIV/AIDS Education and Support Service, which received a special commendation in the prestigious 1996 Ethnic Affairs Commission Multicultural Marketing Awards. Paula Masselos, Co-ordinator of the awards, said the judges were impressed with the service's programs. "They tackle the very difficult issue of HIV/AIDS within the ethnic community", she said. (*Inner Western Suburbs Courier*)

● HIV/AIDS Housing - International Perspectives, was a one day housing conference held in Sydney on Feb 27. The conference highlighted a number of international innovations in housing and support models that have been developed for PLWHA. Conference sessions covered funding, building and providing better housing, and national housing policy. There will be more info on the Conference next month.

● Positive performers are sought for the PRIDE HIV/AIDS Community Development Project's next venture. The work will be co-ordinated by David Paul Jobling. Call him on 9560 2608 asap.

● After months of uncertainty in the community, South Eastern Sydney Area Health Service has funded ACON to employ a manager for 6 to 9 months to find new premises and develop a plan for the 'new look' Positive Living Centre. An interim manager for the centre will also be employed soon.

● Last month we mentioned a working party that has been set up to look at the needs of PLWHA planning to re-enter the workforce. Anyone interested in finding out more can contact Julie at PRIDE on 9331 1333.

● Have a good night out at the theatre and benefit Stanford House, (short term crisis accomodation for PLWHA). Run For Your Wife, a very funny farce starring Gordon Kaye, Max Gillies and Julie McGregor, will be at the Parramatta Riverside Theatre for one week only (no other Sydney showing). The fundraising night is Friday May 2, tickets: \$27 (save \$5). Book soon. Call Gaynor or Kym on 9519 5362.

● Are you hep C + and concerned about the lack of public info and support? Kathy Sport, a final year film student, is planning to make a comprehensive documentary about hep C. If you would like to contribute your story - on film or not - call Kathy on 9564 0680. Confidentiality respected at all times.

individuals also contact the Health Care Complaints Commission about discrimination or poor service.

A full report from the meetings has been developed into an 'options paper', which sets out the different options for the kind of service ACON could provide in the area. Four of the six options were local suggestions, and ACON has not expressed a preference for any of them. This paper is to be circulated in the region for comment during March. ACON Committee of Council will then decide on an option, taking the comments into account, and approach the AIDS and Infectious Diseases Branch for approval. Following approval, ACON aims to have the option put into place within a month, with the new service/s in the process of being established by the end of April.

## HACC review

A DRAFT REPORT ON THE FINDINGS of a review of Home & Community Care (HACC) services will be presented to HIV/AIDS organisations in April. The review, conducted by Bill Rigney, looks at what changes are needed in the services that are currently on offer to the HIV community.

People living with HIV/AIDS have special requirements and many of those Rigney surveyed thought that the services they are receiving are more geared towards the frail aged and younger people with disabilities and that this was evident in the type and quality of care.

Among the recommendations is that there should be more educational material about the services available, the cost, and that people can negotiate that cost if necessary.

Access to training for staff and volunteers is also a high priority, so that they can be aware of the specific needs of the people they are dealing with and can show the appropriate sensitivity.

Another strategy is that an HIV-specific service be introduced to meet the community's needs with-

out compromising the client's right to confidentiality.

Uniformity of services needs attention. For example, in the area Rigney targeted, there are six local councils, each providing differing modes and quality of service delivery of Meals on Wheels.

Rigney also found that several workers had not expected to be servicing people living with HIV/AIDS and were sometimes reluctant to admit their concern and lack of education in this area.

By standardising the training, updating the policy manuals and emphasising access to services across the region, Rigney believes that both HACC workers and the HIV community will be better served and ultimately the service will be improved for everyone.

- Martin Hewetson

Reprinted from *Inner Voice*

## Ankali Review

HISTORICALLY, THE ANKALI Project's mission was to recruit, train and supervise volunteers to provide one-to-one, non-directive emotional support to people with an AIDS defining illness, their partners, family members, and close friends. Much of the volunteer's role involved supporting people through a series of difficult losses and changes, often until the time of someone's death.

Some aspects of the Ankali volunteer role have changed in recent years. Many people with AIDS have experienced fewer health related crises as a result of the arrival of combination therapies. As the medical nature of HIV/AIDS continues to change, so too do some of the emotional and social issues facing PLWHA. Ankali volunteers have had to be responsive to these, recognising that both the length and nature of emotional support relationships have changed.

The Ankali Project has identified a need to provide volunteer emotional support to people living

with HIV who may be asymptomatic but facing emotional issues unrelated to where they find themselves on the HIV/AIDS health continuum. This represents a change from the previous philosophy of only matching volunteers with people who have an AIDS defining illness.

All volunteer/client emotional support relationships will now be reviewed at least twice yearly to check out with clients whether they feel an ongoing need for an emotional support volunteer.

The Ankali Project review is working towards meeting the challenge of developing new approaches to providing emotional support, without losing sight of its traditional role.

The Project is planning to run two client focus groups in April to invite input from people living with HIV/AIDS and their carers about current emotional support needs. These will be advertised during March.

- Stewart Clarke, Project Manager

## Our Pathways

WELL, WHAT A MONTH THAT WAS! A superb treatments campaign launch (Feb 6) with celebrity guest, local iron-man Jonathon Crowe, speaking enthusiastically about the need for community support and acceptance for PLWHA. Other speakers included ACON's Alan Strum and local practitioners from a wide variety of fields. It ended (as all good shows do) with a 'dance sequence' - Tai Chi with sword display by a local acupuncturist.

The next day members sorted through a ton of jumble for our Fair Day Stall. At the end of Fair Day ("Everything 10 cents! We're not taking it back to Wollongong") we had raised a significant amount of much needed funds and came home to fall into the ocean. Bliss! As *Talkabout* goes to press we're banner-sewing for The Parade.



**PLWH/A Convenor Phillip Medcalf, volunteer Norman Last (with friend) and Community Development Officer Greg Allen sweat it out at the PLWH/A Fair Day stall, which promoted the Sex edition of *Talkabout*.**

PHOTO: PAUL ROBERTS

Lots of great contacts developing with PLWHA in Penrith and Parramatta, some of whom will hopefully meet up with us on our picnic/bus trip to Mt Annan Botanic Gardens on Saturday March 22.

In April we will be having another stall at Berry Fair (Sunday 6) and an evening bus trip on Thursday, April 24 to the gay/lesbian/PLWHA-friendly bowling night at Nowra Ten-Pin Bowls. Reports have it that the fortnightly evening is a total scream!

A monthly calendar of events is available (free) by calling OPI on (042) 29 2944.

- Cameron Sharp

## Drug news

AT THE 4TH CONFERENCE ON Retroviruses and Opportunistic Infections in Washington in January there was a general consensus that the goal of antiretroviral treatment should be complete suppression of HIV. This means a plasma viral load below the limit of detection of the test used.

Not everyone will be able to reach undetectable viral load, but

it is the most sensible target for your treatment strategies.

Unless the virus is essentially stopped from replicating by consistent and continuous use of the drug combinations, the person's HIV will evolve to become resistant to the drugs. If viral load is kept undetectable by continuous use of the drugs, then resistance develops very slowly or not at all.

There is no case yet where an established HIV infection has been eradicated by treatment. Viral eradication, if possible at all with current drugs, will take longer than previously thought. As a result, researchers have decided to wait before encouraging any volunteer in their trials to stop drugs in order to test whether eradication has occurred.

Important new data was presented on existing combinations. People have now been on these combinations for long enough that we could see that when they kept to their dosages and didn't miss dosage times, then the reduced viral loads were holding, often at undetectable level.

There was new information on drugs in the 'pipeline'. They may

## Briefs

**X** Roche Products has signed an agreement with Agouron Pharmaceuticals to market Nelfinavir in Australia, New Zealand, and some parts of Asia. Nelfinavir is a new Protease Inhibitor, and should be the next antiretroviral available in Australia. Following approval here, it will initially be available on a Compassionate Access Scheme. Nelfinavir has a specific formulation for kids, as well as the adult product. Adult dosage will be packaged in 250mg tablets, and dosing will be 750mg three times a day.

● A study published in the journal *AIDS* looked at the incidence of AIDS-defining opportunistic infections and other specific medical conditions among HIV+ men. Smokers were found to be more likely to develop bacterial pneumonia, oral candidiasis, and hairy leukoplakia. The effect was stronger in heavy smokers than in light smokers. There was no impact on Kaposi's sarcoma or other AIDS related OIs. The interesting thing they noted was that HIV+ individuals who smoke may be protected from the development of *Pneumocystis carinii* pneumonia (PCP). Researchers noted an almost statistically significant protective effect of smoking against PCP, though stopping smoking and PCP prophylaxis were considered more beneficial overall.

● Clear your calendar for Tuesday April 22. "It's Time II" PLWH/A's second Treatments Forum, at the Albion St Centre Theatre, starting 7.00pm. The latest news and information about where it's at with therapies, and how to get the most out of them. More details next issue.

● The US Centers for Disease Control and Prevention (CDC) released a report on Feb 27 stating that for the first time in the AIDS epidemic there has been a marked decline in the number of deaths. The CDC Morbidity and Mortality Weekly Report documents that deaths among people with AIDS declined 12% during the first 6 months of 1996. Still of concern in the US is the increasing rate of new AIDS cases amongst African Americans and women.

● Since February 1 all topical antifungal medicines have been removed from the Pharmaceutical Benefits Scheme. This cost effectiveness measure of the 1996/1997 Commonwealth Budget will affect HIV+ women especially, who will now be purchasing these products at full cost. Topical vaginal antifungal creams are indicated for vaginal candidiasis, a common and recurring infection for women with immunodeficiency. PLWH/A will be following this up and supporting calls to the Minister for a review of the decision.

- Jo Watson

not all be available here for quite some time, but it's important to be aware of them, and this assists people in planning their treatment strategies with their doctors over a longer period of time. There are drugs coming up in all classes, including 1592U89 (Nucleoside Analogue), DMP-266(NNRTI), and ABT-378 (Protease Inhibitor).

There was some more information available on drug interactions with protease inhibitors. Some drug interactions are stronger than others, and it is important that you and your doctor can select safe and effective drugs. These are the medications to be careful with: Rifabutin (Mycobutin), Clarithromycin (Klacid), Calcium channel blockers (ie: Adalat, Isoptin, Anpec, Norvasc), Erythromycin, Ketoconazole (Nizoral), Fluconazole (Diflucan), Clonazepam (Rivotril), Midazolam (Hypnovel), Triazolam (Halcion). Ask your doctor or treatments officer what responses you could expect.

Call me if you'd like to see summaries of other sessions.

- Jo Watson

## HIV futures

THE NATIONAL CENTRE IN HIV Social Research program for People Living with HIV/AIDS and their Carers is now situated at La Trobe University. Staff are based in both Sydney and Melbourne and plan to renew the research program to investigate the changes in how HIV/AIDS is thought about and lived with by HIV positive people in Australia. This especially applies to treatments decisions, employment and finances, relationships, and community and identity.

In the next 18 months the Centre will run new surveys known as 'HIV futures studies.'

A questionnaire was distributed at the NAPWA Conference and the Luncheon Club last year, asking people to identify important issues. The results from these surveys, to which 120 people responded, have been used to help develop the new program. This in-

formation will help ensure that the Centre's future projects are relevant and supportive.

Report summary:

1. Most important issues (first four, in order of ranking): Luncheon Club: Financial, treatments, health, housing.

NAPWA: health, treatments, financial, support.

2. Sources of information about HIV treatments:

Of the 113 people who answered this question, the leading three sources, in order of ranking, from both groups, were: Doctor; HIV publication; Treatments Officer.

3. Uncertainty about the future and confusion over all the new information was often mentioned. The report names "uncertainty" as a significant concern for many PLWHA.

These issues are obviously interconnected, and the survey responses will not only be important for the direction of social research, but also to the work of PLWHA organisations and AIDS Councils. The Report, "Current Issues for People Living with HIV/AIDS" is now available. If any readers have comments, or want a copy of the report, I'd love to hear from you.

- Jo Watson

## TONetwork

AT THE NATIONAL TREATMENTS Officers Network (TON) meeting in February there was much discussion of the reports from Washington and the significant messages that needed to be delivered to PLWHA. (See above.)

Also on the agenda was a report of plans to get the new ACON treatment booklet distributed around Australia. It's a valuable reference for people wanting info on treatments and drugs available in Australia today. Worth a look!

TON has been set up by the AFAO National Treatments Project. PLWH/A is represented by the Research Officer. TON meets every four months to ensure that information available to the positive community is current, reliable, and supportive of informed choices about treatment options.

# Talkback



## Free choice

I CAN ONLY AGREE WITH MANY OF the sentiments of James Urban's letter last month. It is true that many of us have been guilty of 'militant' treatments-now type messages towards our fellow positives.

James reminds me of how angry I felt about the 'dictatorial' safe sex messages that were thrust upon us (and still are). And just as James has a variety of reasons for not seeking treatment, I had a variety of reasons for not practising safe sex. It was and remains a personal choice.

It is irritating, as James points out, to be constantly asked to consider a behavioural change of some

significance, especially when one is not ready to do so.

I think we should be more respectful of the decisions taken by a minority to refuse treatments and indeed for the right of those people to proclaim their reasons, famously, as in the case of the late Peter Blazey. The fact that I do not agree with the substance of their objections is merely my problem. I know that there were many who strenuously disagreed with my position on unsafe sex: that everyone had the right to do as they saw fit in the circumstances.

In a sense science needs a large number of people with HIV not to take treatments at all. In this way, in the long term, we can find out

whether taking drugs for HIV prolongs life or whether they make no difference compared with those who take nothing. As you would expect, researchers can hardly refuse treatments to some to find out this data.

The jury is still out on that question, but the evidence is mounting for the conclusion that treatments do improve and lengthen life for those of us with HIV/AIDS. Nonetheless, even if this happy scenario is true, as it may well be, we cannot risk alienating HIV positive people by adopting a 'must' attitude with respect to this new technology. Yes, James, there is still free choice.

**Andrew Kirk**

## HIV living

### Orientations

have you recently become HIV positive?  
'you are not alone'

**Orientations** are weekend workshops covering issues specifically for gay men who have become HIV positive in the last two years.

*Workshops are free and confidential.*

The next *orientations* workshop will be **April 5 & 6, 1997**. Limited spaces in each workshop, to book call Guy on (02) 9206 2014.

*These sessions are only for people with HIV.*

### HIV Living Sunday Afternoon Support Groups

**Support groups** give you the chance to meet others with HIV, talk about feelings, exchange ideas, make friends. You may be surprised to find how your own experience can help others. Groups meet for around two hours a week, and run for eight to ten weeks. There are about ten people in each group including two trained facilitators who also have HIV. What's talked about in the group is entirely up to its members, everything said is confidential. To join a group or find out more, call Guy on (02) 9206 2014.

*New groups are starting all the time.*



## HALC

HIV/AIDS Legal Centre NSW

### FREE LEGAL ADVICE

The HIV/AIDS Legal Centre provides free legal advice and assistance to people living with and affected by HIV/AIDS.

We can assist with problems including: superannuation and insurance, making a will, medical treatment issues, powers of attorney, discrimination, debt & employment.

The Centre is open for appointments every Monday from 6.30pm to 8.00pm. You need an appointment to see a lawyer. Appointments can be made by contacting the Centre on the numbers below, Monday to Friday from 10.00am to 6.00pm.

Telephone advice is available for those who are unable to attend the Centre, 2.00pm to 6.00pm Monday to Thursday.

All information is kept strictly confidential.

### HIV/AIDS Legal Centre

At the AIDS Council of NSW  
9 Commonwealth Street  
Surry Hills  
NSW 2010



Ph (02) 9206 2060, Freecall 1800 063 060  
TTY (02) 9283 2088, Fax (02) 9206 2053

## Performance +

THANK YOU FOR YOUR REVIEW OF Performance Positive II. Although the night was very successful it unfortunately did not attract many reviews so yours was appreciated.

One correction. The show wasn't 50 minutes late, although it may have appeared that way to 'Lois'. The show was meant to begin at 8pm and got underway shortly after. We did have (unplanned!) pre-show nude entertainment.

These shows are about exploring those areas of our lives, like 'Unsafe Sex', which can be freely explored in a space labelled 'Performance' but cannot be easily talked through elsewhere.

The method is not new. It's been used in Sydney before and is used all over the world every day. But we Sydney queens need these freed up spaces more than ever before.

It's clear to me that unless we use tools such as performance to engage with 'difficult' issues, issues we'll come up with a million excuses to avoid discussing properly, then they will continue to be swept under the carpet or pushed down the priorities list. And yet we still have numerous problems requiring urgent attention.

We use performance as a community development tool. That is why, as Lois noted, the "quality of the work varied". It was deliberate - both highly and less experienced performers were included. But the depths to which some of the performers reached touched me immensely, particularly those unused perhaps to being 'serious'.

For example, how often do we just use drag queens as simply colour and movement? Faced with an opportunity to comment, Miss 3D touched on the biggies: death and sex and desire. The opportunity was grasped with both hands and she made me, for one, proud.

The next show, in April, will be about relationships. Watch this space for more information.

**Paul Canning**

**PRIDE HIV/AIDS Community  
Development Worker**

## Users' challenge

THERE WAS A SESSION FOR POSITIVE people who inject at the National Association of People with AIDS Conference in November 1996.

The session promoted discussion in order to bring to light the particular problems and special needs of people in this group. Positive injectors are too often stereotyped simply as 'junkies' or as people who acquired HIV 'the wrong way'. The stories told by people at the session focused on examples of prejudiced treatment by GPs, clinics and various government departments. Others talked about userphobic comments and attitudes of people they met in bars and clubs.

Although it was hardly surprising that the main concern raised was the discrimination they face in their daily lives, it was disheartening to hear that some of this discrimination, perhaps the hardest to take, is coming from within their own communities. In the gay community this discrimination is often hypocritical: drug use is condoned, even smiled at, unless those drugs are injected. It was sad to hear audience members saying that they felt separate from the community of men who acquired hiv sexually. Just as AIDS is AIDS however it was acquired, drug use is drug use, only the way we take our drugs differs.

Just because a person is diagnosed positive does not mean they will, or should have to give up drugs; it is an individual matter. People who continue to inject need access to information and health care that will help them to promote their own health and wellbeing. This is not a demand for preferential treatment, it is simply a call to acknowledge that these people are deserving of inclusion in our existing community health programs and that discrimination in all its forms only works to prevent this.

At the end of the session an audience member told us that Community Legal Centres in NSW are advocates for law and policy reform who can help you to take action when you are discriminated against.

They can help you direct your complaints to the right person, tell them what happened (the right way), and argue for what you would like done about it. The HIV/AIDS Legal Centre (9206 2060) and Redfern Legal Centre (9698 7277) have existing ties with both positive people and drug law reform issues. GLIDUP at ACON provides support for gay and lesbian injectors (positive and negative), Call Paul or Sarah on 9206 2096.

People, companies and professions will only change beliefs and policies if they are challenged. Challenge and report discrimination when it happens!

**Paul Yould**

**A/Project Officer, GLIDUP**

## Thanks

... TO ALL THOSE WHO HAVE Emailed, faxed and posted me their messages of support for my World AIDS Day Award. It's been lovely to receive them and I appreciate the support.

**Jill Sergeant,**

**Talkabout Co-ordinator**

We welcome your letters. They should ideally be <300 words and may be edited for length. Please include your name and phone number or address and send them to:

**Talkabout, PO Box 831  
Darlinghurst 2010**



**Important changes  
to confidentiality  
laws are proposed  
What do you think?  
We want your input.  
See lead story, page 4.**

## Tribute



### For Daz

Those dancing eyes, your cheeky smile  
That carried you through life awhile  
Not long enough for you are worth  
Far more than time you trod  
this earth.

And even in your fragile state  
Your love it did not dissipate  
For you asked nothing in return  
Just love to give to those who  
yearned.

So now your precious life translates  
To one hereafter – you won't wait  
To spread that love with all its grace  
Throughout the wondrous heaven  
place.

And if they ask why you're so kind  
The answer, it's not hard to find  
The wealth of love you leave behind  
Will be a torch for all mankind.

Darrell hailed from the land of  
the long white cloud & spent  
many years in London driving  
those famous tube trains.  
He visited family living in  
Australia over the years & most  
recently watched the 1995 Mardi  
Gras Parade from PLWHA, and  
at the party he said he would have  
had to go home if it wasn't for the  
time out room. Darrel was a gorge-  
ous boy who loved to love

- T.K.

**Uniting Our Voices**  
National Aboriginal &  
Torres Strait Islander  
Health Worker's  
Conference 28 - 30 April  
Australian Jockey Club,  
Randwick  
Call Ruth Simon for  
details, 9311 4051

## Poetry



### The crossing

*Standing on the train  
Amidst strangers,  
I am reminded of you.  
So composed I am,  
Hidden behind anonymity –  
If only they knew.*

*If only they knew  
Of your long voyage,  
The destination,  
how our environment swam by –  
City swift,  
People blurred,  
Conversations mute,  
For we were drifting in pleasurable  
thoughts.  
Nothing intimate  
Except us,  
How the news about you  
Brought us closer,  
Slowed the environment down,  
For we took precious time  
To absorb the city –  
Faces descriptive, expressive,  
The traffic in flow,  
Utterances interrupting,  
Painful thoughts.*

*If only they knew  
What the railroad crossing meant –  
City resting,  
Traffic stopped in the moment,  
Voices lost to pain,  
While you sailed through the  
crossing  
And I stepped into darkness,  
Just before it –  
Tiny street lights  
In the distance,  
A metaphor of minute hope . . .*

- Kerry Ridgway



## Notices

30 Y.O. HIV+ GAY GUY, RETIRED  
for 6 years, hasn't died on schedule  
due to new treatments. The money's  
run out so I need to re-enter the  
workforce. (PIs have a lot to answer  
for!) Can type 35wpm, use a variety  
of WP (Wordperfect for Windows,  
Word for Windows), BDB (dBase  
IV) and DTP (CorelDraw) pack-  
ages and can easily pick up others.  
Call David, (0412)25 5571.

IN MAY, TALKABOUT WILL FOCUS  
on cultural responses to HIV/AIDS.  
get your stories, poems and black  
& white artwork/photos in by  
April 11 to be sure of getting into  
the issue.

THIS EDITION OF TALKABOUT IS  
out very late due to staff illness.  
Sorry to disappoint. We hope to  
have the next issue out on time.  
Thanks to Alex Zinzi for filling in  
in the emergency.

WE NEED SOMEONE TO DELIVER  
*Talkabout* once a month and  
*Contacts* every three months.  
You need your own vehicle. The  
job takes a full day and we pay.  
Would suit someone on a pen-  
sion. Call Paul on 93616750.

### Olga's Personals

HIV+ 36 y.o. heterosexual man, good body,  
gft. tall, reasonably fit, seeks friendship/rela-  
tionship with HIV+ woman or woman who ac-  
cepts the disease. Into wining & dining,  
movies, beach, walking. Sydney/Central  
Coast. Call 0419 489 645, ask for Scott.

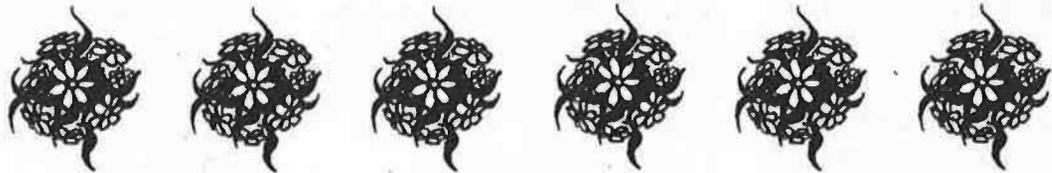
#### How to place your advertisement:

- Write an ad of up to 40 words and be totally honest about what you are after.
- Claims of HIV negativity cannot be made as it is not possible to verify such claims, however, claims of HIV positivity are welcomed and encouraged.
- It is OK to mention that you are straight, bisexual, gay or transgender.
- Any ad that refers to illegal activity or is racist or sexist will not be published.
- Send the ad to Olga, and be sure to include your name and address so that responses can be forwarded on to you. This information is not published and is kept confidentially by Olga.
- Olga can only accept one ad, per person, per issue. If more than one ad is submitted, extras will be published over following months.

# who cares?

*Just about everyone. Positive or negative. Families care. Lovers care. Health workers care. Strangers choose to become Ankalis or CSN carers, and get involved in loving friendships they hadn't expected.*

*We care in many different ways. We give physical care to people who are sick – from feeding them to giving massages. We give medical care. We care by organising the physical and medical attention a person needs. We make sure all their needs are looked after. We care by cleaning their floors. We care by listening. We care by lobbying for access to treatments and services. We also care for other carers. We care for ourselves. And we care by just being a friend.*



## Adrian

*When Adrian's partner became ill three and a half years ago, Adrian became carer as well as lover.*

*How has it affected your relationship – bouncing both balls at the one time?*

I found the transition to being a carer became quite difficult. His health declined quite rapidly and neither of us had particularly expected it. He quit work as he was becoming ill. It progressed so rapidly that I had to leave my employment within a month of him finishing, so financially the time was also difficult.

When it first happened I thought we'd be able to cope reasonably well, but his health declined further and further and the demands to become a carer became more intense. There was a lot of stuff around the carer's role that put an end to the relationship

really. It just changed the dynamic of how we related to each other. I know at one stage I was by necessity doing most of the daily living tasks for him and he experienced that as really disempowering. More of our energy was focussed on caring and surviving than actually maintaining the relationship.



GRAPHIC: KAREN VANCE

Three years down the track we're both well again and I'm just going off the carer's pension now, but I think our relationship's

become one more of friendship than the passionate relationship it used to be.

*How has it affected you to be caring for your lover, being HIV positive yourself?*

We both are quite independent people. As I went into the caring role we managed, but as his health declined further we both got quite distressed by the whole situation and unable to manage by ourselves. And so we went into a relationship with service providers who by and large we couldn't have coped without.

At the time he became sick it was prior to combination therapies and he was certain that he was going to pass away within the next couple of years. His depression surrounding that was really painful for me to watch, and as much as I struggled against it, I had that same depressive feeling that perhaps he was right and there was no long term future for him. And being recently diagnosed positive myself I think that brought up a lot of my own fears.

*What were some of the rewards of caring for him?*

(Laughs) There are rewards – it was damn hard work, but there are rewards. I think we have an intimacy and a knowledge of each other that we wouldn't have had. When you're in a tightly bonded caring relationship with a lover I think you begin to explore things in more depth, try to understand the dynamics of what's going on and how your relationship's actually changing.

I think I got to know him a lot better. Not necessarily the things I might have chosen to know about my partner, a lot of the things are around death and dying and disability and how to cope with all of that.

It was also rewarding to be able to be there for each other at a time when we were both highly distressed. While I was caring for him, he was also offering support for me, as much as he could.

*What were some of the hardest things?*

Dealing with the medical problems. He had a number of conditions that were misdiagnosed and he also had mental difficulties. He was having trouble with anxiety, to the point where he was actually having fits. He would have no recollection of these fits afterwards. And I would be there and care for him throughout it. They often went on for six to eight hours and then he'd eventually fall asleep and I'd be left awake at night thinking about what had gone down and really being unable to talk to him about it because he wouldn't remember what had happened.

It caught us financially unprepared, so it meant living for three years in some degree of debt, and on top of that being unable to make exciting and life enhancing events happen in life, just struggling to cope and survive.

Two years ago we had no goals, no plans, no vision of the future and to contemplate what the future held was really too difficult. At some

stages we were looking so desperate he was on the verge of taking his own life. I made a conscious decision that we had to start to get something happening in our lives.

At that time I felt really isolated. We had a few friends but really didn't feel we could put too much on them, most of them were positive, most of them weren't well, a couple of them are no longer with us. It was scary, depressing. There needed to be a circuit breaker of some sort.

*And now that things have changed, how do you feel?*

Oh, excellent. Just so happy for both of us. It's nice to have worked through a really difficult period, and get back to a stage where we can actually function in life.

Certainly I've learned lots of things. For me the most important thing to realise, is that nothing is forever. Inevitably life will change. If I ever had to live through it again, I'd probably set more short term goals for myself, keep myself engaged to some extent with what's happening in the outside world, so I wasn't so isolated.

We share a friendship now that we'll never lose. I think we've lived a commitment to each other that many people don't get to do. And that commitment will now be a friendship that will go on forever.

## Sherry

*Sherry Pipe lives in Dubbo. Last year she cared for her brother Glenn, who died in October.*

*When did you find out that Glenn had HIV?*

Last May. He rang me from hospital. He was at the Marks Pavillion at Prince Henry.

*When did he come back to Dubbo?*

At the start of July. He just wanted someone to look after him and manage for him, pay his bills, do his shopping. Being in Sydney there was no family, so he came to Dubbo. But he had his own little flat, he still wanted that.

We told my sister and my brother, he said that was alright. It really hit them hard.

*Could you tell me about your experience of caring for Glenn?*

Glenn was the boss. When he came home to Dubbo, it was like someone who had a stroke, he didn't walk properly, or walked with a cane, but he showered himself. I'd just get his meals, go down to the flat and clean up. When he did get ill, he had to go to hospital within about a week. He was only in hospital about three weeks and then he died.



*L - R: Glenn, with sisters Lillian and Sherry and brother Gregory.*

I went up there every day. He'd like me to shave him, I'd chat and do his washing and stuff for him.

**Were other family members involved?**

No. In the end my brother did come, and that was good, because Glenn really wanted to see him. Once he made the effort and came to the hospital he was really good.

**It sounds like a really full-on change for you, over those few months.**

Yeah, it really knocked me around, to see the changes it made in him. But I was grateful that I did get that five or six months. And he was a nice person anyway. That sort of made things easier for me. I think when you live the life I live, very middle Australian, you see something like this and your heart breaks. How do people go through this by themselves? I just can't understand it. I'd never want for anyone to do that by themselves.

**Did you have support from other people while you were caring for him?**

Glenn really didn't want that. He liked Robert, the nurse from Macquarie Health, but Glenn was

a very private person. So many of his friends didn't even know, it was unbelievable. But I had my friends, that was very good for me. Glenn wouldn't let them come to his house, but they were there for me, if I needed to talk to someone. Plus my immediate family, my husband and my children, I had a real lot of support from them.

**Did you go to the Aboriginal Medical Service for support?**

No, Glenn didn't go, but they did approach him and asked if he needed anything. He said no, because he was happy with the way Robert and the others from Macquarie Health were looking after him.

They were very supportive, they also said I could ask them if I needed any help, but there was not a lot that I needed.



GRAPHIC: KAREN VANCE

## Marcella Dorazio

*Marcella has been a carer since finishing her training with CSN in late 1995.*

**Why did you become a carer?**

I was thinking about becoming a carer before '95, and I went off to do some other volunteer work for three months. While I was away it was always in my mind to come back to do.

Also, because my brother's positive. I thought it would be a good way to introduce him to what was available and be able to talk to him. I find it has worked in a way. He asks "What did you do with your client on the weekend", and I can say, "oh we've found this cream and it works really well when you get these skin rashes". It's things that he feels comfortable talking about, whereas he won't talk to me about things that are hurting him, he just says "oh, no, I'm fine, I'm fine".

**What do you do as a carer?**

Basically I just help my client around the house. If he gets a bit sick and he might be in bed, then I'll go over and make some lunch



### Carer Pension

THE GOVERNMENT PROVIDES financial help to carers through the Carer Pension, Child Disability Allowance & Domiciliary Nursing Care Benefit.

You can claim Carer Pension if:

- You are an Australian citizen or permanent resident;
- you and your partner's income and assets are below certain limits;

- you are providing full time care for someone frail, aged, sick or with a disability in their home;
- the person you are caring for is over the age of 16 years and gets a Social Security or Veterans Affairs income support payment, or meets an income and assets tests; and
- the person you are looking after must need this care or supervision for at least six months or more, unless he or she has a terminal condition.

You cannot get Carer Pension and another Social Security income support payment at the same time.

If the person you care for needs nursing home level care,

you may also be able to get Domiciliary Nursing Care Benefit (DNCB). It is not means tested or taxable. This benefit is paid by the Department of Health and Family Services (H&FS). For more information about DNCB contact H&FS in your State.

It will usually take between two and eight weeks before you get your first payment.

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and that's as far as it goes. With all his medications and things he basically looks after himself, and in the time I've known him he hasn't been in hospital.

***What are some of the rewards of being a carer?***

Hmm, lots of rewards. Just that Saturday morning when I go over, is special. Now it's only every second weekend, we have a lot to catch up on. Just opening the friendship and watching it grow. I could honestly call him a really good friend.

***What are some of the hard things?***

I think one of the hard things, especially when you've been with someone for a long time, is not to jump in and think you know what's right, or be too judgemental. You care for them, and then that care goes over the line and the friendship's there. You don't want to ruin that, and you've got to remember that it's the other person's life, and you can't really set that line and say, "well I don't think that's a good idea". They have to figure it out for themselves, and then you should be there to support them if it doesn't really work out.

That's one of the hardest things, you've always got to stop and think, well if I was in this situation I wouldn't want anyone telling me what to do.

It reminds me a lot of active listening, listening to the person instead of always putting your bit in, I think that works really well.

***What do you do to look after yourself & your emotional needs as a carer?***

I'm kind of lucky, because of my family background, I don't feel like I ever bottle anything up. I have my sister to talk to, and my brother, and my mum, she knows everything that's going on. I actually don't need the [support] services from CSN very often. When we started we had support groups once a week and it was great at the beginning, but as the time gap grew larger, I didn't feel I really needed to keep on going back.

## Noelene

I FIRST HEARD ABOUT CSN IN 1990. I decided to do the course, because I had four sons and I wanted to know more about AIDS and also because of my own background. I was one of seven children. When I was ten, the Department of Community Services (DOCS) removed us from the care of our parents. We were all separated. I was adopted at 14. About eight years ago I decided to search for my brothers and sisters. One brother (who had remained a state ward) had died from an overdose of drugs. I felt that by doing CSN I might be able to be there for someone else.

I finished my CSN course in August 1990. During the course a woman came in to talk about caring for HIV women and children. I remember thinking, "hell no, I could never care for an HIV child, it would be too painful". I had

cared for guys and a couple of women when I was asked to do a shift for a woman and her HIV positive six month old son.

Susan and I immediately hit it off. She didn't need or want a lot of care but she did need someone to help her with Steven. I looked after Steven a couple of times while Susan went shopping. I fell in love with Steven. He actually had AIDS, he was very sick. He was on AZT and he had continual diarrhoea.

Susan was not doing too well and she didn't have all the energy needed to care for a sick child on her own 24 hours a day. She asked me if I could take Steven for the weekend so she could catch up on some much needed rest. I brought the baby home (I checked first with my CSN Co-ordinators).

My family had very mixed reactions about having Steven in the house. They were very afraid of



GRAPHIC: KAREN VANCE

becoming emotionally involved with a child who was going to die. Steven was the most adorable baby. He won them over just as he had me.

We returned Steven to his mother on the Monday. I went back to do my shift the next Friday and the same thing happened. Steven ended up coming back home with me, and soon he was coming home on a regular basis. In March 1992, Susan asked me if he could stay longer than the weekend. He never returned home.

We were all in a very bad position. My husband had been made redundant at Christmas, so we didn't have any money, and

CSN were in total confusion about what could be done. I think I became CSN's worst nightmare. What we didn't know was that a child can only stay with non-related people for three months, then DOCS can remove the child. We spoke to Susan about this and we decided that my husband and I would do private fostering, which meant that Steven could stay with us and only his mother could remove him from our care. We continued like this until Susan died in 1993.

Susan and I were great friends. I loved her and her son. I promised her that Steven was not going to be placed anywhere

else, that his home was with us. Things became very complicated after Susan's death. Besides grieving for her we were faced with the fact that Steven had no legal guardian. He eventually became a state ward but remained in our care.

Caring for an HIV positive child is painful but is also the most beautiful experience. We had lots of tears but we had twice as many hugs and kisses. Steven and Susan taught me and my family what unconditional love is. So through all the pain I can still say thank you to them for sharing their lives with us.

Steven died four days after his third birthday.



AIDS Council of New South Wales Inc.

## The Family Support Project

9206 2079

WHEN A CHILD OR PARENT HAS HIV or AIDS, families may need more support than usual but are not always aware of what help is available. The Family Support Project aims to make sure that families living with HIV/AIDS get access to the full range of child care support provided by 'alternate care' services.

'Alternate care' refers to different forms of child care provided outside the home. Alternate care makes it easier for families to stay together by giving parents and carers necessary time out. It includes services and support systems which many parents are able to take for granted: day-care, school, camps, friends, family, baby sitters etc.

Parents with less supportive networks or less money can also make use of more formal alternate care services:

- **respite care** – regular planned overnight care with the same carers, usually one weekend in four depending on the children;

- **crisis care** – emergency care, e.g. when a parent is hospitalised;
- **shared care** – when the primary care of a child or children is shared between two households but guardianship stays with the natural parent; or
- **long-term care** – more often a permanent placement with carers, can include adoption.

Services providing these forms of alternate care include charitable organisations such as Barnardo's and Centacare. Care provided by these services is free.

The Family Support Project helps families to figure out how to make the best use of these services, with the goal of working out arrangements that are permanent and stable. For example, it used to be commonplace that when parents were admitted to hospital, children were placed with a carer neither they nor their parent/s knew. Each hospital admission would bring a different carer. However if arrangements are made while a parent is well, the child/ren are able to develop a relationship with a carer over time and this reduces stress and trauma for the whole family.

The project also offers training to alternate care services to ensure that they are HIV friendly

and carers are supported by the relevant HIV services and organisations. For example, carers have used the CSN transport service to get children to school.

The project also assists the alternate care services with carer recruitment. People who already have a relationship with the child/ren in a family that needs care are the first choice, but, as in Noelene's case (see above), a carer may be recruited from an existing HIV service such as CSN. I am happy to talk to anyone who would like to discuss the idea of supporting a family by becoming a carer.

As well as practical assistance, the project has a policy officer, Vivienne Monro. Vivienne works with the government and alternate care agencies to help them refine the policies that presently affect families and carers involved in alternate care.

There are many different laws, philosophies, issues and services affecting alternate care for children. It's a maze that you don't have to negotiate alone. If you would like to talk about your options and get some assistance in making your plans for your children reality, please don't hesitate to call me.

– Angela Stewart,  
Family Support Liaison Officer

## Kathleen Bourke

*Kathleen has been a CSN carer for about two years.*

### *Why did you become a carer?*

Someone kept telling me I'd be really good at it! I don't have any involvement, I don't have kids, I thought I'd like to do something for the community.

### *Are you caring for someone at the moment?*

Yes, he's going quite well. His condition varies each week. Mostly I do household duties for him, so it's not a very long shift. Sometimes he's pretty much stuck on the couch, others he's a bit more active. One time he was down on the kitchen floor scrubbing it with me!

### *How does it feel to see that deterioration in his health?*

It's a bit of a reality check. That happened with a previous client, when he went from being quite upright to being bedridden very fast. It grabs you around the heart a bit, even when you don't have a particularly close bond.



### *What are some of the rewards of being a carer?*

Made some new friends. You get a support network, not just for what you're doing, but for your own stuff, which is really good. Plus that warm fuzzy feeling you get knowing you're helping someone. That's always pretty good.

I bonded very well with my first client, we became quite good buddies. He was very special. I found he would counsel me sometimes and give me advice. I miss him. The first time I went to my new client I was vacuuming and looked up and there was a photo of my former client on the wall – so I cried a bit.

### *What are some of the hard things of being a carer?*

Sometimes your shift can get in the way of something, occasionally I've resented the fact that I had to do it. A couple of times I've been not in my best spirits and I've had to go to my client and they've been in their stuff and I'd have to hold back, take a deep breath. That's only happened a couple of times.

### *What do you do to get support?*

In our CSN training we did a lot of group bonding, which was really important once you did

## POSITIVE RETREAT

### No 11



Come along to a stress free country location where you can enjoy nature, try complementary therapies and meet other positive people in a relaxed environment. Learn about alternative therapies and sample yoga, meditation, acupuncture, homoeopathy and reiki.

This five day retreat will be held early April 1997. An investment of \$40 unwaged and \$100 waged is the cost of the retreat. For more details, and to obtain an application form, call David on 02 9602 2117, 10am to 6pm, Mon to Thurs.

The retreat will be recreational drug and alcohol free.

## HIV Living

start caring. If you needed to off-load, you could ring someone and go "aarrgh!", or "what do you do when this happens", or "did I do the right thing?". That was really important.

**How would you describe your role as a carer?**

It's just something that I do as part of my belief that everyone who's able bodied should help people who aren't quite so able-bodied. It's just part of the balance of the planet, that you should help people who need bit of help. And I do it for myself too. I need to be needed. It's like I'm doing my bit.

**Melinda Sinclair**

*Melinda, a registered nurse with Royal Prince Alfred Hospital, has been nursing people with HIV/AIDS for three years.*

**Why did you start nursing people with HIV/AIDS?**

I thought I'd like to work in HIV/AIDS because it was still a relatively new area of nursing,

with a lot of change, research and trials, and a lot of people who were wanting to be involved in their own care and life choices.



**Melinda's team, L-R: Claire Harris, Nursing unit manager, Paris Manii, pharmacist, Dr Dave Templeton, Melinda, Mary Moussa, nurse, Nadine Soukoreff, Occupational Therapist.**



**Community Support Network (CSN)**

For care: 9206 2031/2032  
For training: 9206 2032

IN ANY GIVEN WEEK, AROUND 150 CSN volunteers provide up to 500 hours of practical care for people living with HIV/AIDS. This care might include anything from doing the dishes, to walking the dog, to going shopping, to providing basic palliative care – practical support which enables you to continue living at home, in the way you choose.

You can adjust the level of support CSN offers according to your needs. You might have one or more regular carers visiting each week and helping with a variety of things. Alternatively, you may only want a carer for a few weeks while you are recuperating from a stay in hospital. The service is very flexible.

CSN carers come from a wonderfully diverse range of lifestyles and backgrounds – men, women, gay, straight, young, old, lawyers, nuns, public servants, students, artists – you name it, you'll find it amongst CSN carers!

Carers and clients are matched according to a number of practical factors, for example, whether the carer needs a car for shopping, what time of day the client requires a carer etc. If a client has a specific request, for example if you would prefer a male carer, this is certainly taken into account. Both carers and clients can ask to have a different person if they feel mismatched.

CSN carers tend to have a few pretty important characteristics in common – they are generally people who are caring, flexible, non-judgmental, reliable and giving.

CSN carers are asked to make a commitment to provide two – four hours a week of care for up to six months. This time commitment includes attending a fortnightly

support group. (We take care of our carers!)

Before starting caring, all CSN volunteers do an initial training course, which covers things like opportunistic infections and treatments; basic practical skills, like how to push a wheelchair and how to safely lift someone, tips on shopping, cooking and cleaning, massage, and loads of possible scenarios which carers may encounter and need to be prepared for! Further training is provided and regular forums are held to keep everyone up to date with issues like treatments and nutrition.

Twenty five percent of carers are still with CSN more than 18 months after their initial training course – which is fantastic. When asked what keeps them involved most carers say "my client/s". It's a two-way kind of thing.

CSN is a project of the AIDS Council of NSW which also includes housing and transport services. There are branches of CSN at ACON Illawarra and ACON Hunter. ♥

### **What are some rewards of nursing people with HIV or AIDS?**

One of the biggest ones is seeing people go home again. Sometimes we admit people who are very, very sick and it's a big challenge for us to make them well again, to get them back home to do what they enjoy doing.

### **What are some of the hard things about your work?**

The obvious thing is people dying. Sometimes we can't take away the pain, the physical and the mental pain. Sometimes no matter how much we do, we can't help people and that's very, very hard, being in the caring profession and not having enough to give. It's hard, every day there are hard things.

### **What kind of changes have you seen in HIV?**

Even in the three years that I've been nursing PLWHA the biggest thing is that hospital stays seem to have reduced. We've got better oral drugs coming all the time, such as oral Gancyclovir. People used to have to stay 21 days to be induced with IV Gancyclovir and now after a much shorter stay they can go home on tablets. There's community nursing now - Royal prince Alfred Hospital offers a Hospital in the Home program so that people may stay in their own environment. And you always get better faster in your own home, don't you?!

### **How do you get support for dealing with the hard things?**

My peers, the medical and nursing staff, we're a great team here. They're very helpful. We often de-

brief after a particularly difficult time, maybe not as much as we should. Family and friends help too. My boyfriend Steve is very supportive of what I do, he's got a lot of faith in me. I think it's just talking really, getting over things.

This ward is different to a lot of other wards in that we see people come back and back, they become old friends. It's not something that everyone is interested in or understands, so it's a select few people that help me through hard times.

I'm from the suburbs, I'm not from the inner city.

## **Stephanie Taylor**

*Stephanie is a CSN carer who trained in Newcastle and has been a carer for about 18 months.*

### **Why did you become a carer?**

To counterbalance my emotions. I was a sex worker and I wanted to do something that would make me feel good about myself. And I enjoy helping people.

### **What have been the rewards of being a carer?**

There's been heaps. I've made lots of really good friends, my self esteem has improved really dramatically. I've also been able to pick up paid relief work with the Sex Worker's Outreach Project, because of the knowledge of HIV/AIDS that I gained from CSN. I was taking care of someone who died at Christmas a year ago and his parents wrote to my mother, explaining what I'd done for them and their son. [See box] I was really touched by that. People appreciated me.

### **What have been some of the hard things?**

Seeing my client in a lot of pain. At the very end he refused to have any type of treatment. He died at home, he refused to go to hospital. He died quite a horrible death. He suffered from meningitis, malnutrition, CMV. Just watching him in the last three days was terrible. All I wanted to do was put a pillow over his face, the morphine wasn't enough to keep his pain threshold down. That was the hardest part.

### **Dear Janet,**

*I want you to know how important Stephanie has been to us over the last few months . . .*

*My partner and I had a very distressing year, looking after her eldest son, D—, who died at the end of November. His first hospitalisation with an AIDS-related disorder was three years ago . . . but I don't think any amount of foreknowledge can fully prepare one for the eventuality. . . towards the end he was little more than skin over bone. He was in pain all the time. . . Earlier in the year he had allowed us to massage him a little, but I think over the last three months he didn't want us to see his body.*

*. . . with the pain, and the distress over his wife, who died some seven weeks earlier than he did, he had a lot of anger. . . Stephanie was a godsend to us. Several times when his anger and irrationality and distress was getting beyond bearing we called her and she massaged him and talked to him and calmed him down.*

*Stephanie gave him long and very useful massage sessions and eased the pain, both physical and psychological, when other resources did not work. And after D— died, she very graciously helped lay out his body and dress him. Both my partner and I feel very warm towards her . . . we feel that Steph is a very valuable person . . .*

**Sincerely....**

It's been a huge eye opener to a different world. It's been great, working with younger people as well. It's a rewarding job to be in and I really appreciate that people empower themselves, understand their own illness and are very involved in their own care. As a nurse that also makes my job more interesting, I learn from patients as well. I'm happy I've chosen this field.

I cried when he died but I was also relieved because he wasn't in pain. I went into the situation knowing that he was going to die, his wife had died seven, eight weeks earlier.

He was an amazing man. He didn't want to die, he fought to the very end. He didn't want to take any kind of therapy, he hated hospitals, that sort of thing. But he taught me a lot. My partner, she suicided three months before he died, and seeing the resilience in him to live, and the will to live, was an inspiration to keep going.

Seeing his mother in grief and pain was hard. And his wife dying, I hadn't encountered any women

who were HIV+ or dying of AIDS related illnesses, so that was a culture shock. And she died just as horrible a death, although she was in hospital. They were both very attractive people, before they got sick. And to see them shrivel up into shells, and so sickly looking - it was a big eye opener for me.



GRAPHIC: KAREN VANCE

### *What do you do to take care of yourself?*

Well, I used to go and talk to my CSN co-ordinator a lot. I'd take time out when I needed to. I had other people in my group, who I'd done the course with, who I used to talk to. And I'm not bad at detaching, too. I knew when I started caring that I would be looking after people who would eventually die, and coming from a drug scene and having several friends that had died from drug and alcohol related incidences hardened me, in a way.

*Interviews By Guy Taylor  
& Jill Sergeant*



## The cultural impact on carers

The Multicultural HIV/AIDS Support and Education Service provides confidential education and support to people from 16 different language groups in Metropolitan Sydney and the Hunter and Illawarra areas. The Co-worker Program provides emotional and practical support to HIV positive people, their families, carers and significant others from a range of cultural backgrounds.

The Co-worker Program matches people from the same cultures, one to one. While language may be one of the reasons for this it is more often because people from the same culture can understand the subtle ways in which culture influences a person's response to living with HIV/AIDS. This shared cultural understanding allows for a non judgemental approach to issues that people from different cultures may struggle with.

The issues for people living with HIV/AIDS and their carers are generally the same whatever the cultural background. Fear, loss, confidentiality, grief, physical symptoms, mortality and anger are the same whether you are Anglo, Vietnamese or Spanish.

However there are also issues related to a particular community's attitude towards HIV/AIDS. For instance, an HIV positive Arabic man may fear that his family will be stigmatised and isolated by their community. An Arabic carer, who understands the subtle ways in which a community can isolate individuals at a time when they feel they need to belong, may be drawn into the cloak of secrecy that surrounds the positive person.

In some communities, the stigma of HIV can undermine a person's ability to grieve. In Greek culture, grieving is a public ritual, supported by the whole community. It is often difficult for Greek families to explain a son's death from AIDS and seek the support of the community that they would normally rely on in times of crisis.

In both these examples, the co-worker may be the only person the family feels they can talk to about their experience. These examples also illustrate the profound isolation that the

co-worker can experience when caring for a person with HIV/AIDS. This isolation can be magnified because the co-worker may not be able to get the traditional forms of support, (such as attending a funeral) if they come from the same community.

In the gay community, caring for someone with HIV/AIDS is a valued contribution that is recognised on a community level, but in some communities, the fear of stigma may mean that the co-worker's contribution to the care of a person with HIV/AIDS cannot be publicly acknowledged. The Multicultural HIV/AIDS Service recognises this as one of the major issues for co-workers and provides counselling support.

The Multicultural HIV/AIDS Service is always keen to recruit people with experience from different cultures who are committed to HIV/AIDS work. A large pool of Co-workers will protect all of them against burn-out.

If you feel that you have something to offer, or if you would like the support of a Co-worker, contact Peter Todaro on 9515 3098.

**- Maria Petrohilos, Effie Katsaros & Gianni Mazzantini (Multicultural HIV/AIDS Support and Education Service), and Patrick McGee (HIV Services Access Project, AFAO)**

# Patricia Loves Ken

*People with dementia need 24 hour care because although physically they may be well, they can't take care of themselves. Patricia did all she could to make sure Ken was properly cared for, but he went missing for three days and died alone. Their story highlights the urgent need for adequate dementia care facilities.*

I MET KEN SIX YEARS BEFORE HE died. When I met him I knew he was HIV positive, and despite people around me warning me against getting involved, I really fell in love with him. There were a lot of problems in our relationship, but I was very committed. I've remained HIV negative.

As his health deteriorated, I think he gave up on trying to recover from the serious drug problem that he had; he lost hope. He would start to be quite stable and then he would get physically ill, and say "I'm just going to die in a year so what's the point of trying to stay clean?" But drug use in his case, because he didn't have a job and he used quite heavily, meant he turned to crime and then he would end up going to gaol.

He was serving a six month gaol sentence and about a month after he'd been in gaol he rang me one day, and I knew by the way he was talking that he had started to dement. It had never occurred to me that that could happen. I felt very anxious about this, so I spoke to his doctors, and he was taken over to the Prince Henry Annexe, (which is part of Long Bay Gaol) for an assessment.

They diagnosed him as being in the early stages of HIV dementia. He was sent back to the HIV unit in gaol, but they couldn't manage him there and he was put in the psychiatric ward at Long Bay.

I didn't know how he was being looked after. There were some well meaning people, but they

didn't seem to have a very good grasp of dementia. I had a contact in the prison hospital system who said that the prison psychiatrist thought that Ken was just making everything up, that he wasn't dementing. I was disturbed about that because I felt that he would not be very well treated if they believed that.

The time was coming close to his release, and I had been talking to the doctors at Prince Henry and I told them that I was concerned about his wellbeing at Long Bay. So they negotiated to get him over to the Annexe, and the last six weeks of his sentence were to be spent there.

That was a great relief, because I knew he would have people to talk to, he wouldn't be isolated. He needed that stimulation and contact with people. He was a lot happier. He actually started to stabilise. That was the thing that I noticed, that the more stressed he became, the more delusional he became, and that was certainly happening in Long Bay.

His family and I knew that the moment he got released, he was going to be out looking for drugs and I felt that because of his demented state anything could happen. The reality was that he was not only a risk to himself, but he was a risk to others. It was a good weapon to use, in a way, to make sure that he was protected.

I spent a lot of time talking to the doctors about the possibility of public guardianship. The social

worker, Anthony, was very helpful and he supported me, but it took a long time. It was coming up to the time that Ken was about to be released before the doctors finally agreed to put in a submission (which can't go in without a doctor's signature) to the Guardianship Board.

Then there was discussion about, suppose he does get guardianship, where's he going to go? There was a house available, run by Sister Margaret Spencer. She supported the application, all that needed to happen was for the Department to guarantee funding for Ken's care.

We ended up having the guardianship hearing the night before his release from gaol and Ken was given a Public Guardian.

The doctors said that they would support him going on to the Marks ward at Prince Henry while we were waiting for the money to come through to Sister Margaret. I wasn't happy with him just being on the ward as I knew he would leave, so they asked the Department of Health to pay for him to be 'specialled' 24 hours a day. This meant that an agency nurse would be with him all the time and never let him out of sight. The understanding was that this would be a matter of a few weeks, a short time.

Once Ken realised the situation, he wasn't very happy. [although he had consented to it]. He became quite annoyed with me and

with everybody else. He referred to the ward as maximum ward.

The agency nurses, a lot of them didn't have any HIV experience or psychiatric experience, so it was pretty tough for them and it was very tough for the ward. We needed to get him into Margaret's place as soon as possible.

It was explained to Ken that he was going to a house. Anthony was ringing the Department of Health every couple of days and they were saying, "we're doing what we can". It dragged on and on and Ken started to deteriorate physically very badly. I think part of that was because he was having two different carers a day, people that he didn't know, and he couldn't understand why he was in a hospital with people who were dying. It was not the right place for him to be. The staff were wonderful, but it was not appropriate for someone who was demented.

After a few weeks he couldn't dress himself, he couldn't feed himself properly, he became very disoriented and didn't know where his room was, he'd be bumping into things.

We were feeling pretty desperate - six weeks had come and gone, and still nothing from the Health Department. Everybody was feeling really stretched about it. His family and I were very distressed by Ken's rapid deterioration, and the fact that he kept saying to us, "when am I going to my house?" He thought it was never going to happen.

He didn't make any attempt to leave. I think he was actually quite frightened. I think he became really aware that he couldn't look after himself. Sometimes we would walk to the hospital entrance together and he would

take my hand and ask to go back to his room.

So he seemed to be quite safe.

The time dragged on and it was seven weeks, still we heard nothing. Then a couple of people from his past turned up and when he saw them he became really agitated. They reminded him that he wasn't free to do what he liked, and have access to drug using or that sort of lifestyle.

They were telling him that they were going to get him out of there. His mother and I explained to

away for some time, so I knew that these people were really agitating him.

That was the Sunday. I saw him on the Monday morning and spent quite a bit of time with him. I worked back that night and got home about eight o'clock and there was a phone call saying Ken had disappeared and the nurses were searching for him.

He couldn't walk very far without becoming very winded and having to rest, so I couldn't understand why he hadn't been found quickly. I rang his mother and said if he wasn't found during the night, I'd go down there as soon as the sun came up and search the grounds.

I rang at five o'clock in the morning and there was no sign of him, so I met her there and we searched for several hours.

There had been a report the night before that someone that looked a bit like him had been seen about a kilometre away from the hospital. I knew he couldn't have walked that distance, there was just no way.

But we got the address and went round there. I took a photo of Ken and the woman took one look and said yes it was definitely him. About half an hour after he'd left the hospital, he'd

knocked on the door. He wanted a taxi, so she went to ring a taxi and when she came back he'd gone. She thought he looked very ill, so she rang the police and they had actually looked in the area.

We spent three days trying to find him. A number of people were searching in different locations. It was really the worst experience I've ever had in my life.

At four o'clock Thursday afternoon two police arrived at the door. They said, "We've found Ken, and



GRAPHIC: KAREN VANCE

them that he was under guardianship, and that he was going to move into a house. Every time he'd see them he'd get into a terrible state, but we had no way of stopping that.

They'd been visiting him over three days and he took off. He was found a couple of hours later, he'd gone to sleep in a room upstairs. The nurse who was with him was distressed that he had let Ken out of his sight. He hadn't tried to get

he's deceased". I was very calm about it, I guess I sort of knew. Two little boys had been looking for tadpoles, and they found him. He was found in urban bush, two streets away from the place where he'd knocked on the door.

It was just an overwhelming relief for me that he had been found. I was in shock for a long time, but it was not long before I started to feel really angry.

The support that I had in terms of my distress and grief was fantastic, but the support that I had in terms of the seriousness of this case, and any sort of investigation, has just been appalling. I think that has really exacerbated the trauma of it all.

I wrote to the State Coroner, saying that I was very concerned about the circumstances surrounding Ken's death, I wanted it investigated. I got a letter back saying they would investigate.

I thought that would automatically mean there would be a coronial inquiry, but a year after Ken's death I got a letter from the Coroner stating that there would not be an inquiry in this case. I had a month in which to present new evidence giving good reason for them to change their position.

I was devastated because I believed at least, if there could be a public investigation, maybe it would not happen to anyone else.

Maybe there would start to be some proper care facilities and maybe Ken's death wouldn't have been in vain. I got together a number of people who felt strongly about it and various AIDS organisations and positive people put in very strong submissions.

I got a letter dated the day before all our submissions were due in, saying that there would not be a further inquiry. I felt that the Coroner had made up his mind, even before he had read those final submissions.

A solicitor suggested that we mount a Supreme Court challenge to the Coroner's decision, but I didn't feel up to it and I also wondered if we were successful and there was an inquiry, how was I going to be treated by the Coroner, being this person that had already made all these waves? As much as supposedly we're all equal under the law, it didn't feel like that. And it didn't seem like Ken was very equal under the law. If he'd had a different background, would it have been different? If he hadn't been in gaol, if he hadn't been a drug user, would it have been different?

The matter was referred on to the Health Care Complaints Commission and eighteen months later we're still waiting for their findings.

I think it was a week after Ken died, a working party was set up to look into AIDS dementia. Nobody said the two things were linked, but it seemed pretty obvious to me. Six months after he died \$2 million was dedicated by the Minister for specialist services for people with hiv dementia. As far as I understand, that money's yet to be spent. It's two and a half years since Ken's death and I don't see that anything has changed in terms of appropriate facilities for people with AIDS dementia.

*Interview by Jill Sergeant*

*The Guardianship Board is a legal tribunal which appoints guardians for people over the age of 16 who are incapable of making their own decisions and need a legally appointed substitute decision maker. If it's not appropriate to appoint a family member or friend as guardian, the board will appoint a Public Guardian, as in Ken's case.*

*The Public Guardian may make decisions on behalf of the person in areas such as accomodation, treatment or services. The Public Guardian may liase with friends and family. For more info call the Guardianship Board on 9555 8500.*

*For an update on dementia care see news, page 4*

## PLWH/A (NSW) Inc would like to THANK

*the following volunteers and friends who worked during Mardi Gras for us on the Festival Launch, Fair Day, Swimming Carnival, our Parade Float, & the Time-out Rooms at the Party*

*Ben Rabone, Daphne Pothin, Gavin Atkins, Ian Laney, Jill Kristie, Kim Gottlieb, Sandy Thompson, Andrew Pearse, Sasha Dunn, Zara Thompson, Tim Dawling, Larry Wellings, Gary Dawson, Ted Swab, Gary Keogh, Kri Leitner, Chris Blyton, David Jobling, Georgina Dunn, Marcus Nickinson, Whisky Warburton, Ken Irvine, Norman East, Mark Doyle, Jaimie Ayo, Steve Loneragan, Laura Jordan, Marti Harris, Howard Barker, Peter Gordon, Michael Jones, Brendon Williamson, Jo Watson, Janine Strahfeldt, Em Owen, Alison Cunningham, Cath Wadling*

*Also Special Thanks to Liz Andrews at Oggie Haircutters, Bob Moori at The Piercing Urge, C. Moore Hardy at Star Fish Studios, Steel Dingo, The Sun Dial Tanning, Bayswater Fitness, Ken Holmes at Aussie Boys plus Mark Goggin, Gary Leeson, Katrina Martin, Bruno Bouchet, Nigel Calcutt at Sydney Gay & Lesbian Mardi Gras*

# Care for yourself

*Being a carer can be difficult and demanding. The emotional and physical load is high. Looking after yourself improves your chance of being a carer for longer and helps you avoid burn out. This article is based on information in the Community Support Network (CSN) carer training manual and various other sources.*

## Some warning signs of burnout:

- ▶ Physical and emotional exhaustion;
- ▶ You're feeling irritable, withdrawn, sensitive to criticism, frustrated;
- ▶ Loss of idealism, energy and purpose;
- ▶ You have no free time to yourself;
- ▶ Relationships with family, partner and friends are suffering;
- ▶ You feel you cannot say no; but
- ▶ No matter how much you do you feel it's not enough – or not good enough.
- ▶ You have physical and emotional signs of stress – headaches, sleeping problems, muscle aches, get sick easily;
- ▶ You're feeling anxious, angry, guilty, lonely and depressed.

If you experience any of these feelings, take it as a signal that you need time out and support. Burnout is not a sign of weakness, nor does it mean the end of your ability to care. You can do something about it!

## What you can do

▶ Don't be a super carer. It's a strength to know your limits. Although you might be enthusiastic, committed, and think you have to meet enormous needs, you'll be more effective if you pace yourself. If you try and do too much at once, you risk burning out.

▶ Find out what resources are available to help you care for the person. If you're a friend or family of the person you're caring for, it's easy to get isolated. There are services which can help with some of the hands-on stuff call your local AIDS council, PLWHA or HIV/AIDS group to find out what's available (or look in *Contacts* – the latest edition is out now!).

▶ Keep healthy physically and emotionally. Exercise, relaxation and eating well are all ways of maintaining good health. Meditation, yoga, the gym, swimming are a all good ways to relax.

▶ Some people find their spiritual practice is a great source of strength at this time.

▶ Try to avoid getting run down. When you are run down the quality of the care you give may be less than you want to give. It's better to take a break, reassess your commitments and return fresh than continue caring when you feel tired and stressed. It's fine to take breaks, especially if you have something stressful going on in your own life.

▶ Get support. CSN have support groups for their carers. If you live in inner Sydney you can drop in to the Tree of Hope (See below).



GRAPHIC: KAREN VANCE

Elsewhere, contact the local AIDS Council or HIV/AIDS group for information about where to find support (Contacts again!). Support groups are a place where you can talk openly about the problems you face as a carer, and where you can give support to other carers.

◆ If there are no support groups available, find someone you can talk to who you can trust to keep things confidential and who won't judge you or the person you're caring for. It may be family, a friend, or perhaps a health professional involved in caring for the same person.

◆ If you can afford it, you could pay to see a professional counsellor (in some cases you can get a medicare or health fund rebate).

◆ Keep your sense of humour!

### Further reading

*When someone you know has AIDS. A Practical Guide.* By L. Martinelli & P. Peltz, Crown Publishers, 1987.

*The caregiver's journey. When you love someone with AIDS.* By M. Pohl, D. Kay & D. Taft, Harper Colins, 1991.

*The AIDS caregivers handbook.* By T. Edison, St Martin's Press, 1988.



## Net care

THE CAREGIVERS' EMAIL EXCHANGE List is an Email discussion group to support people who are caring or have cared for someone with AIDS. The list manager, Ben Gardiner, describes the list as "a place of light and hope, in a situation that calls for emotional strength and optimism that is both positive and realistic".

The list is confidential. To subscribe, you will need to provide your full, real name but this will only be seen by the list manager. To subscribe or for more info, Email Ben at <ben@sibyllineof-books.com>. The archive of messages can be read on the web page <<http://aidsinfobbs.org>>.

# Changing Roles for people who care

## *A positive perspective from Kim Gotlieb*

TRADITIONALLY, CARING WAS about specific roles for client/patient and carer. Providing support for PLWHs in these changing times calls for softer edges around these roles and a need to develop more heart-centred approaches to caring. The following are some of the strategies which I have found helpful on both sides of the caring relationship.

◆ When you make contact with your friend, be sure you have enough time to engage in general conversation, before lurching into "And how are you really?". When you focus your caring on their illness you are strengthening the burden of identifying as Mr. HIV.

◆ If they are disabled in some way, or perhaps generally weak, negotiate in your own mind around when to intervene and do something, e.g. move the teacup

or open the door. In situations where it is not obvious to you, develop the willingness to ask questions like "Shall I open the door?" or, "would it be helpful to move that pillow?"

◆ On the other hand, be careful not to 'pester' your friend with too many questions - you end up unwittingly being a very demanding helper.

◆ Most of us want to live a normal life (whatever that is) so trying to treat your friend normally will be helpful. Talk about your own life, it can be quite draining when all the focus is on them. On the other hand, be sensitive to the appropriateness of this. Some may feel great pain and resentment hearing about others doing things which they are unable to do. Being tuned in to feedback can avoid problems in this area.

◆ There is a view which relates to Process Oriented Psychology (developed by Arnold Mindell) that the more present you can be

with everything that is happening for you, the more helpful that can be for your friend. This differs from the theory about not having any agenda and just being there for your friend. So I encourage people to talk about their feelings and their limitations, and their lives away from the friend they care about.

◆ Be willing to be uncomfortable. It is more comfortable to presume that someone would like a drink, or a baked dinner - than to risk offering it, and be told no. Develop a willingness to feel awkward or embarrassed in these situations. Most PLWHAS have to learn to get used to this emotional terrain - so should you.

◆ Don't offer more than you genuinely want to give, except in extreme situations. Sit down with yourself and decide what you are willing to offer. Everyone wants to be a supportive person, but some do not have the time or disposition to do this well. If you say you'll call, make

sure you do. We often say nice things we don't really mean in order to feel good about ourselves. It can be experienced as quite hurtful to the person you intended to be nice to when you renege on an initiative.

▶ If someone is depressed and you just hang out with their depression, they are likely to get more depressed – as opposed to suggesting a car ride or getting a video.

▶ Support them in whatever way works for them. Ask questions and notice feedback.

▶ The most important tool you bring with you is a spaciousness around being of service to your

friend. Do not ring and ask how they are when you know that you have three children around you and have to go out in five minutes – unless you state that clearly upfront.

▶ Clearly there are huge changes in life expectancy and general well being experienced by many PLWHS due to new drug strategies. The focus of the carer must therefore adapt from what might have been medical/symptom-based issues to more emotional, psycho-social concerns. For example, it is very difficult for some of us to deal with adapting to a life which now, has a future!

▶ Have someone else to talk to about your caring relationship. They can offer another point of view when problems arise, help you debrief around difficult situations e.g. progression or moodiness. It is often good to talk out difficulties in your relationship with your friend, sometimes it is better to take it on the chin – and go elsewhere to deal with your emotional difficulties. When your friend is pissed off with everything, he may express it in a less than caring way. It can be useful to develop the ability to make space for that without becoming a martyr or a doormat.



### *The Tree of Hope* 9698 3161

ONE OF AESOP'S FABLES GOES something like this: An oak tree which hung over the bank of a river, was blown down by a violent windstorm. As it was carried along by the river, one of its branches brushed against a reed which grew along the shore.

The oak was filled with admiration and could not help asking the reed how he came to stand so erect and undamaged after such a severe storm, one that had torn the oak tree up by its roots "There is no great secret in this", replied the reed. "I secure myself by a conduct which is the reverse of yours. Instead of being stiff and unyielding, and being proud of my strength, I yield and bend to the winds. I let the storm pass over me, knowing how fruitless it would be to resist".

THE TREE OF HOPE IS A DROP-IN centre for carers who look after PLWHA. Here you will find people who are able to listen to you, when you need to talk about how it is for *you*, caring for some one you love. Here you can experience the support you need:

▶ support from those who have an experience of caring for loved ones;

▶ being listened to with respect;

▶ where you can learn ways of dealing with stress and tension;

▶ where you will be encouraged to be in touch with your inner and spiritual self;

▶ where you will be encouraged to state what your needs are;

▶ where you will find a space to relax and be re-created by the peaceful surroundings.

The Tree of Hope is staffed by trained volunteers, and is a service of Centacare.

Another part of our service is to visit PLWHA at home to offer pastoral care and to help people to be in touch with their own spirituality.

We are situated within the grounds of St Patrick's Business College, on the corner of Riley and Devonshire St, Surry Hills. The 301 bus from Circular Quay stops at the gate, or walk up from Central Station.

### Spiritual support

*Joe met Sister Margaret Mines during a visit to St Vincent's Hospital.*

SISTER MARGARET HAS BEEN coming every week, giving me support, also helping me to feel I'm not alone and she has become a good, trusting friend. She listens very carefully to your cry for help, and yet she's not pushing religion at you, unless you ask for it. But no discrimination at all. She still cares about you all the same.

Sister Margaret has been working extremely hard for her new drop-in centre "The Tree of Hope".

Sr. Margaret also provides counselling for families, friends, lovers. Once you meet Sister Margaret you could not help liking her. I would like to say often I have been very low, but I talked to Sister instead of my family, and I know that Sister listens to you and does not judge you. I could not wish for a better friend, because she is one of a kind, very special.



# PRIDE

Calling all Positive people interested in performing on stage!

No this isn't for another 'nude revue', it's to present work created by PLWHA as part of the PRIDE HIV/AIDS Community Development Project.

The work is coordinated by David Paul Jobling and the performance will happen in April.

Men and women willing to strut your stuff on a strategic stage (singers, actors, dancers, acrobats, snake charmers .....) contact either:

DPJ on 9560 2608 or [djobling@ozemail.com.au](mailto:djobling@ozemail.com.au)  
or Paul Canning on 9331 1333 or  
[pride@geko.net.au](mailto:pride@geko.net.au)

by March 20 at the latest



## Talkabout Contacts

the directory of services for people living with HIV/AIDS, their friends, carers & support services

Updated &  
Revised  
February 1997 Edition  
Out Now!

Look for the GREEN COVER at a venue where you pick up your copy of Talkabout

## Vitamin A Cream for Kaposi's Sarcoma

- ◆ Taylor Square Private Clinic is studying an investigational vitamin A derivative (cisretinoic acid) as treatment for Kaposi's sarcoma (KS) skin lesions.
- ◆ Early published work has shown a response in 30% of people with KS, reducing the size and number of skin lesions without causing the side effects of chemotherapy or radiotherapy commonly used.
- ◆ Treatment is with active cream or a placebo for 12 weeks. Everyone then receives the active treatment (or earlier if the lesions enlarge).
- ◆ Clinic visits are every four weeks and payment is made to cover your incidental costs.
- ◆ For further information contact Margaret Slade RN or Neil Bodsworth at

## Review



### The carer's kit

*Carer Support - Practical information on caring at home.* Published by the Commonwealth Department of Health, Housing and Community Services, 1993 with more recent inserts. The kit is currently under review and may be updated.

Each kit contains:

- a Directory of Services;
- a series of fact sheets about particular disabilities, including AIDS and dementia, and about issues for carers;
- a booklet - How to Care Safely at Home
- an Emergency Care Plan;
- a cassette tape - Carers Talk and Carer's Relaxation.

### Directory

In her introductory "Letter to Carers", the Executive Director of the Carers Association of NSW defines a carer as "... a spouse/partner, parent, daughter, son, other relative or friend who has accepted the responsibility of caring for someone of any age with a disability or chronic illness." What about carers from organisations like Community Support Network (CSN) or other community groups that provide carers who may not have a friendship with the person for whom they are caring?

Sections of particular interest to carers of PLWHA are Children's Services, Community Nursing and Palliative Care, Counselling, Food Services, Home Maintenance and Modification, Respite Care

and Transport. The Directory I reviewed does not list services relating to particular disabilities except Carer Support Groups and here there is no listing for HIV/AIDS.

There are 16 regional editions of the Directory, so make sure you have the copy that's relevant to your area.



### Fact sheets

#### AIDS

This is really about HIV and AIDS as the information is relevant to both. There is a brief description of AIDS and answers to a few basic questions and misgivings. There is a section dealing with the importance of taking time off, maintaining outside contacts, seeking help early and talking about grief, anger, fear and depression.

#### Looking after yourself

This important concept is a recurring theme. The Fact Sheet

warns against carer burn-out and stress-related illness and depression caused by isolation. The importance of seeking help early is highlighted. There is a list of tips to successful caring and a summary of your rights.

A number of other sheets contain useful information about getting government allowances and benefits, respite care, medications, legal advice and arranging funerals.

The Emergency Plan, the booklet about safety, and the tape are helpful and practical.

The Emergency Plan will assist you to plan for any unforeseen circumstance that would prevent you from caring.

The booklet helps identify unsafe areas at home that may lead to accidents or reduce quality of life.

Listening to Carers Talk you will realise that there are many people in a similar situation to yours. Other carers will tell you how not to feel guilty about asking for help, how to accept your limitations and will encourage you to go on holidays and to the movies. "Taking a break is like drinking water in the desert."

The relaxation 'exercise' provides a rejuvenating break whenever you need one.

Carer Support is useful for anyone looking after someone with HIV or AIDS at home, either full or part time. CSN carers should be familiar with much of the material though the kit will still be useful for them.

To get a copy of the Carer Support Kit, call 1 800 817 023.

- David Urquhart



## How to put a pulse in your life

*As a carnivorous carer, you may suddenly find yourself with a vegetarian client. What to do? Most vegetarians are well informed about their dietary needs, but this article by Alison Andrews may be helpful to both of you. And to start you off, there are some vego recipes.*

LONG GONE ARE THE DAYS WHEN a meat pie and tomato sauce made up the majority of Australian lunch boxes. Today the latest figures from the Vegetarian Society suggest that approximately 5% of the population are now Lacto-ovo vegetarians and 1% of these are true Vegans. However about 15% of us opt for vegetarian choices (i.e. no red meat, poultry or fish) when we go out for a meal. Many people are concerned with the adequacy of plant based diets but with some knowledge and knowhow, vegetarian diets are consistent with good nutrition and can provide health benefits and other advantages. With reference to positive people however there are a number of key issues to bear in mind.

### Energy

Because most plant foods contain more water and fibre and less fat than foods of animal origin, vegetarian diets are usually less energy dense (i.e. low in calories per serving). This may cause a problem if you are trying to maintain or gain weight. If this is the case, you will need to eat more of the energy dense vegetarian foods, i.e. foods that are relatively high in calories, such as nuts, eggs and dairy produce. However, some of these foods can be high in fat so choose carefully!

### Protein

Protein foods should form a moderate part of the diet. Most of us consume at least twice as much protein as we actually need. Animal proteins are the best sources as they contain all the essential amino acids in sufficient amounts for human requirements. Plant proteins also contain all the essential amino acids but in varying amounts. Therefore it is necessary to combine different plant groups to provide the correct balance of all these amino acids, e.g. baked beans on toast, corn tacos and beans. These can be further supplemented by adding dairy

produce and eggs. If you are sick, recovering from illness or trying to gain weight it is advisable to increase your protein intake.

### Fat

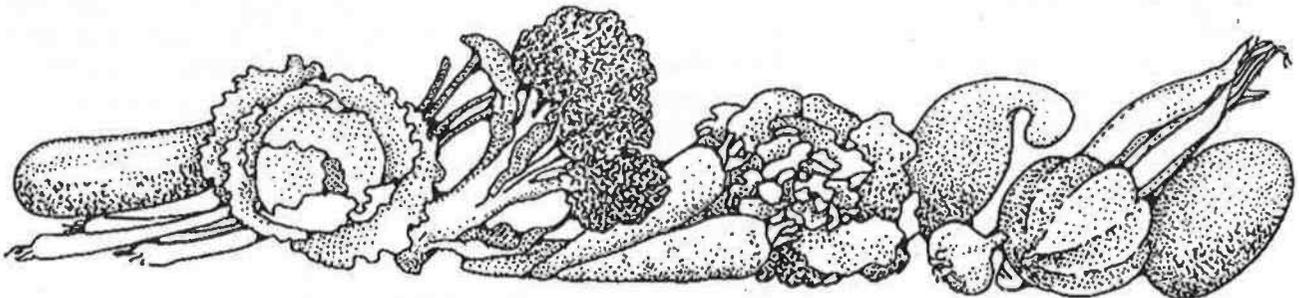
Vegetarian diets tend to be low in fat, as long as there is not an excessive use of whole milk products, nuts and vegetable oils. A lower fat diet is recommended if you have chronic diarrhoea.

### Fibre

Whole high fibre diets are recommended and most vegetarians usually meet dietary fibre recommendations. Fibre adds bulk to the diet, so it may be necessary to replace some high fibre products with more refined cereal products (e.g. white bread instead of whole-meal bread) or by increasing intake of energy-dense foods. High fibre foods may also make any diarrhoea worse.

### Vitamins

Most vegetarians generally have higher intakes of vitamins than omnivores and lacto-ovo vegetarians do not systematically lack any particular vitamin in their diet. A varied diet remains the most consistent way or ensuring you have enough vitamins. Vitamin B12 is



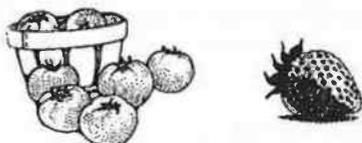
only found in foods of animal origin so if you are a vegan a B12 supplement will probably be required.

### Minerals

The iron found in plant foods, eggs and milk is in an inorganic form and is absorbed from the intestine at a much lower rate than the iron in animal flesh. Absorption of inorganic iron can be increased by eating iron-rich vegetables with foods containing vitamin C, and/or protein. Some HIV drugs such as AZT can increase the likelihood of iron deficiency anaemia so be aware of good vegetarian sources, e.g. wholemeal bread and wholegrain cereals, nuts, dark green leafy vegetables and legumes. Zinc is important for the immune system and is similar to iron in that animal foods are the richest sources. The best vegetarian sources are whole-grain breads and cereals, dairy produce and nuts.

As with all HIV positive people, it may be advisable to take a multi vitamin and mineral preparation as well as having a varied diet. See your dietitian if you have any queries.

*Alison Andrews is a Dietitian at the Albion Street Centre.*



### Glossary

**Lacto-ovo vegetarian** - Does not eat meat, poultry or fish but eats eggs and dairy produce.

**Lacto vegetarian** - Does not eat meat, poultry, fish or eggs but eats dairy produce.

**Vegan** - Only eats plant foods.

**Legumes** - Sometimes called Pulses, these are beans, Peas and Lentils.

**Amino Acids** - These are the basic units of all Proteins

**Omnivores** - No restrictions in the diet.

### Herbed ratatouille with pasta

Sauce can be made a day ahead. Serves two.

- 1 teaspoon olive oil
- 1 clove garlic, crushed
- 1 onion, chopped
- 1 eggplant, chopped
- 4 zucchini, chopped
- 1 green pepper, chopped
- 2 tomatoes, chopped
- 1 tablespoon dry red wine
- 1 tablespoon no-added-salt tomato paste
- 1 tablespoon chopped fresh basil
- 300g pasta

Heat oil in non-stick pan, add garlic and onion, cook until soft. Stir in eggplant, cook until eggplant is soft, remove from pan; drain on absorbent paper. Cook zucchini and pepper separately, following same method as eggplant. Return vegetables to pan with tomatoes, wine, tomato paste and basil. Cook for five minutes or until mixture is heated through.

Add pasta to large pan of boiling water, boil uncovered until just tender, drain. Serve with ratatouille.

### Spinach marjoram crepes

Crepes can be made two days ahead. Sauce can be made a day ahead. Assemble crepes just before serving

- 1 bunch (40 leaves) English spinach
- 125g reduced fat ricotta cheese
- 2 tablespoons grated parmesan cheese
- 1 teaspoon chopped fresh marjoram

#### Crepes

- 3/4 cup plain flour
- 1 egg white
- 1/3 cup skim milk

#### Sauce

- 1/2 cup skim milk
- 2 teaspoons no-added-salt tomato paste
- 1/4 small vegetable stock cube, crumbled
- 1 bay leaf
- 1 teaspoon plain flour
- 1 teaspoon polyunsaturated margarine

Boil, steam or microwave spinach until tender. Drain on absorbent paper, cool, chop roughly.

Combine spinach, cheeses and marjoram in bowl. Spread crepes with spinach mixture, roll crepes, place in oven-proof dish. Cover, bake in moderate oven for about 20 minutes or until heated through. Serve crepes with sauce.

**Crepes:** Sift flour into bowl, gradually stir in combined egg white and milk to make a smooth batter.

Pour quarter of the batter into heated non-stick crepe pan, cook until lightly browned underneath. Turn crepe, brown on other side. Repeat with remaining batter.

**Sauce:** Combine milk, paste, stock cube and bay leaf in pan, bring to boil. Stir in combined flour and margarine. Stir until sauce boils and thickens, strain, discard bay leaf.

### Lentil soup

Serves four.

- 375g green or red lentils
- 2 medium onions, sliced
- 2 carrots, sliced
- 1 celery stalks, with leaves, sliced
- 1 clove garlic, crushed
- 1 tablespoon dried parsley
- 2 tablespoons olive oil
- 1 tablespoon tomato paste
- 10 - 12 cups of hot water
- vinegar
- salt and pepper

Wash lentils and place in a saucepan. Add all ingredients to saucepan (dissolve tomato paste in half a cup of hot water) except salt, pepper and vinegar.

Bring to boil, cover, reduce heat and simmer for about 1 & 1/4 hours. Add more hot water if required. When cooked add vinegar, salt and pepper to taste. Serve with fresh crusty bread, feta cheese, olives and sardines.

Thanks to the National Heart Foundation for allowing us to reprint these recipes from their low fat cookery books.

# Talkabout

## WHERE WE SPEAK FOR OURSELVES Join PLWH/A in the fight against AIDS! Subscribe now!

PLWH/A (NSW) Inc. is part of a worldwide movement to empower people with HIV infection, their friends, supporters, family and lovers to live full, creative and meaningful lives free from fear, ignorance and prejudice. Help yourself and others affected by HIV to create a positive, friendly and supportive environment in which we can all live with HIV & AIDS – join PLWH/A.

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Yes! I want to apply for membership of PLWH/A (NSW) Inc. \$2 per year as a:

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# IT'S YOUR LIFE

"...I may be an 'AIDS infected faggot' but when people ask 'would you come back gay or straight', I don't even hesitate. I'm gay and I wouldn't have it any other way...."

*Safe sex is more than "use a condom everytime". It requires an understanding of the risks involved, thinking it through, talking with your partner and coming up with strategies that will work for you.*

# TAKE CHARGE

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LIKE  
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