

No. 55 June 1995

Talkabout

The Newsletter of People Living With HIV/AIDS Inc NSW

◆ Where We Speak for Ourselves ◆



food for thought

PLWH/A News



MAY HAS BEEN A SAD AND DIFFICULT month for PLWH/A, with the death of Andrew Morgan, an early and influential PLWHA Committee member who continued to be involved with *Talkabout*. (He was a prime mover behind the "Positive Sex" issues of 1990 and 1992.) Andrew's death is a great loss to our community. (See Tribute, p8.)

May also saw the deaths of Neil Sanderson, ex-committee member and Graeme Bray, CSN Volunteer Training Officer. While these deaths have had their impact on our work, the committee has also been set back by the resignation of Steven Ford, who has been Convenor since March. Many thanks to Steven for his dedication to the job over the

past few months. Vivienne Munro, as Deputy, is now Acting Convenor.

As mentioned in the May *Talkabout*, portfolios for specific areas of responsibility have been developed. The preliminary allocation of portfolios to Committee members is as follows:

Treatments/trials:

Chris Hordern

Legal: Larry Wellings,

Vivienne Munro

Housing: Bill Rigney

Education/info: Bill,

Adam Davis

Care: Larry, Vivienne

Administration: Adam

Finances: John Garwood

Media: Vivienne

Events: Claude Fabian (staff).

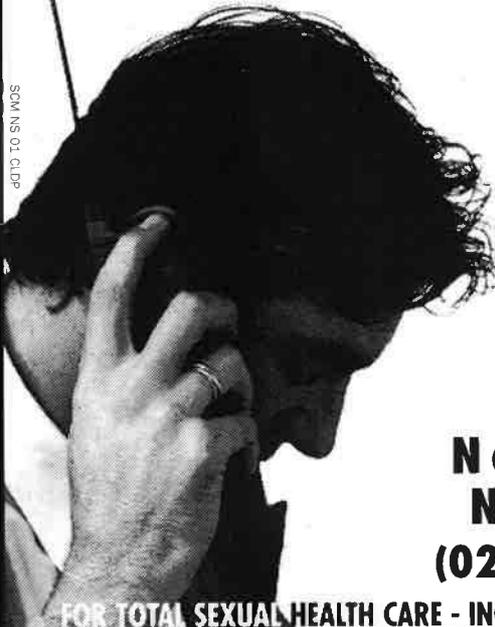
How these will operate is still being discussed. Volunteers are welcome to get involved.

Welcome back to Peter Hornby, who has rejoined the Committee. Peter will be active with the Treatments portfolio and is currently editing *With Complements*.

Notice: David McDiarmid, renowned HIV Positive artist, died on May 25. We hope to publish a Tribute to David in the next issue.

Notice: The August edition of *Talkabout* will be a special issue for people who have just been diagnosed HIV positive. Contributions are welcome.

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PLWHA
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*People Living With HIV/
AIDS Inc. (NSW)*

Current committee

Vivienne Munro: A/ Convenor
John Garwood: Treasurer
Adam Davis: Secretary
Alan Brotherton, Chris Horden,
Peter Hornby, Bill Rigney, Larry
Wellings

Claude Fabian:
A/Coordinator 361 6023
Greg Allen: A/Admin Asst
361 6011

David Wallace: Positive
Speakers Bureau Coordinator
361 6864

Jill Sergeant: *Talkabout*
Editorial Coordinator
361 6750

Fax: 360 3504
Post: Box 831, Darlinghurst
NSW 2010

Office: Suite 5, Level 1,
94 Oxford St, Darlinghurst



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This month's cover

By Phillip McGrath. You don't have to restrict yourself to wishful thinking when it comes to hospital food. Turn to page 20 for some ideas about what can be done. As well as hospital food, this issue takes a look at other foodie subjects, especially from the point of view of the pensioner. Munch on.

Talkabout

Talkabout welcomes unsolicited contributions. However, we cannot accept responsibility for manuscripts and photographs or for material lost or damaged in the post. Letters submitted to *Talkabout* or its editorial coordinator are assumed to be for publication in whole or in part unless specified otherwise. For further information contact Jill Sergeant (Tuesday, Wednesday or Friday). For advertising contact Paul Conning. Send contributions to: PO Box 831 Darlinghurst, NSW 2010.

Deadline for the next issue: June 16

If your venue/organisation is interested in distributing *Talkabout*, contact the editorial coordinator. Call the editorial coordinator on 361 6750 for the date and time of the next Newsletter Working Group meeting.

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Briefs



● Mozambique's Ministry of Health and Red Cross are co-opting traditional healers (curandeiros) into the care of PLWHA. Curandeiros are highly revered community leaders. Few of the country's 16million people have access to health care, with an estimated one doctor for every 50,000. Officially there are only 1,000 confirmed AIDS cases, but experts in the Ministry estimate the number to be more than 10,000. (*Journal of IAPAC*)

● Catholics working on the frontline with HIV/AIDS patients in Zimbabwe are increasingly questioning their church's policies on abortion, euthanasia and contraception. One nun who works with PWA in the capital, Harare, although supporting the church's stand against euthanasia and abortion, described herself as being "in a moral quandary" because she sees the Catholic solution "for people to be in monogamous, loving sexual relationships" as "idealistic — I cannot close my eyes to what I see." HIV infection is estimated at 25% of the sexually active population in Zimbabwe, although rates of 50% have been recorded recently amongst pregnant women attending health clinics. (*The Guardian*)

● HIV/AIDS activists and animal rights activists are at each other's throats in the USA over the use of animals in HIV/AIDS research. High profile group People for the Ethical Treatment of Animals (PETA) is opposed to any research on animals and claims that "everything we know about AIDS came from clinical and in-vitro research, not animal studies. Even assuming that an animal model of AIDS may some day be developed, vaccines for HIV tested on animals stand little chance of proving that these drugs will be effective or even safe for humans." HIV/AIDS organisation the Foundation for Biomedical Research has publicly opposed PETA in ads in the gay press using a quote from PETA's National Director saying that even if animal research resulted in an AIDS cure "we'd be against it." (*LOTL*)

● Indonesia's President Suharto is reported to have told a village meeting late March that, "the acts of leaving and ostracising those who are sick or who carry the HIV virus are not beneficial" and that PLWHA should be regarded as 'heroes'. (*NAB*)

● The U.S. Congress has begun cutting Federal HIV/AIDS money with 'rescissions' from the Ryan White CARE Act and CDC prevention activities. Many PLWHA activists have expressed fears that the new Republican (Conservative) right-wing majority will slash funding for research, prevention and care. (*Newsline*)

● More than 13 million adults are estimated to have become HIV+ in 1994, and 6,000 more sero-convert each day. In the next five years, more than 5 million children will be HIV+. (*The Australian*)

Welcome ...

TO DAVID WALLACE, NEWLY appointed Co-ordinator of PLWH/A's Positive Speakers' Bureau (PSB). David, whose background is in both the commercial and corporate world and alternative therapies (massage and bodywork) plans to get things moving at the PSB.

Although it certainly hasn't stagnated, (with 17 speakers, about 12 more expressions of interest and constant requests for speakers), the PSB has been almost 'on hold' since its launch last December, with PLWH/A staff having to manage it in addition to the thousand and one other things they do. Now, with David settled in and enthusiastic, it should take off. David's initial plans are to organise a training course for new speakers, develop a support system for speakers and promote the PSB — and, of course, the day to day stuff of matching speakers to speaking engagements.

The new training course will probably run over three weekends, with input from existing speakers as well as training in presentation and public speaking skills, and information on relevant issues. Although speakers primarily talk about their personal experience, they often have to field more general questions as well. "I want to make the training as relevant and immediately useful as possible", says David.

Ongoing mutual support is of great importance to speakers, and David plans to set up a speakers' newsletter and perhaps a regular meeting for information and support. He hopes this will be a forum through which speakers can have input into how the PSB functions.

David sees the job as a challenge, particularly as a Positive man. He's keen "to use my knowledge and experience ... in a meaningful way, to be able to put something back into the community, and specifically, to meet the challenges of

raising people's awareness of the issues facing PLWHA."

If you're interested in joining the PSB, call David on 361 6864 or come in and have a chat. He's in the PLWH/A office Wednesdays, Thursdays and Fridays.

Positive Retreats

PLWH/A Inc. (NSW) and the HIV Support Project are pleased to announce that their next Positive Retreat will be held from Monday July 24 to Friday July 28.

For those of you who may be unfamiliar with Positive Retreats, their *primary* aim is to provide a space where HIV Positive people can explore, learn and experience complementary therapies in a non-threatening atmosphere. Positive Retreats provide HIV Positive people with various options and choices that can assist in improving and maintaining quality of life.

They provide the opportunity to meet other HIV Positive people in a relaxed environment which is conducive to building friendships and sharing experiences of living with HIV/AIDS.

Positive Retreats are held at a tranquil and picturesque country location. If you are worried about the winter chill, rest assured the cottages you will be staying in all have open log fires and gas heating so that you will feel comfortable and warm.

You need to be aware that Positive Retreats are not simply a vacation, rather, they are an opportunity to explore complementary therapies at little cost with experienced practitioners.

The cost of the retreat is \$40 unwaged and \$100 waged. This includes all meals, accommodation, transport and therapies.

Please note that all Positive Retreats are strictly recreational drug and alcohol free.

Completed application forms with payment will be handled on a strict first come first serve basis as

places are limited and have filled quickly in the past.

Application forms and information sheets can be obtained by calling Claude Fabian at PLWH/A on 361-6023 Mon-Fri 10am-6pm. See also Positive Retreat ad, p.24.

— **Les Szaraz**

Housing

THE SUPPORTED HOUSING PROJECT, jointly funded by BGF and the Dept. of Housing, is a few bricks closer to opening its doors. Purchase of a property for the ten unit project is underway, and it's hoped that the units will be in use early next year.

The Project will provide permanent housing for people with advanced HIV who can no longer live totally independently, are not eligible for public housing and have no alternative accommodation. The facility will provide physical, practical and social support to residents.

For further information call BGF on 360 9755.

Also on the housing front, about 25 people came to meeting on May 18 to discuss a co-operative housing project for people with HIV and AIDS, using government funding. The meeting was sponsored by PLWH/A, ACON and the Association to Resource Co-operative Housing (ARCH).

Bill Rigney, who holds the PLWH/A Housing Portfolio, felt it was a very successful meeting, as it attracted a number of people who were interested in the project both as future tenants, and as volunteers wanting to develop co-operative housing for PLWHA. The group will continue to meet regularly so as to get the project off the ground. Call the PLWH/A office for details of the next meeting.

Trial talkback

THERE ARE FEW OPPORTUNITIES FOR clinical trial participants to express their views and influence the way

trials are conducted. So make the most of this one: anyone participating in the currently recruiting 3TC trial is being asked to also participate in a social research study conducted by La Trobe University.

The research aims to investigate questions about people's satisfaction with the trial, decision-making that influences what they do on the

trial, and factors that influence their adherence to the trial regime.

The study will have direct benefits for people in future HIV clinical drug trials, since research results will be fed back to the affected communities and organisations conducting the trial as soon as they come to hand.

All people on the 3TC trial are



Sydney remembers our loved ones at the Candlelight Rally and memorial in Sydney on May 14. The gathering of about 13,000 people was addressed by Positive speaker Claude Fabian, who called for Euthanasia law reform, and Health Minister Andrew Refshauge. Photo: Mazz Images.

Briefs



Living on the pension is almost impossible, a meeting called to discuss food assistance, on May 17, was told by community representatives. The meeting discussed a range of difficulties faced by PLWHA, including difficulty paying bills and lack of self respect due to poverty, in addition to having little money for food. The major outcome was that a working group has been set up to address the issue. Anyone is welcome to join this group, which will probably meet on a weekly basis. For more info call Jim Belford, 206 2000 or Michael Glynn, 660 4190. See p. 13 for more info on this issue and p. 24 for a listing of helpful food related resources.

ACON President Bruce Meagher has congratulated NT legislators for their brave step in passing legislation permitting voluntary euthanasia for the terminally ill. ACON expects to put forward a draft Bill for discussion in NSW by the end of June.

The next memorial tree planting at Sydney Park will be Sunday June 25, between 10.30 - 4.30. You are invited to plant a tree for someone you love who has died from an AIDS related illness. Sydney Park is opposite St Peters station at the end of King St. Turn up on the day, or for more info drop a line to PO Box 26, Belmore 2192, or call Mannie de Saxe on 718 1452.

Recently published results from a 1993 International Social Science Survey indicate that Australians are still attached to the 'innocent/guilty victim' stereotype. Only 14% of those surveyed disagreed with the statement that "AIDS sufferers" had only themselves to blame. Blame was most strongly attached to PLWHA who were homosexual, IDU or promiscuous. Most thought that PLWHA should bear a large proportion of the cost of their own treatment. Respondents had similar opinions about people who contracted other 'lifestyle' diseases, such as liver disease from heavy drinking. (*The Canberra Times*)

Several HIV/AIDS associated groups and individuals carried off awards on the glittering Mardi Gras Awards night. Glen Goldsmith (Outstanding Commitment in Addressing HIV/AIDS issues); ACON for their Fair Day stall; Shop Yourself Stupid (Outstanding Community Event) and the Red Ribbon ladies (best small group).

Ian Walker and Trent O'Keefe's TV doco, *Guess Who's Coming To Dinner* won best overall award at the AFAO Media awards on May 23. Other winners included ABC TV's "GP" for best TV drama, SBS reporter Jane Braslin for best current affairs reporting, Barbara Farrelly for best print news and Mazz Images for her photo of Fanny Farquhar at the 1993 Diva Awards. The AFAO Media Awards were created to recognise excellence in covering HIV/AIDS issues in the media.

urged to consider participating in this study. If you are interested, simply tell your doctor, and he or she will give you the information and consent form (with reply paid envelope). On receiving your consent to participate, the researchers will contact you to make the first appointment at a time convenient to you. For more information call me on (03) 9418 6844 or Claire Parson (03) 9418 6909.

— Evan Smith

The family name

CAMP COUNTERAID SUPPORTER AND musical comedy star Jeannie Little has had the last word on the back cover of Sydney writer C.S. Burrough's recently released autobiography *Keeping the Family Name*.

The book, published by PLWH/A (NSW), is available in gay and alternate Sydney bookshops for \$14.95. All proceeds go to PLWH/A. [Yep, that means us].

Jeannie says "In spite of all the hardships C.S. Burrough's life is a rollick, chock a block with glittering and gay adventure. . . . read this book with the compassion it deserves and realise that every life is important!"

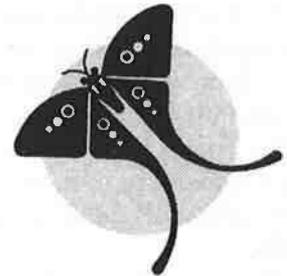
The author, who is openly HIV Positive, says *Family Name* is not a story about AIDS. Says Burrough: "The reason I only mention my diagnosis in passing . . . is that I believe that the virus need not be such an emotionally dominating factor.

"I am hoping that my story will help spread the message within and outside the HIV/gay communities — that we are all unique, we each have a story to tell and it is our birthright to create, play by and enjoy our own rules; that everyone is just as 'normal' as everyone else and just as 'Queer'."

Ankali turns 10

THE ANKALI PRO-ject, a volunteer emotional support network for

PLWHA, celebrated its 10th birthday on May 29 at the Lizard Lounge. Ankali was established in 1985 by three counsellors attached to the Albion Street Centre, Lou McCallum, Jenny Watts and Jim Dykes, and then President of the Gay and Lesbian Counselling Service, Terry Goulden.



The last decade has seen a total of 1,046 volunteers trained, who have provided emotional support to 1,159 people affected by AIDS. As the Ankali Project moves into its 11th year of service, it has a diverse population of 225 committed volunteers, some of whom are living with HIV/AIDS themselves. With a staff of six, the Project also offers some professional counselling services, particularly in the area of grief and loss.

At the ten year mark, the Project remembers all those who have died from AIDS and their loved ones, and is committed to continuing to provide accessible and caring volunteer and professional services.

Oral ganciclovir

ACCESS TO ORAL GANCICLOVIR (SEE *May Talkabout*) is still under a cloud, As *Talkabout* goes to press, a stockpile of 100,000 capsules of the drug, a treatment for CMV retinitis, lie waiting in the warehouse of manufacturer Roche. The drug is to be distributed free, prior to formal approval.

Oral ganciclovir can be used either for maintenance therapy, if you have had CMV retinitis, or for prevention of the disease. Currently, you can get oral ganciclovir for maintenance through the Special

Access Scheme (SAS), but protocols for access to the drug for prophylaxis under SAS or the Clinical Trials Notification Scheme (CTN) are still being developed. In theory, a hospital doctor can apply to Roche for the drug for prophylactic use under the SAS. In practice, no-one currently has access to the drug for this purpose. Getting access via the CTN could take a couple of months, according to CHRN (Community HIV Research Network) Director Don Smith.

Part of the hold up is the protocol approval process by hospital ethics committees; another issue is how to make the drug available through GPs. At present, GPs would only be able to access the drug through liaison with a hospital.

Peter Hornby, a member of the PLWH/A treatments working group, is angry about the delay. "I see access to this drug as at least of equal importance to 3TC access," he says. Hornby suspects that hospitals may not be co-operating with GPs because they want to restrict its access to hospitals on the grounds that that's the best place to monitor the possible severe side effects. "My understanding is that this is not so", he said. "Any competent HIV GP can monitor the use of the drug quite satisfactorily."

If not the hospitals, Hornby suspects Roche of holding up the process, perhaps not wanting to give out too much for free. "In the US the drug is available to every doctor who wants to use it", he says, "what's the difference here?"

Don Smith thinks this is not the case. "Roche don't seem to have any problem with GP access", says Smith. "I think they realise that oral ganciclovir will be licensed in the next year or so and be available to GPs".

Treatments bites

- Australian scientists have dis-

covered how HIV spreads through body cells. A protein called Vpr opens channels from the virus into the cells. It is believed to be responsible for causing HIV to become active in the body after a period of dormancy. If this is the case it offers hope that effective treatments may be developed to target Vpr and prevent HIV infection progressing to AIDS. Vpr is not prone to mutation, which has been a problem for drug development targeting other sites on the virus. (*The Sydney Morning Herald*)

- The 3TC trial is enrolling so rapidly that "Fast' is not the word for it", says CHRN Director Don Smith. Manufacturer Glaxo and community groups will meet on June 1 to discuss compassionate access to the drug.

- Interim results of a US study comparing three different anti-viral therapies in children indicate that AZT alone is less effective than ddI monotherapy or ddI with AZT. Those on AZT alone had more rapid rates of disease progression and a significantly higher rate of side effects. (*BETA*)

- PCP prophylaxis should be started in all infants born to HIV+ mothers, according to new recommendations from the US Centers for Disease Control and Prevention (CDC). Treatment may be stopped at six months if the baby tests negative to HIV. (*BETA*)

- The Kombucha mushroom (actually a combination of yeasts), "cure du jour" in some circles in the US, has recently found its way to Oz. Before you rush out and buy, be aware that the mould which sometimes grows on Kombucha mushrooms may contain a fungus called *Aspergillus*, which can attack the brain and prove fatal. PWA groups in the US are warning people not to use it. (*PWAC NY Newslines*)

- Acyclovir, a treatment for herpes recently thought to also be effective as an antiviral drug, has

come under attack recently. Overseas studies have indicated it may not have much survival benefit after all. Before you chuck out the pills, however, consider that the acyclovir trials in Australia have had quite promising outcomes, so perhaps there are different, local factors at work here. Australia is at the forefront of acyclovir trialling.

- DNCB, the interesting new treatment that gives you a rash, is so popular in Sydney that the only pharmacy (that we know of) that stocks it sold out last month. But (phew!) the bottles, costing \$5.00 each, are now back on the shelves. If you want to chat about your DNCB experiences, there's an opportunity to do so at a regular DNCB support meeting. It's on every Monday at 5.30 in Room 14, lower ground floor, ACON, 9 Commonwealth St, near Whitlam Square.



Participants in the Wollongong Candlelight rally called it a "great success". About 120 people gathered for the memorial in the Wollongong Mall.

Tribute



Andrew Morgan

ANDREW MORGAN DIED ON TUESDAY, May 9, 1995 and with his death the AIDS movement in this country lost one of its greatest heroes. It is difficult to record all of his achievements because the list is enormous. Suffice to say that he was fighting for our rights as HIV Positive people right to the very end of his life.

Andrew began his involvement in the dark days of the mid 1980s when most of us still thought of AIDS as something that was happening elsewhere. In those days there were no AIDS Councils, no PLWHA groups, no health facili-



ties such as Ward 17 and the likes. People with AIDS were being evicted from their homes, sacked from their jobs and treated as pariahs by our health care providers. Ignorance and fear were everywhere and Andrew was one of a

small group of dedicated people who sought to change the system and fight against those injustices.

In a climate that made it all but impossible for people to be open about their HIV status Andrew stood up loudly and proudly and told everyone who wanted to listen that he was HIV positive. Importantly, he was one of the first to exert his rights as an HIV positive person and demand to be included in any decision making process that affected PLWHAs. He firmly believed that only people with HIV could fully understand the complexities of living with a Positive diagnosis and in the importance of their voices being heard. He refused to be merely a client or user of services, rather, he fought for HIV Positive people to be in positions of control and influence.

He was one of the first to enrol as a volunteer for Ankali and CSN. He worked with Terry Giblett in the early days of ACON's HIV Support Groups and facilitated some of those groups, eventually helping to write the Facilitator's Training Manual. He was the HIV Positive person with the first Prisons' Peer Educators Training at Bathurst Gaol and worked again with ACON in their Rural Project. He was the driving force behind the PositHIV Sex poster and postcard campaign and



a participant in other campaigns for HIV Positive people. At different times over the years he was a member of ACTUP, a committee member for PLWH/A (NSW), internal convenor of NAPWA, and an executive member of AFAO.

But Andrew was more than an impressive list of achievements and commitments. He was an amazing man. He was complex and eclectic. When consumed with passion for a particular cause he was a formidable opponent and a fierce ally. He hated being categorised and reinvented himself (and his look) on many occasions just to avoid it.

He was a fierce advocate of women's rights (at times a lesbian wanna be), an occasional drag queen (does anyone remember Texas Chainsaw at the Stonewall rally of '93 [see

Left to right: Texas Chainsaw, a.k.a. Andrew Morgan, at Stonewall '93 (photo: David Urquart); Chris Hoye; Graeme Bray puckers up at the CSN Christmas Party '93 (photo: David Urquart).

photo - EdJ), a fabulous source of gossip and, when he wanted to be, an absolute bitch! Some people loved him and some people hated him, but just about everyone respected him.

AIDS might have lost a hero last Tuesday, but some of us lost one helluva girlfriend. Bye Nat!!

— Mark Hoskins

Chris Hoye

CHRIS HOYE, WHO SPENT THE LAST two years of his life educating school students and community groups about AIDS issues died of AIDS-related causes in March. Chris worked with the Central Coast Sexual Health Services as an outreach worker and program adviser.

Chris was a very brave man. In one year alone he spoke to more than 53 organisations about his experiences of living with HIV, his experiences of caring for his partner Jon who died almost two years ago from AIDS and about the discrimination that is so often found in our society. But he also spoke of the great amount of support and understanding he received from many people.

Chris's work included regular meetings with Kincumber High School's AIDS awareness group headed by teacher Bruce Atcheson.

He lectured about HIV and AIDS at nearly every high school on the Central Coast as well as some in Newcastle, Tamworth and Sydney. "He addressed parent meetings and community gatherings and shrugged off discrimination, because he needed to

help young people survive through spreading his message", says Bruce. "Chris knew he could change the attitude of so many people if he could just talk with them."

Bruce Atcheson and a number of students visited Chris at home three days before his death.

The kids had written a poem for him which they read to him and they gave him a teddy bear. He was pleased to see them. Students will make a quilt panel to add to the international AIDS quilt and the school will dedicate a garden to his memory.

— Sue Edwards & Paul Drielsma

This tribute originally appeared in the *Central Coast Express*.

Graeme John Bray

GRAEME BRAY DIED AT 9.15PM IN Royal Prince Alfred Hospital on Monday, May 8, 1995 after a massive coronary. In true style, he was in the middle of a bowl of pasta. Not unusual since he was known to have, on occasion, at least two lunches a day. He had a huge appetite for life and all the things that it had on offer, on sale and on the side! His passing has left a gap in many people's lives that may never be filled.

The driving force in his life was a deep belief in promoting and supporting independence and choice for all people, which led him into nursing at Royal Adelaide Hospital after leaving school, then on to becoming House Co-ordinator for a residential project for people with developmental disabilities. In 1980 Graeme spent a year in Tokyo where he worked as... wait for it... a jeans model (he was slim once, you know), and where he met Ryosuke, his partner for 14 years. Their desire to share their life together led Graeme to the Gay and Lesbian Immigration Task Force (GLITF). He became convenor of the Force and was instrumental in its long political fight to allow people from overseas to live in this

country with their Australian partners. Many people owe their residency status to the work that Graeme did for them through GLITF.

Graeme joined CSN in September 1989 as Volunteer Training Officer, and was the foundation and guiding force for some 52 of the 97 carer training courses that CSN has run since 1984. Graeme's commitment and enthusiasm for his work were renowned, as was his wicked sense of humour which more often than not dared to push the boundaries of political incorrectness to new heights, much to the delight of his colleagues! One of his claims to fame was being crowned Ms. Bastille '94 at ACON's Ms. Bastille Beauty Pageant in a rather fetching creation some likened to Jean Paul Gaultier at his best. Plastic garbage bins and feather dusters took on new meaning!

At present there are major changes taking place in the Care Housing and Transport Unit of ACON with the aim of improving and extending services to clients. Graeme wholeheartedly embraced the vision and his enthusiasm for change and re-direction was infectious. His constant search for ways to improve CSN's training program helped to develop the peer support model which is now working successfully, in supporting volunteers. This also engendered CSN's Group Facilitator training program.

CSN's volunteer carers loved him. His generosity of spirit, deep concern for people, wisdom about human nature and basic kindness drew people to him. He helped many people to find a new path in their lives and consequently Graeme had a huge circle of friends who in turn supported him through his own difficult times.

Each of the people who knew Graeme have very special memories of him. For them Graeme is just out to lunch. He'll be back any minute now.

— Tess Ziems

Talkback



Inappropriated!

FOUR MONTHS AGO I MOVED TO Sydney in order to access better medical assistance and support. On the two occasions I have had dealings with ACON I have come away disappointed with the lack of understanding, compassion and respect that some on their staff seem to have towards people who access their services.

A support group I joined was that in name only. I don't think my expectations were too great having done a support group and facilitators' training course a number of years before. Haven't times changed!

Some members who came to the group frequently arrived 'stoned' which in itself is not a problem for me. What was a problem for me was when they frequently interrupted others who were talking by giggling and laughing and making inappropriate comments when some of the people were trying to discuss some very personal issues. I assumed that this sort of behaviour was now tolerated as none of the facilitators to my knowledge spoke to these people about their behaviour, and so it continued. This support group lasted six weeks and in the final weeks only two or three people attended. Ce'st la vie!

Of greater concern to me was the occasion when I contacted ACON to find out if they have a list of GPs and specialists who bulk bill. The answer I received was "NO" and from the conversation that followed I got the impression they were not interested in finding this information out for me or anyone else.

Similarly when I approached Ankali about trying to get 'a buddy' (a woman or a man), I was told that the service was available to only those with full blown AIDS!

Do I have to give up work and lay down and practically die before I can access the services of these exclusive 'CLUBS'?

Perhaps our tax dollars would be better spent in addressing some of the more fundamental problems that ACON and other 'support' organisations seem to have within themselves and with their dealing with clients. Instead of sending a delegation to HIV/AIDS conferences in South Africa or Canada, they could perhaps send one person who can pass on this information to others — after all they are conferences and not holidays!

Peter Rawlinson

ACON has a complaints procedure. Anyone who is dissatisfied with their service can speak to the Deputy Director (206 2000) or fill in a form which can be obtained from ACON Reception.

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



**Talkabout, Po Box 831
Darlinghurst 2010**

Olga's Personals

Sydney — HIV+, 42yo bi male, 182cm, 75kg, healthy, outgoing & personable is looking for HIV+ bi/straight woman to share good times and who knows, probably more. I'm easy going, intelligent, hard working and homely. Enjoy travel, dining in/out, country trips and friends. Genuine and honest, expect same. Letter please with phone number. Contact Jeremy, Box 950605

How to respond to an advertisement

- ☞ Write your response letter and seal it in an envelope with a 45c stamp on it
- ☞ Write the Box # in pencil on the outside
- ☞ Place this envelope in a separate envelope and send it to: Olga's Personals, PO Box 831, Darlinghurst NSW 2011 and you can be assured that it will be passed on

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.



Are you interested in learning how to meditate?



ACON MEDITATION GROUP

THE MEDITATION GROUP is now meeting again on a regular basis. Beginners are more than welcome to come along and receive instruction in how to meditate. Just turn up, or if you would like further information phone Claude on 361 6023.

MEETING TIME
6.00 to 7.00 pm Monday evenings

PLACE
AIDS COUNCIL OF NSW
Basement, 9 Commonwealth St, Surry Hills

All hands to the party!

MANY YEARS AGO I ENJOYED the privilege of being able to party with the best of them. Every Friday meant the beginning of long periods of time without sleep, rest, and more often than not, long periods without food. These days however I have failing health and Fridays mean a chance to rest, sleep and relax. And a Mardi Gras Party means time spent in the PLWH/A Time Out Room.

This year I co-ordinated the PLWH/A Time Out Rooms at the Mardi Gras. The rooms were located upstairs in the Horden Pavilion and upstairs in the Royal Hall of Industry (RHI). As a volunteer I donated up to 25 hours a week for a period of seven weeks

prior to the party. It took my contribution together with that of a large number of volunteers, all using their many skills and knowledge of gay and lesbian culture, to operate the Rooms.

This year, as in years past, we created a quiet and comfortable space where PLWHA, our friends and carers, could take some time out from the party. The Time Out Rooms were enjoyed once again by a large number of HIV Positive people. The rooms were mostly used as a place to relax and recharge energies with fabulous fruits and foods and beverages, which this year included nutritional supplement beverages including the highly sought after Fortisip and



Advera. This year the Time Out Rooms allowed hundreds of people the time needed to rest and rejuvenate so that it was possible to rejoin the party and friends later. The rooms were cosy, with comfortable couches and bean bags.

Time Out Rooms will always be needed at such cultural events and have become an important aspect of many of our parties. But each Time Out Room requires approximately 20 volunteers to ensure everything flows smoothly. Without this year's team of volunteers the Rooms at Mardi Gras would not have been possible. Our volunteers set up and operated the Rooms, sought out donations of both goods and services from pri-

vate business, cleaned the rooms constantly throughout the evening and restocked the food and beverages. Then at 10.00 a.m. when the party finished, our volunteers dismantled the Rooms and transported everything back to where it came from.

When the Queen's birthday weekend rolls around in June, it's time for all good Queens to be out partying at the annual Hand in Hand party, a benefit for the AIDS Council of NSW. (This year, it's called The Party.) As usual, PLWH/A will be setting up a Time Out Room at The Party. The bad news is, we don't yet have enough volunteers to staff the rooms. Without your assistance and skills, the future of the Time Out Rooms is threatened.

We need reliable people to volunteer. If you are interested

in doing a two hour shift at The Party, then we want you. Each shift is shared between two people, so consider volunteering with a friend.

Your job will be to make sure people using the room are happy and comfortable, and that foods and beverages are topped up throughout your shift. If you have a bit more time, we also need help to either set up the rooms during the day or pull them down after the party finishes.

Your reward? A nice warm & fuzzy feeling, and a free ticket to the party.

If you can help out on the night, call Greg on 361 6011.

See you at the Time Out Room.

— Andrew

The night Nick kissed **Boy George**

MARCH 4 STARTED OUT LIKE MOST other Saturdays, but for one difference — this was Mardi Gras Saturday. My lover Nicholas and our flatmate Cyprian had some friends over for a pre-Mardi Gras barbecue, which despite the storm clouds that hovered overhead and the occasional drizzle, was a huge success.

After that, it was a mad scurry to get changed into our outfits for the Ankali float and gather suitable clothing (or lack of) for the party afterwards.

The Ankali Project trains volunteers to provide emotional support for people with AIDS, their partners, family members and friends. Nicholas and I joined the Ankali float which boasted a large, brightly coloured butterfly (the well known Ankali icon) and had a really enjoyable time dancing up Oxford Street. If you watched the ABC coverage of the Mardi Gras closely, you will have noticed me on the small screen for about three seconds of fame!

Afterwards, at the party, Nicholas and I did a two hour shift together in the PLWH/A Time Out Room. We were asked to look after a young man who was very ill and had lost the medication that would see him through the night.

During the 12 hour party Mardi Gras usually stages several major spectacular shows and these are quite often attended/performed by overseas or local celebrities. The surprise guest for the 1.00 am show was none other than Boy George. His first song, 'Hare Krishna', was



performed before a truly magnificent backdrop with a smorgasbord of Egyptian dancers.

We watched the whole show from the Time Out Room, which was located high up in the Royal Hall Of Industries. We could see and hear everything without having to endure the crush of the other 19,000 party goers.

After the show had finished Boy George paid an unexpected visit to the Time Out Room, where we were still in the middle of our shift. Here we were, in the same room (which was slightly smaller than an average kitchen). A group of about six people gathered around Boy George to admire and talk with him when all of a sudden Nicholas decided that he simply had to introduce himself to Boy George. He dashed across the room, planted a kiss on Boy George's cheek and said, "Hi, I am Nicholas Gibson, and I have a young man over here

who is quite ill. Would you come and talk to him?"

Without hesitation, Boy George excused himself from the gathering, crossed to the other side of the room and introduced himself firstly to Daniel and then to me and talked to the three of us for at least fifteen minutes. Daniel

looked absolutely amazed by what had just happened, possibly by this stage he had forgotten all about losing his medication. It was one of the rare moments in my life. I will always remember, not so much that I met Boy George, but how it happened, the way that he interrupted what he was doing to meet and talk to somebody less fortunate than himself. Someone who quite possibly might not see another Mardi Gras parade or party.

— Paul R. Maudlin

with **Complements**

JUNE ISSUE:
More on DNCB, Positive
Retreats, Nicky's Kitchen
and more...



Starving to **death?**

*It's pension day tomorrow and boiled rice for dinner tonight.
Sound familiar? Hope is at hand: Michael Glynn
tackles the food crisis.*

"IT'S TEN DAYS SINCE MY LAST PENSION cheque arrived and I've run out of money. I don't know how or what I'm going to do to feed myself for the next few days until my next payment arrives. This afternoon a friend calls and invites me around for dinner with his lover. Once again they've saved me from eating just rice or pasta. Their care and support for me has been literally life-saving and I owe them a debt of gratitude that I can never repay (they don't expect it) but I honour them for their incredible kindness.

"In the past few months food prices seem to have risen dramatically. I can't seem to make ends meet any more. I wonder how I'm going to pay to heat my home this winter. Even with subsidised housing and help from BGF with the utilities I find that every fortnight I'm running out of money. Two years ago I had to have my dog 'put down' when he became sick and I couldn't afford the more than \$1,000 owed to the Vet.

"Any hope of going out to community events, even with the concession prices on offer, is impossible. I feel isolated from the community. I may lose my 21 year old car, which I depend on for shopping and helping other PLWHA, because it seems that this year I may not be able to afford to register it again. This would repre-

sent a significant loss of independence and push my food costs up as there are no supermarkets in the immediate area — just corner shops that charge almost a dollar more for everything.

"The despair of not having enough money to feed myself brings up issues of loss of dignity and pride, of isolation and loneliness. I have no assets to fall back on. If it were not for the kindness and generosity of a few friends I would be totally lost, without hope."

This is the story of many people who are trying to live with HIV/AIDS. For many years I had thought that I was the only one who was suffering but in the past few months I have become aware of others who are living in abject poverty, unable to feed themselves and isolated from the community. The size of the problem is not known. It may well be hundreds.

The Metropolitan Community Church has a Sunday lunch and at least fifty people use the service every week. As well, MCC puts together food parcels of basic items

such as rice, pasta, coffee, tea and other non-perishable goods. The Luncheon Club at the Exchange Hotel on Mondays sees at least 70 people coming every week. The PWA Day Centre, originally known as Maitraya, now run by Eastern Area Health, has seen a drop in numbers since they moved from Bourke Street in Surry Hills to their present location in a laneway behind William Street, halfway between the Cross and the city.

While these three efforts are to be commended it has not stopped the growing seriousness of the



graphics by Simon Clarke

PLWHA food crisis. It is clear that something more needs to be done.

There are many issues involved. Everyone has a problem paying the rent at some point in their lives, even with a full-time job. But to admit to, and try to cope with, the

fact that you can't even feed yourself is a frightening and demoralising confrontation with failure, loss of dignity and utter despair.

Young people who have no life experience, who do not know how

"We are perilously close to seeing people begging on the streets for food money."

to budget, how to shop wisely or how to cook nutritious meals face an almost insurmountable mountain.

Long term survivors use up whatever assets they may have had. There are stories of people selling their furniture and other personal effects in order to pay for food and medicine.

One issue that has not been publicly talked about much is the loss of friends and support networks because a lot of these people have died. In many cases, when you share the fact that you are HIV Positive, or you fall ill, many of your friends simply disappear from your life.

The effect on people's health is devastating. For many years I have held the opinion that my food is my medicine. Even with the most advanced and expensive drugs how can you maintain good health or recover from illness if you cannot provide good nutrition, the basic building block of life?

How has this situation come about? What can we do about it?

Firstly, I believe that the general perception in the community is that we have all these wonderful community organisations to take care of people and as long as we support various fundraisers everything will be right. In many instances a lot of money goes into running these organisations. AIDS activists have criticised the building of bureaucracies and careers at the expense of getting the money to people directly. (I was astounded recently at the amount of money

spent on administrative costs by the AIDS Trust.)

Some people have received rather large Superannuation payouts when they have fallen ill and can no longer work. They decide to spend much of that money on

world trips and other extravagances, thinking they won't be around for too long, not realising of course that they may continue to live for years more than they expected.

Others, quite simply, don't have any assets, or no family and few friends to help and support.

We are perilously close to seeing people begging on the streets for food money.

We need to set up a facility to provide one hot meal seven days a week. We need to provide a discount grocery store where people

can buy food at fifty percent of normal retail cost. We need to provide training in buying and cooking nutritious food. As well, we may be able to set up a program with all of our community organisations so that people can do volunteer work and receive a voucher that entitles them to free food in lieu of payment. This would restore people's dignity and pride, a sense of contributing to the community and not feeling like a 'bludger'. Community organisations would also benefit by having more volunteers.

The food crisis issue should be the highest priority in our community. We can create a better life for ourselves. The challenge is to do it. It could mean the difference between life and death.

Michael Glynn is a community activist, journalist, and photographer. Diagnosed HIVPositive in 1985, he is a long-term survivor who believes passionately in the benefits of combining western medicine with complementary therapies.

Pick one up. Now.



The National AIDS Bulletin.

Australia's leading national AIDS magazine gives you the latest in national and world news, analysis and comment, treatments and legal issues, features, information and reviews — all with a fresh and contemporary approach.

For a free copy and subscription details, write to the National AIDS Bulletin, PO Box H274, Australia Square, Sydney NSW 2000.

Contacts



AIDS Council of NSW (ACON)

**9 Commonwealth St,
Surry Hills
(near Museum Train Station).
Switchboard: 206 2000.**

COMMUNITY SUPPORT NETWORK (CSN) Trained volunteers providing practical home/personal care for people with AIDS. 206 2031.
COUNSELLING Professional counsellors available for anyone living with or affected by HIV/AIDS. Free and confidential service, including: One-to-one counselling; home or hospital visits; telephone counselling. Call 206 2000 for appointment
CSN WESTERN SYDNEY Pat Kennedy 204 2404.

FUN AND ESTEEM WORKSHOPS For gay and bisexual men under the age of 26. Groups in Parramatta, Campbelltown and city. 206 2077.

 **GAY & LESBIAN INJECTING DRUG USE PROJECT (GLID UP).** Outreach, information & referral. We are sensitive to the issues faced by lesbians & gay men who inject drugs. 206 2096.
HIV/AIDS LEGAL CENTRE Legal advice/advocacy on HIV/AIDS related problems. 206 2060.

HIV living

SUPPORT GROUPS give you the chance to meet others with HIV, exchange ideas and make friends. If you'd like to join a group, become a facilitator, or just find out more about them, give us a call on 206 2014.



ACON HOUSING PROJECT We offer help & advice about public housing, in particular: accessing priority housing; transfer; and the special rental subsidy as well as housing discrimination, harassment and homelessness

The Housing Project also has a number of houses and units available to clients who are waiting for public housing. You must

be eligible for priority housing and in the process of applying
Call Arnel or Fred on 206 2043 for an appointment



POSITIVE ASIAN MEN'S PROJECT Looks at the needs of all HIV+ Asian men. Michael Camit. 206 2036 or 206 2090.

 **POSITIVE WOMEN** Individual or group support for and by HIV/AIDS positive woman. Non-judgemental and completely confidential. Women and AIDS Project Officer or Women's HIV Support Officer, 206 2000, TTY for the Deaf 283 2088.

ACON WESTERN SYDNEY 9 Charles St, Parramatta. 204 2400.

ACON ILLAWARRA 129 Kembla St, Wollongong. (042) 26 1163.

ACON MID-NORTH COAST 93 High St, Coffs Harbour. (066) 51 4056.

ACON NORTHERN RIVERS 147 Laurel Ave, Lismore. (066) 22 1555.

ACON HUNTER 13-15 Watt St, Newcastle. (049) 29 3464.

GENERAL AIDS TRUST OF AUSTRALIA 221 2955.
ALBION STREET CENTRE INFORMATION LINE 332 4000.

ASIANS & FRIENDS SYDNEY A social, cultural and support group for gay Asians and their friends, meets every Friday from 7.30-10pm. Gus or Jim (02) 558 0061 a/h.

AUSTRALIAN FEDERATION OF AIDS ORGANISATIONS (AFAO) 231 2111.

AUSTRALIAN NURSES IN AIDS Special interest group for nurses. John Miller 339 1111 or Maggie Tomkins 332 1090.

CIVIL REHABILITATION COMMITTEE Family Support Centre. HIV education and support to families of ex-prisoners and ex-offenders. Joanne Wing 289 2670.

KIDS WITH AIDS (KWAIDS) and parents of KWAIDS. Inquiries c/- Paediatric AIDS Unit, Prince of Wales Hospital, 39 2772.

HANDS ON PROJECT Community based

HIV/AIDS training program for youth workers. 267 6387.

INNERSKILL Needle & syringe exchange, information & referral, also a range of free services for unemployed people. 810 1122.

METROPOLITAN COMMUNITY CHURCH (MCC) 638 3298. MCC Sydney 32 2457.

MULTICULTURAL HIV/AIDS EDUCATION AND SUPPORT PROJECT Workers in 15 languages who provide HIV/AIDS information. Also provides cultural information, training & consultancy. Peter Todaro 516 6395.

NATIONAL AIDS/HIV COUNSELLORS ASSOCIATION Mark Cashman 206 2000.

NATIONAL AUDIO VISUAL ARCHIVE OF PLWA Royce 319 1887 (after 1 pm).

NATIONAL CENTRE IN HIV EPIDEMIOLOGY & CLINICAL RESEARCH 332 4648.

NATIONAL CENTRE FOR HIV SOCIAL RESEARCH (Macquarie Unit). 805 8046.

NATIONAL ASSOCIATION OF PEOPLE LIVING WITH AIDS (NAPWA). Russell Westacott, 231 2111.

NSW ANTI-DISCRIMINATION BOARD Takes complaints of AIDS related discrimination. 318 5400.

NSW USERS AND AIDS ASSOCIATION (NUAA) Community/peer based organisation providing support, referral and advocacy for injecting drug users and their friends. Needle exchange services. 369-3455.

QUILT PROJECT Memorial project for those who have died of AIDS. 360 9422.

SEX WORKERS' OUTREACH PROJECT (SWOP) 212 2600.

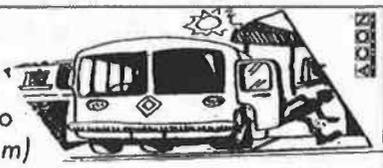
SILK ROAD Social and support group for Asian gay and bisexual men. Meets every Friday. Workshops, discussions, social activities. Arnel 206 2000.

SOCIAL WORKERS IN AIDS (SWAIDS) A special interest group for social workers working with people with HIV/AIDS. Also acts as a lobby group for people affected by HIV/AIDS. Anthony Shembri or Pina Commarano on 661 0111.

SUPPORTING POSITIVE, ASIANS Volunteer group for Asians (men and

Tiffany's Transport 206 2040

Tiffany's provides transport for PLWHA to hospital or clinic appointments. The service operates early morning to early evening, Monday to Friday. For more info, or to make a booking, please call 206 2040. Ask for Monica. (Office open 8am — 3pm)



Sydney Sexual Health Centre

Sydney Hospital
Macquarie St (near
Martin Place Station)
for an appointment
or information
223 7066
*no medicare card required
for recorded information
11646

Services provided:
>STD test, treatment and
information
>HIV/AIDS tests and care
>Hepatitis B tests and vaccinations
>Counselling
>Safe sex information
>Free condoms, dams and lube
>Multicultural information and
interpreter services
>Needle syringe exchange

S.O.P.Y. **SUPPORT OF POSITIVE YOUTH**

SERVING YOUTH LIVING WITH AND/OR AFFECTED BY HIV/AIDS. MALE, FEMALE, GAY, STRAIGHT. WE DON'T DISCRIMINATE

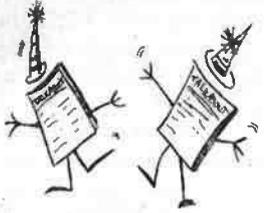
SUPPORT/SOCIAL GROUPS. PHONE BUDDY SYSTEM. FOOD ASSISTANCE. HOUSING ASSISTANCE. NEWSLETTER VOLUNTEERS ALWAYS NEEDED
PH: 318 2023 FAX: 690 1475

TAYLOR SQUARE PRIVATE CLINIC

Dr Robert Finlayson • Dr Ross Price • Dr Mark Robertson
Dr Anna McNulty • Dr Neil Bodsworth • Dr Debbie Couldwell
Fellows of the Australian College of Venerologists
and Dr John Byrne
8am to 8pm Monday to Friday • 10am to 12 noon Saturday
302 Bourke St Darlinghurst
331 6151
Call for appointment • Health Care Card Holders Bulk Billed

Livingstone Road Clinic

We provide HIV/STD testing, treatment, counselling and education in a friendly cottage environment. We provide total confidentiality (medicare cards are not required) and there is easy off street parking.
182 Livingstone Rd, Marrickville
560 3057



Please let us know if you want to update your listing or add a new one!

women) who are positive. Do you need support, info? 206 2036.

SYDNEY PWA DAY CENTRE Daytime recreation/relaxation centre for people with AIDS. Advice, information & daily activities in an informal supportive environment. Lunches on some days, massage, acupuncture & other services available. 20 William Lane Woolloomooloo. 357 3011.

SYDNEY SOUTH WEST NEEDLE EXCHANGE For access and locations 827 2222, 828 4844 or Mobile 018 25 1920.

VOLUNTARY EUTHANASIA SOCIETY OF NSW INC. 212 4782.

CLINICS & HOSPITALS

ALBION STREET AIDS CENTRE Main Sydney clinic providing ambulatory care, HIV testing and counselling. Also conducts experimental AIDS treatment trials. No Medicare card required. 332 1090.

CALVARY HOSPITAL Rocky Point Rd, Kogarah. Inpatient, respite and pain/symptom control (care by Victoria Furner). Full community support team. Stuart Pullen 587 8333.

EVERSLIGH HOSPITAL A palliative care inpatient facility and community service. 560 3866.

GREENWICH HOSPITAL Palliative care inpatient unit, day hospital and community outreach. 439 7588.

HAEMOPHILIA UNIT Royal Prince Alfred Hospital. 516 7013.

KIRKETON ROAD CENTRE Community based primary health care facility of Sydney Hospital. Nursing, medical services, counselling, 9am-8pm, Mon-Fri. Social welfare service, needle & syringe exchange 2-6pm, Sat-Sun. Outreach bus 8pm-midnight, 7 days. Darlinghurst Fire Station, Victoria Rd, Kings Cross. 360 2766.

LIVERPOOL SEXUAL HEALTH CLINIC/HIV OUTPATIENT CLINIC Elizabeth/Bigge Sts., Liverpool. Free, confidential HIV/STD services, counselling, HIV support groups, practical support. 827 8022.

LIVINGSTONE ROAD SEXUAL HEALTH CLINIC 182 Livingstone Rd Marrickville. Open Mon, Wed, Thur 1-5pm. For appointment, 560 3057. No medicare card required.

NERINGAH HOSPITAL A palliative care inpatient facility, domiciliary and community service. 4-12 Neringah Ave. South, Wahroongah. 487 1000.

PRINCE HENRY (Special Care Unit) Anzac Parade, Little Bay. 694 5237 or 661 0111.

PRINCE OF WALES Children's Hospital (Paediatric AIDS Unit) High St Randwick. 399 2772/4. Dental Clinic, Acoca St, 399 2369.

ROYAL NORTH SHORE HIV outpatient, day treatment, medical consultations, inpatient services, counselling, support groups, sexual health clinic, testing. 438 7414/7415. Needle & syringe exchange 906 7083. Pacific Highway, St Leonards (by railway station).

ROYAL PRINCE ALFRED (AIDS Ward) Missenden Rd, Camperdown. 516 6437.

SACRED HEART HOSPICE A palliative care facility. 170 Darlinghurst Rd, Darlinghurst. 361 9444.

ST GEORGE HOSPITAL HIV/AIDS Services Inpatient, Outpatient and Day Treatment Centre: South St, Kogarah. 350 2960 Sexual Health Clinic: Belgrave St, Kogarah. 350 2742.

ST VINCENTS HOSPITAL HIV MEDICINE UNIT Victoria St, Darlinghurst. Multidisciplinary HIV specialist care including medical, nursing, counselling, physiotherapy, occupational therapy, nutritional advice and community liaison. Switch 339 1111. Inpatient care: Ward Cahill 17, 361 2337/2285. Outpatient care: Immunology B clinics, Tu, Thur and Fri AM by referral, 361 7111. Ambulatory care/Urgent triage nurse practitioner on call, 339 1111. Clinical Trials, 361 2435. Dental Department, 361 7129.

SYDNEY SEXUAL HEALTH CENTRE Sydney Hospital, Macquarie St. 223 7066.

TRANSFUSION RELATED AIDS (TRAIDS) UNIT. Crisis/long term counselling, welfare support. Pam 843 3143. Red Cross BTS: Jenny 262 1764

UNITED DENTAL HOSPITAL Chalmers St, Surry Hills. HIV/AIDS service, Sue Mathieson 282 0246.

WESTMEAD CENTRE (Westmead and Parramatta Hospitals). Westmead 633 6333. Parramatta 843 3111.

EMOTIONAL SUPPORT

ACON COUNSELLING SERVICE (see under ACON, previous page). Call 206 2000 for appointment

ANKALI Emotional support to PLWAs, their partners, family and friends. Trained volunteers provide one-to-one non-judgemental and confidential support. 332 1090.

CARERS SUPPORT GROUP South West Sydney. Runs Wednesday Evening in Liverpool, 6pm. Janelle or Julie on 827 8022

CLASH Confidential group of HIV+ heterosexuals who support each other by taking away some of the hardship of being alone. (Free call) 1-800 812 404.

FAMILY SUPPORT City: A support group for family members of people with AIDS.

Regular short term groups. Helen Golding on 361 2213. Outer Western suburbs:

Meets evenings on a regular basis. Claire Black or Kevin Goode at Wentworth Sexual Health and HIV Services on (047) 24 2598.

FRIDAY DROP-IN for PLWHA at ACON Western Sydney. Scott on 204 2402 for confidential information.

HIV+ SUPPORT GROUP South Western Sydney. Meets in Liverpool Wed 6.30pm. Julie 827 8022. Transport can be arranged.

PARENT'S FLAG Parents and friends of

lesbians and gays. Meets 2nd Mon of the month. Heather, 899 1101, or Mollie 630 5681.

POR LA VIDA Un servicio de informacion y apoyo para personas afectadas por el VIH y El Sida. 206 2016.

QUEST FOR LIFE FOUNDATION Emotional support and education for people with life threatening illnesses, their families, loved ones and health professionals. Support groups, meditation/relaxation classes, one-to-one counselling. 906 3112.

SUPPORT GROUP FOR PARENTS OF HIV+ ADULTS Every 3rd Fri in the month 7-9pm at Ankali House 335 Crown St. Confidentiality assured. Grahame Colditz/ Bern McPhee 332 1090.

SYDNEY WEST GROUP A Parramatta based support group. Pip Bowden 635 4595.

YOUTH HIV SUPPORT WORKER Counselling, advice, information to positive youth and their peers in the Central Sydney area. 690 1222.

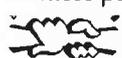


YOUNG & POSITIVE A confidential service for young HIV+ gay guys. Support, information, groups, workshops, social events. Call Aldo or Jaimie 206 2076.

PRACTICAL HELP

BADLANDS Residential harm reduction service providing safe, non-coercive space for people who are at high risk of HIV transmission or acquiring HIV. Residents are mainly injecting drug users and/or sex workers. 211 0544.

BARNADOS FAMILY SERVICES Support for families affected by HIV/AIDS. Respite care, short/long term foster care and assistance with permanency planning for children whose parents have HIV/AIDS. 387 3311.



BOBBY GOLDSMITH FOUNDATION A community based, registered charity providing some financial assistance to approved clients. 360 9755.

DES KILKEARY LODGE Respite and Step-down support for PLWHA and their carers. Small day centre. Located on the Northern Beaches. Paul, 982 2310.

DOG GROOMING Reduced rate for PWA pensioners. Ben on 519 8785. Free to PWAs on limited incomes. Judy on 559 3225.

FUNERAL CELEBRANT General funerals, free in cases of financial hardship. Patrick Foley on (018) 61 1255.

FOOD DISTRIBUTION NETWORK Cooperative distributing cheap boxes of fruit & vegetables. 9am - 4pm M-F, 699 1614.

HANDS ON MASSAGE AND REIKI for PLWHAs. Training of volunteer masseurs. Richard 660 6392.

PETS The Inner West Veterinary Hospital will never refuse urgent treatment for a pet because of lack of money. Please call 516 1466 for more information.

THE SANCTUARY Centre for complementary Theories focussing on relation therapies. Tu-

Fri 1.30-5.30pm. Gebe Neighbourhood Centre. Transport can be arranged. Bookings essential. Phone Lindy on 516 7830.

SHOPPING SERVICE FOR PLWHAS Fortnightly on Fridays, inner-city only. Bookings/& further information 360 2043.

OUTSIDE SYDNEY

HAWKESBURY & BLUE MOUNTAINS

BLUE MOUNTAINS HIV/AIDS CLINIC Services include testing, treatment, monitoring and counselling/support. (047) 82 0360. 9am-Noon, M/W/F.

BLUE MOUNTAINS PLWA SUPPORT CENTRE Wed 11am-3pm (lunch). Fri 6.30-10.30pm (dinner). (047) 82 2119 or Dennis (047) 88 1110.

CSN BLUE MOUNTAINS Hands on practical help for people with HIV/AIDS. Pat Kennedy, (02)204 2404.

KARUNA BLUE MOUNTAINS Emotional support for PLWHA, their partners, family and friends. Ann (047)82 2120.

SOUTHERN HIGHLANDS HIV/AIDS VOLUNTEER SUPPORTER GROUP Emotional and practical support for PLWHAs, their family and friends, living in the Bowral district. Marion Flood (048) 61 2744 or David Willis (018)48 3345.

WENTWORTH SEXUAL HEALTH & HIV CLINICS Nepean Hospital Mon 3-8, Thurs 9-4. Ross St Clinic, Windsor, Tues 4-8pm. (047) 24 2507 for all appointments.

CENTRAL COAST & HUNTER

CENTRAL COAST SEXUAL HEALTH SERVICE Offering HIV clinic for testing, monitoring, treatments, support. Patrick (043) 20 2114.

CSN NEWCASTLE Rosemary Bristow, ACON Hunter, 13-15 Watt St, Newcastle. (049) 29 3464.

COASTAL CONNECTIONS Gay & lesbian social group. (043) 65 3461. PO Box 259, Toukley 2263.

HUNTER AREA HIV SUPPORT/ACTION GROUP 6.30pm, 4th Wed every month at ACON. Inquiries (049)29 3464.

JOHN HUNTER HOSPITAL (Clinical Immunology Ward). Lookout Rd, New Lambton, Newcastle. (049) 21 4766.

KARUMAH DAY CENTRE. First floor, 101 Scott St, opposite Newcastle Railway Station. Open Tues 6-9pm (games night), Wed 6-9pm (games night & masseur when available), Thur 11am -3pm (lunch & activities). (049) 29 6367.

KONNEXIONS DAY CENTRE 11am-3.30pm Mon for lunch & social. Lesley. (043)23 2095.

NSW ANTI-DISCRIMINATION BOARD Newcastle. (049) 26 4300.

NEWCASTLE GAY FRIENDSHIP NETWORK Peer support, workshops and activities for gay

NSW HIV/AIDS Information line

Mon-Fri 9am-8pm, Sat 10am-6pm
Advice and referral information for HIV/AIDS

008 451 600
Rural Project, ACON
Mon-Fri 10am-6pm

General advice and referrals on HIV/AIDS in country areas

008 802 612
Take Control Line
Mon-Fri 10am-6pm

Confidential and frank information on treatments for HIV/AIDS

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Jill Sergeant 361 6750

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Paul Canning 361 6750

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GRAFTON HIV/NESB WORKER Sharyn Dillossa. (066) 42 3333x229

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Regional Health Service HIV/AIDS Coordinators

CENTRAL COAST

Paul Drielsma
 Ph: (043) 20 3399 (018) 43 6044

CENTRAL SYDNEY

Lesley Painter
 Ph: 550 5366

CENTRAL WEST

Dr. Martha Gelin
 Ph: (063) 32 8576/8538/8571

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Marlene Velecky
 Ph: 399 4832

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The word is out. Hospital food is awful. Well we all knew that. Or did we? And is anyone doing anything about it? Jill Sergeant finds out.

LAWSON WAS IN A MAJOR SYDNEY Hospital for four weeks:

"The food is terrible. Anyone would tell you the meals not to order, for example the fish, the quiche. The vegies were never cooked, the boiled eggs were like card, the chops were burned to a crisp. The lasagne would give people diarrhoea. It was very unappetising, you wouldn't feed it to a dog. There was never enough. The coffee and tea were like water. There were no supplements. The only safe thing was the roast chicken, and breakfast wasn't too bad.

I wouldn't recommend it. I was 66 kilos when I went in and came out 57 kilos. I was so weak, I had no strength in my arms and legs. Just to pick up a shopping bag was hard."

Lawson's story is not unusual. Extreme weight loss (wasting) is a common and dangerous problem for people with HIV. Caused by a variety of factors (such as loss of appetite due to sores in the mouth, or depression; malabsorption of food or diarrhoea due to opportunistic infections — OIs), it is a problem because the weight lost is actually lean muscle tissue, not just fat. Once lost, this is difficult to regain, and it becomes a downhill spiral as, if you are underweight, it's harder to fight off infections — which can cause further weight loss. Lose too much weight, and you may die from malnutrition.

For kids with HIV, weight loss



is particularly serious. Their energy needs are higher because they're growing and losing even a small amount of weight can have a bigger impact.

Wasting is not a direct consequence of having HIV. It is preventable. Prompt treatment of OIs, strategies to improve appetite, the availability of good nourishing food and, if things get serious, various forms of supplementary feeds (see p.22), are the answer.

When you are ill, your nutritional needs are higher. Healing a wound or fighting off a fever requires more calories, so even though you may think you're eating adequately, this is a time when you could lose weight. This means that what you eat while in hospital is of vital importance. It's ironic, then, that there's a common belief

among hospital veterans (like Lawson) that a guaranteed way to lose weight is to check into hospital for a few weeks. They say this is because the food is often unappetising, monotonous (especially when you're in for a long stint), or not available when you are hungry. Another factor in hospital weight loss may be fasting for procedures or treatments. And, of course, you might continue to lose weight because medical staff are finding it difficult to get your symptoms — like diarrhoea — under control.

But let's start with the food.

One source in the hospital catering industry estimated the cost per meal at \$2.00 - \$3.00. You can't expect too much for that. However, Dr. Peter Williams, Chief Dietitian and Food Services Manager at Royal Prince Alfred Hospital

graphics by Phillip McGrath

(RPA), puts the figure higher, just over \$7.40 per meal, including labour costs. "Our menus are not designed to be low in food costs", he says. Good quality of ingredients, Williams stresses, are a high priority at RPA, precisely *because* the food is for people who are sick.

Some hospitals have food cooked outside, brought in and reheated a few hours later; others operate by

"When you are ill, your nutritional needs are higher... This means that what you eat while in hospital is of vital importance."

"cook-serve" — the food is served fresh from the hospital kitchen (as at St Vincents); and increasingly hospitals are moving to "cook-chill" (as at Prince Henry), basically because it's more cost effective. In cook-chill, meals are rapidly chilled to be later reheated in special trolleys which actually complete the cooking.

Some hospitals combine methods to achieve as diverse and nutritious a menu as possible: RPA will be introducing cook-chill for some dishes such as casseroles and soups, but combining it with freshly cooked vegies or grills. In addition, there are frozen 'single serve' meals catering to more specific needs, eg. vegetarian, high protein, particular cultural preferences.

Meals are likely to be bland to cater to more conservative tastes. Williams also points out that very ill people often prefer bland foods, although at RPA there are spicy meals on the menu. Meals are often low in salt, in line with national dietary guidelines (but you can add your own) and you won't find much tasty 'junk food' like hot chips. In the case of PLWHA, says Anne McMahan, RPA's HIV Dietitian, spicy foods could aggravate painful conditions such as mouth ulcers or oral thrush. On the other side of the coin, some medications affect your tastebuds, so the food might not always be as bland as you

think. If you're in for a long stay, however, it's likely to get boring. Hospital menus have about a two week cycle before they start again.

WHAT THE HOSPITALS DO

Hospitals have not been completely ignoring the complaints about their food. They also appreciate the importance of nutrition to PLWHA,

to the extent that the hospitals with a regular HIV caseload usually have an HIV nutritionist on board. This person's role is to assess the nutritional needs of each patient, advise them about alternatives, prescribe supplements, liaise with other staff on the person's case and, often, follow up to ensure that after a patient is discharged there is adequate nutritional information and support. They juggle your dietary preferences with your nutritional and medical needs to come up with meals and supplements to suit each individual.

They may advise nasogastric feeding to help you put on weight. You may be referred to a dental hygienist — oral health is a very important aspect of nutrition; a physiotherapist or occupational therapist — exercise helps build muscle tissue; lined up with an Ankaali, or sent off to cooking lessons (after discharge).

A relatively new hospital strategy to address weight loss problems is the "kitchen on the ward" (KOW). These are only available in hospitals with a high PLWHA caseload. How these operate and how they're stocked vary from hospital to hospital but the basic recipe is: fridge, microwave, toaster,

sometimes a larder of easy to prepare food and supplements and sometimes (if you're really lucky) volunteers to prepare a bite of what you fancy.

RPA has the most comprehensive KOW, which is funded from donations to the ward. The larder includes canned and frozen foods that can be heated in the microwave, ice cream, waffles, pancake mix, milk and soy milk for smoothies and a range of supplements.

The success of a volunteer effort relies partly on the volume of HIV patients in the hospital. If there aren't many, it's difficult to sustain. ACON Northern Rivers have organised volunteers to cook up frozen "foodbanks" for some patients, who pay for the food



themselves.

St. Vincents' don't supply food (due to cost and lack of storage space), but there is a fridge beside every bed in the ward, if friends and family bring food in. There are microwaves, blenders and toasters available. Supplements are provided, however, and they have also developed an alternative menu of spicier, more fatty foods, in response to complaints that the food was too bland, and in recognition of the fact that PLWHA often have poor appetites that need tempting, as well as higher energy needs. So you can get hot chips on Cahill 17.

The Royal North Shore Hospital (RNS), which doesn't have the numbers to warrant a KOW, is also introducing an alternative menu of

high energy, high protein meals. RNS HIV Dietitian Louise Pollard encourages "nutritious snacking", which the food service can provide: milkshakes, cheese and biscuits, supplements.

The Northern Area Health Service is about to start a pilot program of supplying subsidised vitamins and supplements to inpatients and

outpatients of RNS.

At the Prince of Wales Children's Hospital (POW), some effort goes into making foods look attractive so that children are more tempted to eat. Plenty of nutritious snacks are available and there is a KOW on every ward (there is no AIDS ward) so that parents can prepare food for their children.

All the hospital staff I spoke to for this article pointed out that food is offered to patients six times a day: three meals as well as morning and afternoon teas and supper. It's often nurses who'll prepare a smoothie for a patient. In addition, Diet Aides can often prepare tea, coffee and snacks. At RPA they're trained in nutrition and can advise you on the best menu choices.

Clearly these strategies can work if the KOW is adequately stocked, there are volunteers or friendly staff to prepare a snack, the alternative menu is truly alternative, and you are mobile enough, or have sufficient friends and family around to prepare food in the KOW. But it's not enough.

WHAT YOU CAN DO

As a patient:

Make sure you ask to see a dietitian as soon as you're admitted. Smaller hospitals won't have an HIV dietitian, so ask to see the regular dietitian.

If you are mobile enough, and

have the money, go on little excursions to the hospital cafeteria or even outside the hospital walls to the local cafe society.

Order take away — club together with other patients and order a feast. (Try and make sure this doesn't totally stuff up the dietitian's plans!)

Ask other patients what to avoid on the menu.

Nurses or Diet Aides can help you with cutting up food if you need it and any other difficulties you might have with actually eating. Ask them.

Ask friends, family, your Ankali or CSN carer to help you. Don't be ashamed to ask for help.

Inform the hospital administration if you're dissatisfied with any aspect of the nutritional service. They can't fix what they don't know about.

As a visitor:

Don't pinch the equipment. (Seriously! The microwaves are bolted down for a reason.)

Bring in home cooked or take away meals and snacks. Call first in case your partner/friend/relative (visitee) has a particular preference. Share a meal, it's nicer for them than eating alone.

Chat to the dietitian, if you can, about any limitations on the visitee's diet, so you don't contribute to their lactose intolerance by bringing in cheesecake.

Fasting

Fasting for treatments and procedures is a common experience in hospital. Often you'll need a lot of tests to find out what your mystery illness actually is. X rays, CT scans, barium swallows may all have to be done on an empty stomach. If you are in hospital for a weight loss related problem, it's vitally important to get a diagnosis so your condition can be treated and the weight loss stopped — so it's worth putting up with it.

Most fasts are just overnight, so you'll only miss breakfast. Children are not usually fasted more than four to six hours. If you fast for an appointment that is cancelled at the last minute, you may end up fasting twice as long as necessary. Or you may get back to the ward to find out that lunch has already been cleared away. If this happens, make sure you ask one of the staff on the ward to order something for you. You're entitled to the meal, and you need it. Sometimes staff anticipate this problem and keep your meal back to be reheated when you want it.

Outlets

Here's where you can pick us up!

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Bankstown
Women's Health Centre
Bondi Junction
NUAA
Grosvenor Clinic
Camperdown/Annandale
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If you can't find *Talkabout* at any of these outlets — ask for it! Then they can order more copies to be delivered.

If there's no microwave, food can be brought in insulated vacuum flasks so it keeps hot (or cold) for later.

People with difficulty in swallowing or chewing due to sore mouths appreciate soft, smooth food. Hold the chilli!

While visiting, find out if there's anything you can do foodwise, like whip up a smoothie in the kitchen, with maybe a bit extra for the person in the next bed, if he or she'd like it.

Don't just bring in one fabulous capuccino from the local espresso bar, bring in a *tray*. They're bound to disappear.

Take your visatee for meals or snacks outside the ward. Ask for a wheelchair.

A word on weight loss

Don't ignore it, and don't leave it too late to get treatment. Gradual weight loss over a few months may not be noticeable at first, or you may not think it's worth worrying about. It is. You can see an HIV dietitian as an outpatient at major Sydney hospitals or the Albion St Centre. If you live outside Sydney, contact your local Area Health Service or ACON branch for referral.

Don't bring in fruit, it's easy to get in hospital.

You may have to act as an advocate for your visatee, and complain if there are problems with the food.

As a community:

Not all patients have the support

network or the money to act on these suggestions. And Ankali or CSN carers, if they are a person's only support, can't be called on constantly.

It's vital that the community mobilise more assistance for PLWHA in hospital in the form of volunteer support and food banks. Fundraise for a KOW. Lobby your Area Health Service, ACON branch or PLWH/A.

Doctors, nurses and dietitians, particularly in smaller and rural hospitals, must be educated about the nutritional needs of PLWHA. Organise a forum for your local hospital.

Community organisations also need to maintain a dialogue with hospitals about their food services.

It's supplementary

Weight gain is not just about eating more chocolates (unfortunately). Jill Sergeant takes a look at the products and devices you're likely to encounter in your quest for calories.

Nutritional supplements

There is a wide range of supplemental foods which can be eaten or drunk straight from the packet or added to other foods to boost their caloric and nutritional value. Before you go gung-ho with the supplements, discuss your nutritional needs with your dietitian, alternative therapist or doctor.

Weight gain drinks and powders are the most common variety, based on milk, soy or egg protein, with additional fat. Some are lactose free. Examples are Sustagen and Endura Opti.

Then there are the complete nutritional supplements, which you can live on if you have to, such as Ensure and Fortisip. These are particularly useful if you're not eating much.

Special nutritional supplements, like Lipisorb and Criticare, are de-

signed for when you have difficulty absorbing food, for example if you have diarrhoea. Advera is a supplement designed specifically for people with HIV.

Modular supplements generally contain just one nutrient: eg. protein (Promod), or carbohydrate (Polyjoule). These can be added to drinks, soups and stews.

Supplements are available at a cheaper cost from ACON's vitamin and supplement service, but you need a script to purchase them.



Nasogastric feeding.

Not very appetising, no. Nor even very attractive, a tube which goes down your nose and into your stomach. Putting it in and taking it out are not pleasant either, but nasogastric feeding is an effective way to give you the nutritional

boost you may need to start gaining weight. You can sleep and talk with it in place, and you do get used to how it feels.

The tube is connected to a supply of nourishing fluid which contains all the essential nutrients — you can live on it. This system is great if you are too tired to eat or can't chew or swallow due to infections such as oral thrush.

It's usually relatively short term — up to six weeks — but it can be used for years. Nasogastric feeding is often used with children.

Anne McMahan, HIV Dietitian at RPA, often suggests nasogastric feeding to people who are in hospital for something unrelated to food, like PCP, for the nutritional benefits. She's seen people put on six kg in two weeks.

Percutaneous endoscopic gastrostomy (PEG)

Although it sounds even more gruesome than a tube up your nose, the PEG could have broad appeal as the ultimate in body piercing. Basically, a hole is pierced into your stomach and after about six - eight weeks (it heals in a couple of

weeks), it's sealed with a plastic 'button', which snaps open and attaches to a supply of the same nutrient fluid mentioned above.

The PEG is more appropriate for people who've had problems with wasting for some time and need nutritional assistance for a longer term.

The advantage is that it can't be seen (unless you want to make a feature of it), the button can be covered with large size Band-Aids, and you can even swim with it. You don't have to be connected to the feed all the time so it allows for more flexibility. You can still eat and drink if you want to.

The button can be taken out if there's no longer a need for it, and the hole will gradually seal over, like other piercings. However if you need to have a PEG, keep in mind it probably will be pretty permanent.

Total Parenteral Nutrition (TPN)

TPN is intravenous feeding, through a tube inserted into a major vein in your chest. A variation is to insert the tube into a peripheral vein on the back of the hand or in the arm (PPN). Although this sounds dramatic, the principle is the same as an IV drip. The tube supplies all your energy and liquid requirements.

TPN is used in PLWHA for exactly the same reasons it's used in other people: because it's impossible to use the digestive tract for nutrition, usually due to a condition such as fistulas (holes) in the bowel or oesophagus. It's likely to be used if symptoms such as diarrhoea, which are causing weight loss, cannot be controlled, you're unable to take (and retain) any food orally, and strategies such as the nasogastric feed have failed.

It is usually short term, very expensive, and you are more at risk from complications such as infection than with the PEG. Most health care workers prefer to use the gut for nutrition if at all possi-

ble. TPN is generally quite successful and temporary, (although in the US it's often used just to sustain life).

There is disagreement among health care workers about the level of infection risk of both PEGs and TPN for people with compromised immune systems. Hilda High points out that most recipients of TPN are likely to have compromised immune systems, HIV positive or not. She says studies have indicated no difference in infection rates.

Not the final word

Don't be scared of artificial feed-

ing. Although the PEG and TPN are used in palliative care, it is better to try them sooner rather than later as the improvement in nutrition can prolong your life and increase your quality of life.

As your weight picks up, so does your appetite, and with the PEG and nasogastric feeding, you can still eat and drink if you want to.

Also, if you leave this kind of intervention until you're already severely wasted, there are more likely to be complications and infections with the PEG and TPN.

If you're finding weight loss a problem, supplementary feeding is definitely something to consider.

HIV positive and living in rural NSW?

Getting hold of relevant information about a whole range of topics can be difficult, and with information changing so frequently it can all be quite confusing.

Would you like to know about the latest treatment options and drug trials (and where to get them in rural NSW), as well as pension entitlements, housing, lifestyle factors and progression to AIDS, complementary therapies, legal rights etc.? Well, now you can.

The ACON HIV living project will be running a series of confidential four day workshops covering these topics and many more. Where? These workshops will be held in private and secluded locations in the Riverina, Far West, Northern Rivers, Hunter and Illawarra regions of NSW.

HIV Information forums give you the opportunity not only to find out the latest information in a completely confidential and private setting but also the chance to meet other positive people. These workshops are free and include all meals and accommodation (if required).

HIV Information forums are organised by HIV positive people for HIV positive people. To find out more phone Stephen Gallagher on

(02) 206-2011 or 1-800-063 060 any Monday, Wednesday or Friday between 10am and 6pm.

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Programs & registration forms are available from: ADC Coordinator, c/- Sacred Heart Hospice, Darlinghurst Rd, Darlinghurst 2010
(Ph: 361 9444, Fax: 361 9555)

Sponsored by NSW HIV Study Grants and coordinated by the HIV Services of Eastern Sydney Area Health Service

- ADC diagnosis, treatment & new directions
- HIV psychiatry
- Neuropsychological assessment
- Decision-making capacity, testamentary capacity & the role of the Guardianship Board
- Pharmacology
- The role of allied health professions
- Issues for clients and carers
- Counselling strategies
- Management Strategies
- Accommodation Strategies
- Legal issues
- Home care
- Education Issues



Come along to a stress free country location where you can enjoy nature, try complementary therapies, meet other positive people in a relaxed environment, learn about some of the alternative therapies on offer, do yoga, meditation, acupuncture, homoeopathy, reiki and others.

The retreat will be alcohol and recreational drug free.

This retreat will be held from Monday July 24 to Friday July 28.

An investment of \$40 unwaged and \$100 waged is the cost of the retreat. For more details, and to obtain an application form, call Claude on 361 6023, M-F between 10am and 6pm.

A joint initiative of the HIV Support Project and PLWH/A Inc. (NSW)



feeling queasy?



The long term aim of relieving nausea is to treat the causes. Dr Ron McCoy explains how juggling medications and meal times to fit your lifestyle can help.

SYMPTOMS ARE A SIGN OF AN underlying disease and health care providers look at symptoms when trying to diagnose an illness. This means that the symptom itself is often overlooked when it comes to treatment and it can cause a lot of distress.

Nausea is the feeling that you are going to vomit. It can vary in strength from a slight queasiness to actual vomiting. As well as being very distressing, nausea can cause weight loss if it is ongoing because it stops you from feeling like eating.

The causes of nausea are many and long-term control of nausea really depends upon looking for the cause. If nausea lasts longer than 24 to 48 hours, you need to see someone to help sort out the cause.

Many people feel that nausea is a natural part of HIV infection and then don't bother to tell anyone about it. It isn't!

Nausea has many causes including medications, infections and emotional stress. There are both short term and long term aims in treating nausea. In the short term (over one to two days), the aim is to relieve the symptoms, regardless of the cause. This is important because weight loss can occur even if you do not eat much for one or two days. If you cannot eat solid food, small sips of fluid frequently can help to relieve nausea.

Suitable fluids include sips of iced water, icy poles and fizzy indigestion drinks such as Dexasal. The best home cure I know (which sounds revolting), is half a glass of

dry ginger ale mixed with half a glass of water. It fizzes up, tastes like creamy soda and it works!

Some find salty foods easier to tolerate than sweet foods. Fasting can cause nausea. If you are nauseated in the morning you may just have an empty stomach! A bit of a nibble (say on dry toast) before breakfast often helps. Cooking smells can worsen nausea, so open the windows when cooking. Food smells are less when food is allowed to cool a little before eating rather than served piping hot.

Medications to help relieve nausea include metaclopramide (Maxalon), prochlorperazine (Stemetil) and domperidone (Motilium). There is a much higher rate of nasty, but not serious, side effects from the first two of these medications, especially if your T cells are below about 300. Many doctors are unaware of this, as they

are commonly prescribed. If you're taking medication to relieve nausea over a longer time (perhaps because it is due to other medications), it is better to use domperidone. However, all such medications have an important place and this should always be discussed with your own doctor, as everyone is different, and none of this may apply to you.

Some people also find that marijuana can help control nausea as well as stimulate appetite.

The long term aim of relieving nausea is to look at and treat the causes. Juggling medication and eating times to fit your lifestyle can relieve nausea, and this is where the dietitian and pharmacist are very helpful, as some drugs are affected by food. Don't let nausea ruin your life: get it sorted out.

This article originally appeared in Positive Living (Vic).

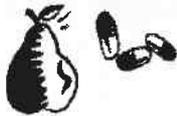
HIV/AIDS SERVICES IN ST. GEORGE ??

In-patient, out-patient. Day-only treatment and counselling phone 3502955
HIV/STD screening and treatment, counselling, information and referral: phone 350 2742
Hospice/respice care phone 587 8333

Clean fits, condoms, lube, information and referral: phone 018 479 201
Home Nursing, clean linen, equipment loan: phone 350 2955
Drug and alcohol counselling: phone 350 2944

You don't have to travel to the city for HIV/AIDS care. Call us.

Fair Treatment



Complementary Therapies: the evidence

Jim Arachne addresses the common fallacy that there is no scientific evidence that complementary therapies are effective.

COMPLEMENTARY THERAPIES (CTs) are used by very large numbers of people with HIV/AIDS. Australian social research shows that more PLWHA use CTs than use medical treatments. Recent Australia wide discussions conducted by AFAO among PLWHA found that:

"In practically all the recent consultations the need was expressed for information on complementary therapies. In fact this need for information was perhaps the single most recurrent theme of the consultations."

In October '94 HIV Peer Support workers from around Australia, meeting in Sydney, delineated, rated and prioritised the issues and problems facing PLWHA. Complementary Therapies were rated No. 1 in current importance from a list of 65 issues.

However, practical support and services in this area are almost non-existent. Medical treatments receive active support, advocacy, promotion and advertising from AIDS Councils and AFAO in the form of full page ads in the gay press, at least two hundred thousand dollars spent on Treatment Officers' salaries, salary and production costs of the *HIV Herald* etc. Conversely, these organisations have continually decided to ignore PLWHA needs in this area and to withhold

such resources from effective CTs — such as medical herbalism, naturopathy, homoeopathy or Chinese medicine.

One major public reason for refusal to advocate for CTs is usually: "There's no evidence CTs work".

This claim will not stand any valid scientific scrutiny. A very brief review of scientific investigations into the effectiveness of CTs for the treatment of HIV related illness shows the following results:

Chinese Medicine

A large, multi-centre trial using both herbalism and acupuncture for individual treatment of 212 positive people was undertaken by the Department of Traditional Chinese Medicine, Nanjing, China. This trial began in 1988 and enrolled people from Africa, America and China. Twenty four people had AIDS, 115 had "AIDS Related Complex" and 23 were generally well. After a three year period 76% of people had had a significant improvement in symptoms compared to when they started on the trial.

Considerations about placebos can be left aside here as placebo effects cannot normally be sustained for such a long period. It is also clear that, in the normal course of HIV over three years, 76% of people with AIDS and ARC would not "spontaneously" have improvements in their symptoms.

Homoeopathy

A 1988 trial in Africa, conducted by Belgian homoeopathic doctors,

showed that homoeopathy could substantially improve the health of people with AIDS. Thirty six people with AIDS were randomly divided into two groups: 18 who would receive homoeopathic treatment and 18 who would not. After one year the homoeopathically treated group had experienced 83% less diarrhoea, 66% fewer opportunistic infections (including PCP) and 50% fewer fevers than the untreated group. They'd also had an average weight gain of 3kg (6.61bs) compared to an average weight loss for the untreated group of 22kg (48.41bs). Average T4 counts had also increased for the treated group.

This treatment only cost around 17 cents per day compared to around \$27 per day in Africa for AZT.

Traditional African Medicine

Much research has also been carried out on local African medicine. This should feature highly in next year's planned International Complementary Therapies & AIDS Conference in Africa.

One trial examined the effects of African traditional medicine on the life span of people with HIV. Two matched groups of people with AIDS and ARC were treated either with Western medicine alone or with combinations of both Western Medicine and African traditional medicine. After a nine month trial the group receiving both African and Western medicine had marked improvements in infections and symptoms (including TB,

PCP and KS) and gained an average of 14kg in weight. Five percent of this group died.

The group receiving only Western medicine had little or no improvements in symptoms and 52% died. That is, the African and Western Medicine combined was *much* better than the Western medicine alone.

Naturopathy and Herbalism

A recent investigation in this area was a combined Romanian/Japanese 20 month study of 50 babies with HIV/AIDS which concluded in 1994. One group of 25 babies were treated with AZT for one year. The AZT was then stopped after it was shown to be no better than herbal treatment. All babies receiving AZT were switched to only herbal treatment. After another eight months researchers found that: "more than 90% of the patients were improved with mortality markedly reduced".

The other group of babies received only herbal treatment for the full 20 months. Researchers reported that: "except for one case, all patients with AIDS symptoms improved and they returned to being simply HIV Positive".

A much longer and larger study of naturopathy for the treatment of 175 adults with HIV/AIDS was conducted in Germany. They received normal combinations of different herbs, homoeopathic medicines, nutritional supplements, gut bacteria replacement and some counselling — much the same as anyone visiting a naturopath might receive. They also used ozone infusions — which are not a standard naturopathic procedure. No one used any antiretrovirals for the five years of the study (ie. no AZT, ddI, etc.)

After five years their T4 counts were compared to matched groups drawn from medical and scientific literature who had received standard medical treatments for HIV/

AIDS. Of those using naturopathic treatments, 52% had significantly higher T4 counts than groups using medical treatments. Investigation also showed that the naturopathic patients had a better quality of life than the medically treated people and had no significant side effects.

Another study, in Canada, enrolled 20 people with T4s less than 500. Half the group took AZT while the rest took a herbal formulae (called 'GSPH'). The results, after 10 months, are shown in Table 1.

The herbal treatment appeared superior to AZT in its effects on these blood counts over this time period. The herbally treated group also had marked improvements in

over two years. All have shown positive results.

There have been many more trials and experiments conducted on CTs for the treatment of HIV related problems than are mentioned here. It is important to realise that, in Western countries, these trials were done with no government grants. Generally, millions of dollars have not been needed to develop new CTs but already existing therapies, often hundreds of years old, have been successfully used.

Some of these therapies are just as successful as medical treatments in dealing with HIV related problems and others have been shown to be more effective. If CTs can perform this well with virtually no

Table 1: Comparison of AZT With Herbal Treatment ('GSPH')

	10 Months on AZT	10 Months on GSPH
T4	Small Drop	Small Rise
T8	2.4% ↓	33% ↑
T3	3% ↑	25% ↑
Lymphocytes	3% ↑	24% ↑
White Blood Cells	16% ↓	10% ↑

swollen lymph glands and beta-2-microglobulin levels. As well, 70% improved their overall health with the remaining 30% remaining stable.

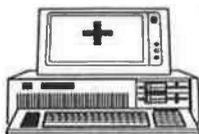
Trials of single herbs have also shown very encouraging results. Mistletoe injections (used safely for 80 years for people with cancer), bitter melon enemas (Note: only the leaves and vines have been shown to increase T4's — not the fruit), extracts of liquorice, St John's wort (*Hypericum*), turmeric and garlic have all shown sustained, beneficial effects in trials. There are now four limited scale trials completed for dinitrochlorobenzene (DNCB) — including one lasting

government money, Medicare subsidy or research, how much better would things be for Positive people if CTs received just a small fraction of the thousands of millions of dollars given to medical research?

HIV Information & Support BBS

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Aussie Gay
Net. *Talkabout*
supporter

Service Update



WOLLONGONG

HI TO THE HIV+ AND GAY AND lesbian community from your brothers and sisters from Wollongong. It has now been over 12 months since you heard from us, so here's an update on what's been happening in Wollongong. The first thing I must clear up is The Path of Hope that was mentioned in the last issue of *Talkabout* (p5). This new project is just that — a new project. The Path of Hope is only in the planning stages and a great deal of work is yet to be done. I don't know how it made it to press — crossed wires I think — but we in Wollongong will keep you informed on how the project progresses.

Now for the really good stuff on all that is happening.

The Club

The Club is both a social and support group for Possies (or Hivvies) here in Wollongong.

We are a group that comes together to support each other and improve our social lives. We meet every second Thursday at ACON Illawarra. These meetings provide a light supper and great conversations.

Social events are open to partners, family carers or friends of club members. We have had a fun Melbourne Cup Day at Jamberoo Pub with a barbie and a hat fashion parade, as well as a couple of days in Canberra for the "Art in the Age of AIDS" exhibition (fully subsidised). We try to celebrate each member's birthday and we are about to have a night at the flicks.

The best part of the Club is that there are now over ten members (and we're growing) and as a group

of Possies we are a united voice. So watch out, HIV organisations in the Illawarra: get it wrong and The Club will let you know. If you want to know more, give us a call. The Club co-ordinator can be contacted every Thursday between 1-3pm on (042) 26 1163.

— Missy, Co-ordinator

ACON Illawarra

129 Kembla St, Wollongong

This year has been an important period of change and growth for ACON and the Community Support Network (CSN) in the



The staff at ACON Illawarra

Illawarra. We are a small but very busy Branch, staffed by six (soon to be seven) paid workers, at least six regular volunteers based at the office each week and two students on placement. We also currently have over 50 trained volunteer CSN carers who provide care and support for PLWHA in their own homes. We have a bi-monthly ACON/CSN

newsletter, *The Beacon*; Speaker's Bureau services; condom and lube sales; vitamin service; massage; and needle exchange. Many of these activities, and in some cases the entire project, rely heavily on volunteer support.

Something that is frequently overlooked is the capacity of a Branch like the Illawarra to act as a meeting place for informal community development activity. Call it having a cup of coffee with a friend or two if you like, but the importance of having a place to drop into, chat with staff or friends, read the latest *Star* or *Talkabout* and find out what's happening in general, should never be underestimated.

Being 'kind of', yet too close to Sydney to be 'really country' makes the Illawarra a very complex area to live in, particularly if you are HIV Positive or gay or both. So, if you are in the area, please drop by for a cuppa and we guarantee you a warm reception!

CSN

In the two months I have been with CSN, I have been amazed at the dedication of its volunteers and the amount of time and energy given up to provide support to individuals living with HIV/AIDS, from emotional support to on hands caring, transport and general house maintenance.

CSN has grown from a small group of individuals back in 1988. It was not until late 1994 that

ACON provided financial assistance for two part time positions.

While we currently have 52 trained volunteers, access to these carers is not always possible due to a number of factors. Training of future CSN volunteers must continue.

— Glen Barrington, CSN

HIV community

Hi, I'm Andree the HIV Community Development Project Officer at ACON. I have been doing a needs assessment of PLWHA in the Illawarra and Shoalhaven to find out what services and support people

need. One of the main findings so far has been the need for a safe space for people to just hang out in. We are currently lobbying to make this a reality.

Even though Wollongong can be seen as a city, it still operates very much as a country town. Social isolation as a result of the fear of discrimination is still a big problem. Hopefully the Community Development Project that follows on from the needs assessment will have a big impact on this problem. I still want to hear from anyone who has anything to say. The more people who

voice their issues, the more likely it is to get a response.

HIV Prevention Service

5/5 Rawson St, Wollongong

We have meeting rooms available for PLWHA, their carers or HIV/AIDS workers. People are more than welcome to use our resources and library. HIV/AIDS Co-ordinator Vivienne Cunningham Smith is also available if you would like to know what services are provided in the area, or if you are experiencing any problems such as discrimination in obtaining services.



HIV Information Workshops

AS MANY READERS ARE PROBABLY aware, the HIV Support Project (ACON Sydney) has been running HIV Information Forums for the last few years. These forums are specifically targeted at HIV Positive people, their carers and friends. The number of topics for these forums has grown from the original three — "HIV and the immune system", "Treatment", and "Check ups and prevention" — to topics ranging from Social Security entitlements, complementary therapies, Positive sexuality and the various services for HIV Positive people, to virtually anything that Positive people want to find out about.

The philosophy of the HIV Support Project is to present topics from an HIV Positive perspective. We neither promote nor endorse particular treatments, but by presenting relevant up-to-date information enable people to make their own conclusions and choices.

Fine, if you live in Darlinghurst, but what if you live in rural NSW? Not a problem: late last year the state government funded a project to take these HIV Information Forums to various rural centres.

The forums will be run as weekend workshops in secluded locations around NSW throughout

the year. These weekends will be very intensive, but with plenty of time to get to know other participants. Meals and accommodation will be provided free of charge and as spaces are limited priority will be given to Positive people.

Confidentiality is a major concern for most of us with HIV, so the names of people participating in these forums will not be released to anyone under any circumstances. Before the workshops commence participants will be asked to sign a confidentiality agreement. This document states that no participant will divulge the name, HIV status or any identifying information about any of the other participants.

The forums are to be held over the next twelve months in the Riverina, Far West, Northern Rivers, Hunter and Illawarra regions of NSW.

Recently become HIV positive? The HIV Support Project will also be running a series of Information Workshops in Sydney for people who have become HIV Positive in the last two years. These workshops will cover a full range of issues of interest to newly Positive people.

If you would like to attend one of these workshops, or for more information, contact Stephen Gallagher, Monday, Wednesday and Friday on 206 2011 or 1-800 063 060.

**Cần giúp đỡ hay hướng dẫn
về siêu vi khuẩn HIV/Bệnh AIDS
trong vùng Nam Sydney?**

Máy ghi âm giải thích kín đáo, Điện thoại : 391 9987

Những Trung Tâm Bài Trừ Hoa Liễu Miễn phí và bảo mật, Điện thoại : 350 2742

Những dịch vụ Nhà Thương Miễn phí và bảo mật Điện thoại : 350 2955

Dịch vụ Trao đổi Ống và Kim Chích Miễn phí và bảo mật :

Xung quanh vùng Canterbury, Điện thoại : 016 288 504

Xung quanh vùng St George, Điện thoại : 018 479 201

Xung quanh vùng Sutherland, Điện thoại : 018 277 717

Living on the pension



Colin Burroughs kicks off the first in an occasional series which will list useful info and resources for people on a pension. This month, Colin went hunting & gathering to find out what's available foodwise in the Sydney metropolitan area.

ANYONE WHO'S BROKE AND HUNGRY, especially when its off-pension week, can choose from this listing. Some of the services are specifically geared toward catering for people living with HIV/AIDS. Others cater for a wider assortment of mouths to feed.

COOKED MEALS

Sydney People With AIDS Day Centre 14 - 20 William Lane, Woolloomooloo, 357 3011.

Lunches 1.00 pm Tues - Fri. Top quality, delicious, nutritious meals. Free. Great place offering many other services.

Metropolitan Community Church Heffron Hall. 322 2457.

Sunday lunch \$2.00. Very friendly and gay/HIV orientated.

PLWHA Luncheon Club Lizard Lounge, Exchange Hotel, Oxford St. Darlinghurst

Monday lunch. Starts at noon. Free, Fabulous.

Eastside Community Centre 2 Newcome Street. Paddington. (Paddington Markets' hall), 331 2646.

12.00 noon lunch, Mon - Sat. High quality and nutritious servings. Gay & HIV friendly. Cost: \$1.00.

King Street Community Centre Uniting Church, King St. Newtown. 519 9000.

Lunches 12.00 noon Mon - Fri,

Cost: \$1.00. Sunday lunch 12.30 pm \$1.30. Interesting assortment of people.

Then there are the more basic, generalised eateries:

Wayside Chapel 20 Hughes St. Potts Point, 212 1700.

Open Mon - Fri, 9.00 am - 4.30 pm. Meals \$1.50 - \$3.00. They also sell packaged food at charitable rates. No frills but friendly.

Makunda's Hari Krishna Victoria St, King's Cross (up from the Fire Station).

Dinner 5pm, seven days a week. Vegetarian food and wash your own plate after the meal.

Village Community Centre 2 Newcombe St, Paddington, 331 2646.

\$1.00 lunches from 12.00 - 1.30pm, Mon - Fri. \$1.50 lunch Sunday, 12.00 pm.

The Station 107 Clarence St. (Near Wynyard station.) 299 2250.

Mon - Fri breakfast 7.30 am. Free. Lunch 12 noon. Free. Drop-in centre, caters for everyone: street kids, aged pensioners, us...

Vincentian Village Cnr Stanley & Yurong Streets (near Museum Station). 360 6674.

Restaurant open seven days. Lunch 2.30 pm Soup/first course free, main course \$1.00. dessert \$1.00. Dinner 6.00 pm, \$2.00.

Foster Street Hostel Surry Hills, 212 1065.

Lunch 11.30 am - 12.00 noon \$1.00. Evening meals 4.45 pm \$1.00 (free soup).

Lady of Snows 464 Pitt St. Sydney, 212 2402.

Mon - Fri, meals served 6.00 am - 4 pm, Sat: 6.00 am - 10.00 am. Queue-up, soup kitchen style. Basic but not bad. Free.

There are lots of other places in Sydney, too many to list in a short article, some of which you mightn't feel comfortable visiting - although when it comes to being choosy, if you're hungry then you're hungry! Those listed above are a few of the main ones. For more extensive information call the Sydney City Mission Startover Line on 212 2000.

In the Blue Mountains, there's "The Centre", 2 Station St, Katoomba. Lunch Wednesdays, dinner Fridays. Transport within the area is provided.



If you're a positive woman and you're interested in receiving occasional information, social news, invites and medical updates - especially for women - then call **Vivienne Munro**, at **ACON's HIV Support Project** on **206 2012** to join the mailing list

FOOD DISTRIBUTION NETWORK

For only \$5.00, approximately \$20.00 worth of fresh fruit and vegetables can be collected from their Darlington office by either yourself or your carer. 699 1614. (To be eligible you need to live within the city of Sydney and South Sydney Council areas.) If you need them to deliver to your home this can be arranged. Or you can order through the PWA Day Centre (listed above) if you are already a Day Centre visitor.

VOUCHERS

Food vouchers, which can be used instead of cash in supermarkets, are available to pensioners who can prove hardship, from the Salvation Army, 264 1711.

CASH FOR FOOD

Under certain circumstances The Smith Family will help you in this way. You will need to make an appointment, but the wait is worth while as they also help with clothing, bills and a number of other necessities. 550 4422.

FOOD PARCELS

There are many agencies who will give you a generous hamper of food. Three particularly helpful ones are Citycare, Waterloo, 98 3622; Lifeline, Chippendale, 951 5577, (Lifeline also has Credit Line, a service to help and represent you when negotiating with debtors); and Careforce, 196 Albion St. Surry Hills. Careforce also sometimes help with electricity bills, gas bills and clothing. Open 9.30 - 4.30.

Remember to make use of your DSS concession on public transport to get around. If you find some service that's particularly good, call PLWH/A and let us know.

Happy hunting.

Talkabout

WHERE WE SPEAK FOR OURSELVES

Join PLWH/A in the fight against AIDS! Subscribe now!



Phillip McGraw

PLWH/A Inc. (NSW) 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.

PLWH/A membership

Yes! I want to apply for membership of PLWH/A (NSW) Inc. \$2 per year (Membership is only available to NSW residents)

Talkabout annual subscription rates

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Individuals

- I am a member of PLWH/A Inc. (NSW) \$13 per year
- I am not a member of PLWH/A Inc. (NSW) and/or I live outside NSW \$30 per year
- I am receiving benefits and living in New South Wales FREE
- I am an individual living overseas A\$70 per year

Organisations

- Full (business, government, universities, hospitals, schools etc.) \$80 per year (Extra copies \$30 each per year)
 - Concession (PLWHA organisations, non-funded community based groups etc.) \$40 per year (Extra copies \$15 each per year)
 - Overseas A\$120 per year (Extra Copies A\$40 each per year)
- (Please specify number of extra copies _____)

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Total amount forwarded: \$ _____ (include membership fee, if applicable, and fees for extra copies)

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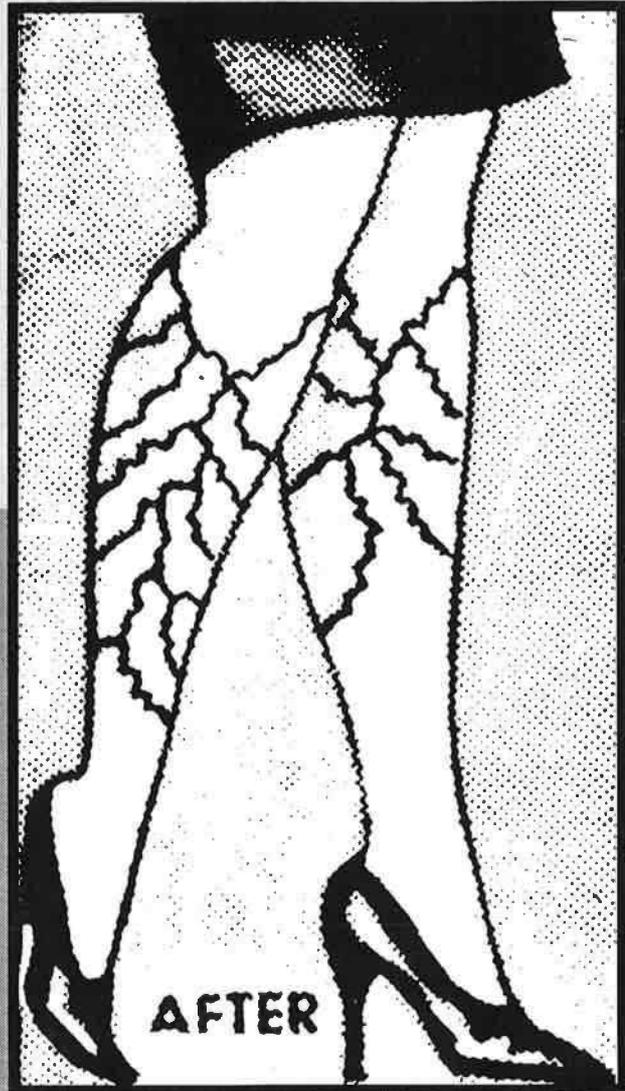
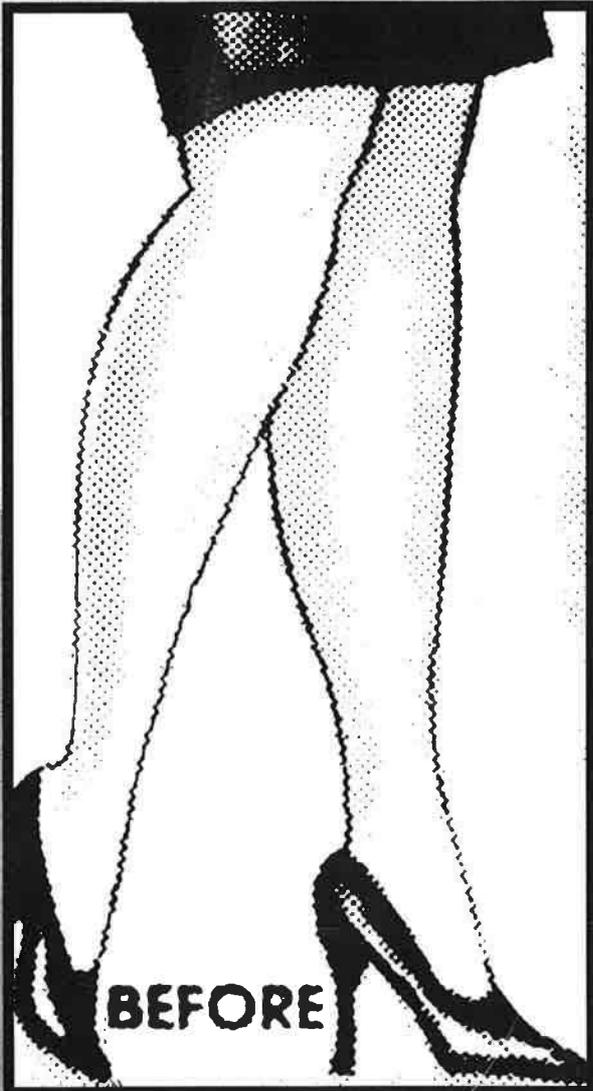
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