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Association of Community Health Councils for England and Wales

30 DRAYTON PARK, LONDON N5 1PB. Tel: 01 609 8405.

AIDS AND HIV INFECTION

July 1988

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INTRODUCTION

The mass advertising, leaflet drops, television programmes and newspaper coverage of HIV/AIDS have all disappeared or greatly diminished - low-key targetted advertising has taken their place. The government survey covering their 1986/87 advertising campaign shows an increased knowledge about HIV/AIDS, what causes it and what is or is not considered a high risk activity. However the number of people ill with AIDS or who are HIV positive is on the increase. Most regional health authorities have more than 150 reported cases of HIV positive people, in North West Thames RHA the number stands at over 2000. These figures clearly indicate that the spread of HIV infection will not miraculously disappear, nor will it just remain a problem for a minority of health authorities.

This Health News Briefing looks at the issues associated with AIDS and HIV infection: the needs of those who are HIV antibody positive or who have AIDS, the need for a continuing publicity campaign on how the risk of infection can be avoided or greatly reduced, the training needs of health professionals, resource requirements for care services, the arguments that surround testing for HIV anti-bodies, and the role of voluntary groups and support networks. The paper offers an overview of available literature and also uses information gained at lectures, in interviews and through correspondence. Forty CHCs have provided ACHCEW with views on HIV/AIDS, a further nine were consulted in detail on the draft of this document.

This paper does not attempt to give an overview of initiatives and projects in the area of HIV/AIDS. Such a directory, although

needed, was beyond the resources of the current exercise. Instead this paper considers the desired levels of care, training, education etc which any district might be expected to offer. However we would echo the words of one CHC secretary in seeking to "emphasise the positive work being done by groups of people with AIDS/HIV/ARC and professional workers in local authorities and some health authorities".

WHAT IS HIV AND

WHAT IS ACQUIRED IMMUNE DEFICIENCY SYNDROME? HOW IS IT SPREAD?

A major means of infection by the human immuno-deficiency virus (HIV) is sexual intercourse due to HIV-infected semen or vaginal secretions. Therefore unprotected vaginal, anal or oral sex carry a risk of infection. The other two proven routes of infection are blood to blood, (particularly in the sharing of needles) and maternofetal. HIV has been found in saliva and tears but infection via these routes is considered highly unlikely. Commonplace social interactions such as drinking from the same glass are utterly safe. HIV can be irradiated outside the body by a solution of bleach and water in appropriate concentrations. It is much less hardy than Hepatitis B. HIV can only be transmitted via intimate contact. Thus to use words such as 'plague' and 'contagious' in describing HIV are wrong and misleading.

HIV appears to be a lentivirus which means it has a long incubation period and is currently considered to be life long. The virus attaches itself to certain types of blood cells in the body, notably T4 cells. T4 cells or lymphocytes act as 'helper' cells in the body's immune system. A section of the virus enters the nucleus of the cell and becomes incorporated into the cell's own DNA. When an infected T4 cell reacts as part of its immune role, it can activate the latent viral genes, leading to the spawning of complete viruses from the infected cell. The virus spreads, infecting more T4 cells. T4 cells, in which the virus has multiplied, die, selectively damaging the immune defences and leaving the body open to infection. Anti-bodies to HIV are made but they are not effective against the virus. HIV can also cause brain disorders such as subacute encephalitis leading to a gradual loss of intellectual function.

After infection with HIV a person may continue in good health for months or years. Persistent generalised lymphadenopathy (PGL), AIDS related complex (ARC) - also known as chronic HIV infection - or acquired immune deficiency syndrome (AIDS) may develop. PGL is a strictly defined swelling of the lymph glands. Chronic HIV infection indicates that the immune system is somewhat impaired although not warranting the term AIDS. It may result in fever, persistent diarrhoea (for more than a month) and weight loss. There is no certain progression to any of these and no set time scale, although it has been estimated that 30% of those who are HIV+ will develop AIDS within 5 years (Pinching 1987*). Dementia is affecting a growing number of those who are HIV+ or have AIDS. AIDS has an 'episodic and opportunistic profile' as people are only 'ill' due to opportunistic infection which can often be

successfully treated, resulting in short episodes of illness. Between such episodes, people with AIDS will be comparatively fit. Opportunistic infections may affect the lungs, gut, skin and nervous system. People with AIDS may also develop tumours such as Kaposi's Sarcoma. The damage done to the immune system allows disease in the body an opportunity to present that it would not normally have. However, susceptibility increases with time. The mean survival rate after one episode of pneumocystis carinii was reported as 12.5 months in one study (Marasca & McEvoy 1986*). However, these are estimates of life expectancy based on averages of the best and worst cases - the limits they set on life are unhelpful as a prognosis for the individual.

The uncertainty about life after infection can cause severe problems for those who are HIV+ as well as for those who have actually developed AIDS. Yet, as with most illnesses appropriate care support and drug treatment allows a person to manage their disease and continue to live a purposeful and pleasurable life. As one CHC pointed out "It is important to . . . emphasise that HIV/AIDS is not a death sentence. It is more positive to think in terms of living with AIDS rather than suffering from it"

PREVENTION WORK: THE NATIONWIDE CAMPAIGN

The disease, the way in which it spreads, the activities which put people at risk and the way the disease leads to illness all show the need for effective health education which reduces the spread of the disease. This has led to a nationwide education campaign conducted by the government. The campaign was monitored between February 1986 and February 1987 to find out whether it was effective in clarifying the myths and facts about the disease, in offering advice and reassurance, and in influencing the climate of opinion and the attitudes amongst the general public about safe sexual practices.

TV advertising/programmes and leaflets reached a wide audience. A large number of adults and youths (70% and 84% respectively of those surveyed) claimed to know more about HIV/AIDS by the end of the campaign. Homosexual men were the only ones to express a real fear of infection from the HIV virus, 70% of adults and 40% of young people believed they would never be infected. There was an increased knowledge of high risk activities, although this was not necessarily translated into safer sexual activities.

Homosexual men were most knowledgeable about safe sex activities and had drastically changed their sexual habits. Only 4% of those interviewed had made no changes to their sexual habits.

Only heterosexuals who claimed to have had more than one sexual partner in the last twelve months were asked about their sexual habits: 32% had made no changes and only 26% had used a condom on their last encounter. The number of heterosexuals claiming to have had more than one sexual partner in the last twelve months stayed constant at 7%, being higher among men (10%) than women (3%). The percentage was greater among younger people: 13% for 16-17 year olds, and 22% for 18-22 year olds.

The disease is likely to continue its spread while knowledge is not translated into effective preventative action, particularly amongst heterosexuals who do not seem to be accepting safer sexual practices.

One major failing of the campaign was the lack of leaflets etc in ethnic minority languages. Neither was mention made of education for the physically or mentally disabled.

SAFER SEX AND CONDOMS

A high level campaign to encourage the up-take of safer sex, in particular the use of condoms, still appears necessary. Condoms are not a total safe guard against the risk of HIV infection, however they are believed to reduce risk considerably. The use of a spermicide containing nonoxynol '9' increases their effectiveness.

ACHCEW welcomed the advertising of condoms on the TV. It is important to create an atmosphere that enables people to take up safer sex options, so that they do not find it embarrassing to buy condoms and do not stop using them after only a few occasions. Unless people feel happy buying and using condoms then advertising costs may well be wasted. This suggests that a variety of purchasing outlets for condoms is needed, including good quality coin operated dispensers. Condoms are also needed in a variety of strengths. One CHC informed us that a leading high street chemist has decided not to stock Red Stripe condoms through fear of being seen as the 'gay's chemist'.

Wider publicity for family planning clinic services (where condoms are provided free of charge) for both males and females would be welcome. Condoms should be seen as a means of disease control as well as a form of contraception and should be distributed with this in mind. As more people go to their GP for contraceptive advice, doctors should be able to dispense condoms free of charge to men and women. Trials are already being carried out to see whether this would be an appropriate move. Drug misuse agencies and possibly chemists participating in needle exchange schemes should be able to provide condoms free of charge to drug misusers at the project.

THE NEED FOR A CONTINUING CAMPAIGN AIMED AT HETEROSEXUALS

Some may doubt the need for further health education for heterosexuals. Reported infection rates due to heterosexual contact in Britain remain low. However, heterosexual transmission is well established, although in some studies male to female infection is higher than female to male. Infection rates studied in the sexual contacts of infected heterosexual haemophiliacs stand at between 7 - 10% (Proceedings of the 1986 Newcastle conference on AIDS). Infection with HIV has a random nature - one sexual encounter (possibly a person's first ever sexual encounter) has been known to transmit the virus. One does not necessarily know one's partner's sexual history nor can HIV+ status be ascertained by merely looking at someone.

Therefore safer sex has been described as an inescapable personal responsibility coupled with the need to respect one's partner. Complacency is bound to lead to either a 'grumbling' epidemic, or a larger epidemic in years to come, either of which will have a devastating effect on those infected.

Furthermore there are heterosexual groups, possibly businessmen, or servicemen who may indulge in high risk activities away from home and need to be reminded that all unprotected sex carries risk whether at home or abroad. Health education material should reflect this. Health education material needs wide dissemination at air and sea ports.

Prostitution involving heterosexuals may also spread HIV infection. Amongst regular prostitutes in London there is believed to be a high degree of knowledge about risks of sexually transmitted disease and safe sex. (Para 91 Vol I of the House of Commons Social Services Select Committee report on AIDS). Rates of HIV infection amongst London prostitutes is thought to be very low (A Johnson, writing in the BMJ review, BMJ 9/4/1988). The situation outside of London and the predicament of women who are only prostitutes on an occasional basis and therefore may be less knowledgeable and consequently more at risk, is not known. Men must be educated to accept safer sex and use condoms if they visit prostitutes. In Denmark where this happens the sero-conversion rate among prostitutes is almost nil. Little health material has been written directly for prostitutes.

YOUNG PEOPLE AND CONTINUING HEALTH EDUCATION

Young people indulge in more casual sex than the rest of the heterosexual population on average, the percentage of 18-21 year olds who had more than one sex partner in the last 12 months was higher than for any other group according to DHSS survey findings. For this reason further campaigns on safer-sex and risk of HIV infection particularly targetted at young people would appear appropriate. Future campaigns need to provide clear messages in language young people understand, for instance some young people seem to be unsure as to why the condom should be used, saying things like: "I'm on the pill, now that's a contraceptive, so is the condom, does that mean I won't get AIDS?"

YOUNG PEOPLE AND SEX EDUCATION AT SCHOOL

Schools provide a captive audience for educating young people. Although this is not without problems. Teachers must be confident about teaching on HIV/AIDS. Ideally training should not be limited to an expert few, as prejudice or misinformation by teachers generally can be damaging. The House of Commons Select Committee report on AIDS, is convinced of the need for in-service training and some is taking place although the government has indicated that the impetus for this must remain with LEAs.

In practice teaching on HIV/AIDS may be made difficult by the existing equivocal approach to sex education. It is feared that this situation may have been aggravated by the 1986 Education Act

which gave new powers to school governors with respect to sex education. HIV/AIDS education without preparatory sex education introduces children to a fairly frightening and clinical aspect of sex in an incomplete context. On the other hand, the new powers given to school governors (and hence parents) could be seen as an opportunity to spread the educational work of schools directly into the wider community - a further reason for teaching staff to have a thorough understanding of the issues in order to persuade governors of its place in the curriculum. Various organisations such as the HEA and the National Children's Bureau have been working to improve sex education and education on HIV infection in schools. The DES has made a very good video available to all LEAs on this subject for 14-16 year olds.

HIV AND DRUG INJECTING

HIV infection is also a potentially major problem for drug injectors. Drug misuse has risen greatly over the past few years. It is estimated that there are between 60,000 and 100,000 drug misusers in the UK of whom one third were thought to be injecting and possibly 5,000 are HIV+. Between 1982 and 1984 the number of drug notifications to the Home Office rose 90% in general, and 119% amongst the under 24 age group. Drug injection into skin, vein or muscle are all equally harmful, in relation to the spread of HIV.

Are drug users open to health education? The interim evaluation report of 15 pilot needle-exchange schemes commissioned by the DHSS showed that the majority of clients who shared equipment also attempted to clean it. Furthermore the major reason given for attendance by the 769 new clients seen between June and October 1987 was concern about AIDS. Possibly this concern could be translated into preventive action, an approach by drug agencies which would imply an acceptance of the need to prioritise work on combatting the spread of HIV over policies directed at eliminating illegal drug use, as risk of HIV infection does not come from using drugs but from sharing infected needles. Although separate educational campaigns aimed at discouraging the uptake of drug injecting would seem perfectly compatible.

Contact with drug injectors and the establishment of trust are necessary if health education messages are to be promoted. In Amsterdam a Methadone Bus regularly stops at pre-arranged sites giving out free methadone prescriptions to registered addicts. (The methadone substitution method is not widely used in the UK but with the onset of AIDS this may be reappraised. It will have to be ascertained what use is made of the methadone by clients.) The bus also provides new for used needles and a back-up service of health monitoring and education. The educational aspect of any needle exchange scheme is of vital importance.

In the UK the statutory bodies working with drug addicts, along with some voluntary sector drug projects may have a restricted clientele and access, long waiting lists and a therapy based on

withdrawal. The rise in the numbers of drug users over recent years has increased the workload of clinics and strained finances. The short-term nature of voluntary project funding should also be reconsidered.

Some projects address all areas of the drug users life and cover legal, medical and social problems. Yet however 'need' related the project may be, 'detached work' ie contacting users on the street is necessary in meeting unmet need. One Turning Point drug project found that of the 88 new addicts they met through detached work, 72% had never had contact with a specialist drug agency. They also found that women drug users were under-represented in residential and non-residential services.

The 15 equipment exchange schemes mentioned above successfully attracted new clients and promoted preventative health measures. The schemes set out to change the behaviour of drug injectors in order to reduce the spread of HIV infection by counselling on drug misuse and injecting, reducing injecting behaviour which produces risk by shared needles, and reducing high risk sexual behaviour. Schemes varied in size, accessibility, and funding. They also varied in their services to clients, ie the number of needles distributed on each visit (on average seven, but some gave 2 or less). Problems were experienced: in the high drop out rates after two visits particularly among younger clients; the under-representation of women users; and counselling on safe sexual behaviour. However, the schemes successfully contacted users never previously in contact with drug services (31% of clients) and those who were not currently receiving treatment but had previously (35% of clients). Schemes helped obtain primary medical care or social care for users to which they had previously had limited access.

Equipment exchange schemes could become a valuable new tier of care for drug injectors oriented to risk reduction and harm minimisation, properly integrated with but not substituting existing drug treatment services. In the voluntary sector, some agencies are already running equipment exchange schemes often through local chemists who provide needles and syringes either for a limited fee, free of charge or on exchange. (The draw back with chemist based exchange schemes is that counsellors are not on hand to advice users on withdrawal etc.) Some drug projects also provide 'users' with condoms, occasionally DHAs have been reticent about providing resources in order for projects to provide needles and condoms.

Decisions on expanding needle exchange schemes have been left to district health authorities since the government claimed there is insufficient evidence to recommend an expansion of schemes. Guidance will be offered to those authorities who wish to set up schemes based on the experiences of the 15 pilot projects. The report by the Advisory Council on the Misuse of Drugs clearly presents the need for service expansion, the direction it should take and the urgency of risk education for drug users. The report recommends outreach work, community based services and specialist hospital back-up. GPs are identified as important

providers of care to drug misusers. The government made £1 million available in 1987-88 to enable drug misuse agencies to reach more users and to provide counselling for HIV/AIDS. This sum will be made available in future years. However there appears to be no detailed analysis upon which this figure is based.

There is a difference in the percentage of drug users thought to be HIV+ between different towns. Serious consideration should be given to coupling health education for drug users with the implementation of wider policies to which lower incidence of infection are attributable, ie policing policies.

All health workers should address the issue of drug injecting and HIV infection. Drug injectors are not immediately identifiable. Many are not addicts but are only 'social' users. Users who do approach services for help are a minority. Therefore information on safer drug practices needs to be made readily available through a variety of outlets. Many HIV+ drug injectors may go on to develop AIDS. Inpatient care may be necessary. Decisions will have to be taken as to whether to withdraw a person from drug use, possibly against their will on entry into hospital, bearing in mind that continued use of such drugs may damage the immune system, while at the same time recognising that withdrawal will be painful physically and psychologically. A person already in a crisis, possibly facing terminal illness may see withdrawal from drugs as untenable and arguably this should be respected. If a person decides to withdraw they will need help in this, as well as in facing their illness. Behavioural problems related to the use of drugs may be experienced and health care staff will have to assess their feelings, abilities and needs in relation to this. One hospice worker said recently "when we start getting the drug users we will start getting our problems" (Health Service Journal 21.1.88). This may be a misplaced apprehension but nevertheless needs confronting.

DRUG MISUSE IN PRISON

It is suspected that there is wide spread drug misuse in prisons, The prevalence of drugs, and the low supply of needles makes the spread of HIV and AIDS extremely likely. In one Italian prison 30% of prison inmates were HIV+. A survey carried out on behalf of the Council of Europe into HIV/AIDS in prison concluded that "the extremely low figure reported from England and Wales (0.1%) is surprising in view of known high level of drug dependent prisoners in English prisons, but may well reflect a low level of screening" (T W Harding Lancet 28.11.87 p1260). The survey did not conclude that more screening was necessary but that there should be proper consideration of infection control which at the same time maintained prisoners' civil rights. Steps to integrate the prison system into national AIDS health education and care networks are being taken. However, the supply of condoms to prisoners has been rejected by the government. A decision which appears contrary to safer sex initiatives and is regrettable.

HEALTH EDUCATION AND THE PROVISION OF CARE

As well as health education for the public, training programmes are necessary for health staff and local authority workers, to ensure care for patients is humane, without fear or prejudice.

Training should aim to dispel myths, relate the facts on AIDS and HIV, provide information on infection control procedures, confront prejudice, and offer a blue print of practical advice for the sufferer, family and friends on coping with the disease. Training in counselling, care procedures and diagnostic techniques will also be necessary for some professionals. A wide variety of people need training.

Health Education Units are already involved in training and AIDS education. A survey carried out by the HEC in February 1987 found that 99% of Health Education Units are involved with AIDS work, the vast majority have also been contacted about providing in-service training to professional groups. However the list of professionals contacted by different HEUs indicates a great variation in the groups receiving training from district to district, ie not all HEUs mentioned teachers as a contact group. Some CHCs have worked on joint projects with HEUs over AIDS. District and Regional plans for AIDS should include an outline of the role of HEUs. Good practices should be identified and promoted. In some instances extra staff have been employed to work on AIDS, but generally resources in terms of staff time, training and educational equipment, including posters etc are low. One CHC reported that their DHA employ only one health education officer and yet is still expecting any HIV/AIDS work to be undertaken by that department. Extra finances are needed.

CARE IN THE COMMUNITY - IS EXTRA TRAINING NECESSARY?

Counselling

"Believe you me - when you are actually counselling people who may be HIV positive, when you actually have those people coming into your surgery and you are having to give them the result of the test, you are emotionally drained because it takes it out of you tremendously and we cannot just sit there and say that those sort of people are going to come out of the sky. We have got to train people to meet this problem . . ." BMA spokesperson giving evidence to the House of Commons Select Committee

The need for counselling in the NHS had never been fully looked at before the onset of HIV and AIDS. A group of specialist counsellors is emerging and the need for them has been recognised. The psychological stress suffered by people who are HIV+, their partners and family should not be underestimated. A person who is found HIV+ will see their counsellor on at least three occasions and possibly many more. The family of an infected person may feel very isolated and need considerable support. At present, in some districts with high levels of HIV+, counselling of relatives is being taken up by voluntary organisations. In districts where established voluntary support

networks are lacking, statutory services must be mindful of relatives' need for support. The government is committed to funding three counselling training centres in London, Birmingham and Bolton. By February 1987 these had already trained 2000 people. However the training courses are of two days duration and are therefore only helpful as a grounding. Whilst recognising the benefits of these training courses the Albany Society and the British Association for Counsellors emphasise the need for further counselling training for some workers. Some work may need to be done nationally on the job description/training levels of counsellors in order to establish recognised standards.

Irrespective of their expertise, the AIDS/HIV worker may be isolated, and need training and support. A scheme in Sunderland has recognised this. Co-ordinated by the Drug Treatment and Advisory Centre, meetings are arranged on a six or three monthly basis for those working with and counselling clients who are HIV+. This sort of scheme ensures the build up of a body of expertise from various agencies who would otherwise be working in isolation and avoids 'burn out'. The British Association of Counsellors see membership of their group as useful support for counsellors. A national organisation for those working with people who are HIV+ or have AIDS is also being set up.

Counselling, care and the role of GPs

The ability of GPs to counsel and care for HIV+ patients and those with AIDS has been questioned. One CHC claimed: "there have been some occasions on which the counselling offered has been extremely undesirable. For that reason we think that either GPs need to agree to a formula for pre screening counselling, with corresponding training being available or that counselling should only be made available in one centre in each district to which GPs should refer people". A CHC survey of the North West Thames Region found that some GPs were testing without pre-test counselling. This is particularly worrying as in only four of the ten districts covered was self-referral to GUM clinics for HIV tests readily available.

The Royal College of General Practitioners feels strongly that GPs should be carrying out HIV tests, pre and post test counselling and be supporting patients who are HIV+ through all parts of their illness whenever possible, although referral to specialist counsellors would on occasion be necessary. They point out that GPs already care for the physical, psychological and social effects that many major diseases may have on a patient. The care for those affected by HIV or AIDS is seen as a logical extension of their present role. Indeed many GPs are already caring for people with AIDS. In a survey of Oxfordshire GPs one in four of the 235 GPs who responded were caring for infected patients. However, GPs attitudes and confidence varied, in the Oxford survey 85 GPs felt the best they could offer patients who were HIV+ was referral to someone else. Furthermore a study in East Berkshire reported that one in six of responding GPs would not dissent from the idea that AIDS could only be controlled by criminalising homosexuality. This attitude shows a complete lack

of understanding about HIV/AIDS and removes the possibility of impartial or informed care.

Producing a solution to the divergence between the perceived role of the GP and what is found to be the reality on the ground in certain cases, including support for the many GPs who genuinely desire to provide better care, is difficult. The RCGP have produced "distance learning material" for GPs and feel there is evidence that doctors are preparing themselves to "meet the needs of this epidemic". The BMA has produced a video for GPs on AIDS which will be shown nationally to GPs and their staff. The Chair of the RCGP working party on AIDS outlined for ACHCEW the essential role of GPs in the good care of those who are HIV+ or who have AIDS: "General Practitioners need to convince infected people that they are wishing to contribute to their care and will maintain strict confidentiality about the diagnosis. Active steps need to be taken to improve the communication between departments of genitourinary medicine, general practice and the voluntary agencies who are involved in the care of HIV infected people. It needs to improve so that trust can be established and the care of patients improved."

The idea that communication (eg. sharing knowledge about clinical aspects of HIV and AIDS or about local initiatives) should be strengthened between GUM clinics, GPs/the primary care team and voluntary organisations is widely accepted. AIDS patients are estimated to spend around 80% of their time in the community between bouts of severe illness, during these periods it may not be possible for specialist counsellors or hospital medical staff to care for them. With an increase in the number of patients with AIDS personal specialist care will become less available. As with many other illnesses it will be the primary care team and GP who provide the care in these instances. GPs may become responsible for medical surveillance of Zidovudine side effects as more people start to use this drug. As GPs familiarise themselves with the diagnosis of AIDS they will be the first to inform patients of their condition if no test has been taken. The important role that GPs could play is beyond question. (GPs were responsible for first ascertaining the spread of HIV infection through contact with drug users in some areas of Scotland and remain very much involved in their care.)

In reassuring the public that they are constructively working to improve the standard of care to those who are HIV+ or have developed AIDS, GPs may wish to tackle questions such as: Have we the time to counsel and care? What are our training needs? Who are the experts we should be contacting to help us and our patients? With better co-ordination and training much of the concern about where the initial test is taken and who does the counselling and care may subside. GPs could also play a major role in the education of the public regarding the manner in which HIV infection is spread and how to minimise risks - a point which has been given due emphasis by the RCGP Working Party (Journal of the RCGP May 1988 p219).

St Stephen's Hospital has been running courses on the aspects of

AIDS for doctors including GPs. The Government have created six part-time training courses for GPs in the Thames Regions. Further training courses are needed both within the Thames Regions in recognition of the high number of people with AIDS who live in these regions and also in areas away from London where it may be more difficult to get up-to-date information.

Health visitors, community nurses and GP receptionists will all have varying levels of responsibility in providing effective primary care for those with HIV/AIDS, appropriate training for these workers is vital. The primary care team needs to be co-ordinated in its response to HIV and AIDS. This is essential if effective care is to be provided. A policy on AIDS for the whole practice team could be beneficial. The training needs of others working in the community such as community midwives and family planning clinic workers also needs consideration.

Dentists

Dentists need to be aware of infection control. Sterilisation can be a lengthy process. Infection control procedures should encompass all members of the dentist's team including hygienists and nurses. Dentists need to be aware of the oral symptoms unique or very common to HIV as this may be the first indication of someone's HIV status. Dentists should therefore be sensitive to counselling needs etc. The provision of dental care in each district for those who are HIV+ should be resolved and services publicised. Several community health councils have reported HIV+ people finding difficulties with obtaining dental care. One CHC commented: "Even in hospital departments some individuals (haemophiliacs) are being told that dental work will only be carried out as a last resort and that preventive dentistry is not available to them. It is unreasonable for haemophiliacs to expect dental care from General Dental Practitioners because they need Factor 8 cover when work is being done. However for other groups, it would seem likely that they would have difficulty in obtaining good dental care from General Dental Practitioners if they were to inform them of their infection. If the hospital service is also over-defensive, then health is jeopardised."

Local Authorities

Another important participant in care is the Local Authority. There is a need for Local Authorities to train staff, such as home-helps and social workers, if good quality care at home is to be provided for the AIDS patients. In London when the House of Commons Committee reported only one borough - Hammersmith and Fulham - had a fully functional and effective care service for people with AIDS, due in part to the training courses run for staff since 1985. The pressures put upon staff by relatives were taken as a serious aspect of training. Many boroughs are rapidly taking steps to improve services and training. An all-London social services AIDS group hopes to establish a common policy. The national co-ordinating bodies for local authorities are also considering AIDS, HIV and the role local authorities can play. Finance is proving to be a major obstacle in providing adequate

services in several London boroughs and their number will increase. In a recent national HEA survey of Local Authorities and AIDS work of the 82% replying, only 19% mentioned the involvement of social services departments and 20% that of education or housing departments. AIDS programmes have tended to centre around environmental health departments. 42% of local authorities have a nominated AIDS co-ordinator, 9 have employed a person specifically to do this job. Only a fifth had AIDS staff groups but 62% had embarked on in-service training. 194 out of the 294 local authorities mentioning the existence of a health authority AIDS group had observers on the group. Some local authorities were unaware of an existing DHA AIDS group.

HOSPITAL CARE - TRAINING AND RESOURCE NEEDS

Hospital staff, as well as primary care staff need training to deal positively with HIV/AIDS. Resources are also causing problems for some districts.

Since 1984 the Royal College of Nursing has produced guidelines for the nursing and management of AIDS patients. In February 1987 it set up the first post-basic training course in AIDS for nurses which trained over 100 people in 1987 and will train many more in 1988 as 12 further courses running throughout the UK get underway. The government has also announced 14 short-term fellowships for nurses to study and formulate ideas for nursing patients who are suffering from AIDS or are HIV positive but not in hospital. The RCN has an AIDS forum which can investigate complaints received when nurses refuse to care for AIDS patients. Only a small number of cases have arisen and in all but one inadequate training resulted in fear about the disease and to the refusal to care. This can be speedily rectified and the need for adequate training can be highlighted to senior staff. The RCN feel that a de-mystification of the disease will allow nurses to realise that they are not being asked to care for something totally new - in as far as people with AIDS die from cancer, pneumonia, etc. At the same time the RCN is quick to point out the new problems that AIDS has caused nurses:

"they are looking after a group of people who for five years have been told by the media that they are not worthy of care, and that they are going to die. Death for most people is extremely difficult; for the young it is even more difficult. It is extremely difficult sometimes for nurses to care for young people who are dying, so I think that we are highlighting gaps in our educational process both for doctors and nurses in actually communicating with patients, and indeed, listening to patients which is the most important aspect of communication. . . . There is a gap in people's knowledge, therefore support is not coming from above sometimes or it is not coming vertically, but once nurses meet their patients and know it is nursing interventions which will make the path they are going to travel better . . . so nurses see the challenge of caring for this patient population."

Richard Wells - RCN AIDS Officer giving evidence to the House of Commons, Social Services Select Committee

There is also a need for nurses and doctors to know when to call in nutritionalists, occupational therapists, social workers and most importantly trained counsellors, as counselling 'takes far more time than doctors and nurses have to spend with any one patient'. The RCN's approach to AIDS would appear commendable.

Resources have been stretched in certain areas of hospital care for HIV/AIDS. For Genito-Urinary Medicine clinics the pressure of testing and counselling can become great. There are 200 GUM clinics in the UK. Attendance at GUM clinics has risen rapidly over the past two decades, diagnosis has become more difficult and consequently consultation times have increased dramatically. The demands of the HIV disease are reported to be overstressing the service. The Secretary of State did write to all DHAs advising them of the worth of GUM clinics and highlighting them as a priority area for future allocation of resources. A DHSS research team is looking into the pressures GUM clinics face. The South East Thames Regional Health Authority has suggested that in Districts where the pressure on GUM clinics from HIV infection is high, community units dedicated to testing, counselling and outpatient care should be established. Although this may arguably lead to a duplication of resources. All GUM clinics would seem to need full-time counsellors so as to allow doctors the time to carry out medical tests.

The House of Commons Select Committee recommended that "the resources of a teaching or a well-equipped district general hospital are needed, including specialist facilities for bronchoscopy, gastro-intestinal endoscopy and radiology, CT scanning and strong pathology support in microbiology, cytology and histology; access to clinical immunology laboratory services is also needed" during episodes of treatable infection.

The first AIDS only ward was set up in the Middlesex hospital in April 1987. Various arguments surround the setting up of AIDS only wards, ie do patients benefit from being treated wards where people are ill from a variety of diseases, or can a special and necessary comradeship be established on an AIDS only ward? As the number of people with AIDS grows, will a designated ward be able to cope? Does it further stigmatise those with AIDS? Decisions about AIDS only wards will vary from district to district, however efforts should be made to ascertain the preference of those who are HIV+ or who have AIDS. There should be a referral point in each region for advice and training for districts. This referral point should not be seen as a 'dumping ground'.

There is concern over a lack of trained medical specialists involved with AIDS. These would not be 'AIDS experts' but experts in their own field who were willing to use their knowledge in work with AIDS. A particular example of this would be parasitology, as AIDS patients are particularly prone to parasitic diseases such as pneumocystis carinii, and there are a limited number of parasitology departments within the NHS. The House of Commons Select Committee recommended that the DHSS acted to ensure that these staffing requirements were fulfilled rather than rely on districts to ensure that they were met. This is

essential particularly in the light of the statement made by Dr Pinching the senior lecturer in immunology at St Mary's hospital medical school to the House of Commons Committee that "if clinical academics were withdrawn now, this country would not be able to cope with the AIDS problem. It is as simple as that".

CO-ORDINATION OF WORK AT DHA/RHA LEVEL

Many DHAs have appointed AIDS co-ordinators and AIDS action groups to look into training and education needs, as well as care and infection control. Regional health authorities have also appointed AIDS co-ordinators. However, the make up of the AIDS team, the time members can devote to the work, whether or not the co-ordinator has other duties all bear upon their effectiveness, as will the recognition of health service colleagues of the importance of their work. There is already a great variety in the plans being put forward by districts. This does not necessarily reflect the prevalence of AIDS/HIV. Norman Fowler, the former Secretary of State, claimed that analysis of DHA plans showed that 90% had trained counsellors, 83% had made provision for health education and 66% have an HIV action group - it is these DHAs who tend to produce the best plans. It may be necessary to set a prescribed minimum for planning, training, and provision of information to the public on services. The NAHA Working Party Report "AIDS: The Challenge for Health Authorities" makes comprehensive recommendations for DHA action.

In some instances, AIDS work has been taken on in addition to existing duties and this can be overburdening. Hopefully fears that HIV/AIDS action groups and AIDS plans would become smoke-screens for lack of effective action will not materialise. This situation should be clarified if under the AIDS (Control) Act 1987, the present draft circular requesting uniform reporting of DHA action on HIV/AIDS is implemented. In the Government's response to the House of Commons Social Services Committee it stated that "a fundamental requirement is likely to be the agreement by each Regional Health Authority, in collaboration with its District Health Authorities, of a Regional strategy for the provision of services for people with AIDS or HIV infection. Such a strategy will need to clarify the services which each District should plan to provide from within its available general resources, services which need to be provided on a sub-Regional or Regional basis". This implies a thorough exploration of future needs but stops short of a national strategy.

TESTING FOR HIV ANTIBODIES

The circumstances in which the HIV anti-body test should be carried out and its usefulness are disputed.

Testing has a value as an epidemiological tool if it is carried out as part of a programme with high scientific and ethical standards and if it can be shown that the information gathered allows resources to be directed in the most appropriate way. The recently published report of the working group on the monitoring and surveillance of HIV infection and AIDS headed by Dr J Smith,

Director of the Public Health Laboratory service has as its major recommendation that "as a first step in the surveillance of the general population, appropriate antenatal testing programmes be undertaken on a voluntary named basis. There should also be provision for voluntary unnamed testing". The rationale for this is to establish a "reasonably well determined baseline for the prevalence in the general population from which future changes can be detected". Smaller studies mainly centred around GUM clinics are recommended for specific groups, many of which would be expanding upon present surveillance programmes. The report makes clear that there will be contact tracing although acknowledging the sensitivities and difficulties involved.

If the recommendations of the working group are accepted by the Government, ACHCEW would like assurance that: participants (including women at antenatal clinics) receive adequate pre- and post-test counselling; participants (including women at antenatal clinics) are fully informed of the possible implications of a positive test; confidentiality is safeguarded; contact tracing is carried out only with the free consent of the patient; and comments in the report such as "it is important that individuals will not be disadvantaged by having a test" will be acted upon. It is possible that the Government will support the un-named testing of individuals without specific consent. For the present this position has been rejected by Prof. Smith's working group as they felt sufficient numbers of people would accept voluntary testing which provides greater epidemiological information. Un-named testing without consent raises several points: the manner in which the blood is obtained; the maintenance of complete confidentiality; and the ethics of testing someone for an infection with no possibility of informing the patient of the result despite the great bearing this information may have upon their life.

Consent

Legal opinion on the question of 'consent for HIV antibody testing' was sought by the BMA (BMJ 10.10.87). At present, the advice is broadly speaking that:

1. Testing is a form of treatment. Unless consent is sought for treatment, it is potentially assault under the definition of battery "an unlawful application of force to the person of another".
2. The defence that treatment without consent was carried out from the best of motives is restricted to rare exceptions eg, action taken in a great and unforeseen emergency to save the life or preserve the health of a patient. Whether this justification would stand if an HIV antibody test was taken in an emergency involving an unconscious or desperately ill patient remains open to question.
3. Implied consent is unlikely to apply to the HIV antibody test. By presenting oneself for treatment a patient may be seen as giving implied consent to routine procedures

necessary to comply with the request for treatment. However due to the serious implications a positive HIV test carries, the test may not be seen as routine by the courts.

4. Informed consent requires a full explanation of the test and consequences. If consent is given for an HIV test without the patient being fully informed, a charge of negligence or fraud could be levelled against the doctor.

The 1988 BMA AGM may see this guidance challenged.

Consent to testing for HIV under the terms of the Mental Health Act is being reviewed by the DHSS expert advisory group on AIDS to ascertain whether further guidance is needed. Legal advisors at MIND stated verbally that although several months ago they were worried about the possibility of tests being taken without consent, they are now fairly certain that requirements for testing for mentally ill people will be the same as those for the general population. Clearly firm guidance to this effect would be welcomed as a safeguard to patients' rights.

CHOOSING TO TAKE THE HIV ANTI-BODY TEST

Lord Scarman once argued that whereas doctors will be concerned with medical objectives such as the relief of pain, the patient will have in mind "circumstances, objectives, and values, which he may reasonably not make known to the doctor but which may lead him to a different decision from that suggested by a purely medical opinion". What are the medical objectives and personal responsibilities which may lead a person to either seek or refuse an HIV anti-body test?

Uncertainty continues as to the medical benefit of an HIV anti-body test for the patient since it offers no medical solution if someone is infected. This may change if the drug Zidovudine (often referred to as AZT) becomes more widely used and it is established that treatment should begin with the identification of HIV infection rather than with the onset of AIDS related illness. Zidovudine is a drug of high toxicity, which can adversely affect bone marrow and blood. It needs careful monitoring and possibly a number of blood transfusions during treatment. The drug is not a 'cure' but restricts further impairment of the immune system, improves the health of the person with AIDS and prolongs life. Because of the cost of Zidovudine (currently around £5,000 per patient, per year although this may be reduced) DHAs are finding budgetting for demand difficult. Not all DHAs have stocked the drug, although patients can go to a hospital outside their district for medication. GPs can prescribe Zidovudine. GP's prescriptions do not effect DHA budgets. Other drugs are emerging which will also be beneficial in the treatment of HIV/AIDS. These new drugs, unlike Zidovudine, may be free from harmful side-effects, however it would seem that they are likely to carry the same heavy price tag which will pose fresh questions for DHA budgets and GP prescribing policies (Duncan Campbell New Statesman/Society June 1988 p10).

Nutritional levels may be important for those that are HIV+ who need to bolster up their immune system. The cost of extra foods can be high. Payments for special diets for those claiming social security benefit ended in April 1988 although those claiming before then will have their benefit protected.

A pregnant woman who has reason to believe she could be HIV+ may wish to be tested as pregnancy is thought to encourage the manifestation of AIDS in the mother, as the immune system is lowered in order for the foetus to be accepted, which gives the virus a chance to gain ascendancy. However researchers in Edinburgh have concluded that HIV infection per se does not effect the outcome of pregnancy (Frank Johnstone et al BMJ 13.2.88 p467). Abortion is therefore not the only option. A decision either way may be extremely difficult for the mother. Some children born to HIV mothers have gone on to develop AIDS. On the other hand, children have been reported as being HIV antibody positive and then become HIV negative. Whether the child is born a virus carrier or whether the HIV antibodies alone are passed on from the mother remains unanswered. Adequate counselling needs to be given to all women who are pregnant or thinking of becoming pregnant and are HIV+ or think they may be.

For someone who is HIV+, there are problems with whom to tell. Difficulties at work and in getting general medical and dental care may be experienced. The HIV antibody test makes it difficult to get a mortgage or life insurance. Life insurance companies now ask if a person has had a test for HIV, if so further follow up work is done, supposedly to ascertain if someone is in a so called high-risk group. If the test has been carried out for routine blood-testing further enquiries should be unnecessary. In other circumstances insurers would wish to ask additional questions eg. on life style. The Association of British Insurers (ABI) told the House of Commons Social Services Select Committee that extra investigation of a single male regardless of sexual orientation may be carried out, although if living alone or monogamously there would be little problem with cover. Serious questions arise as to how this could be proved.

Representatives of ABI claim that a negative result should not lead to a refusal of insurance. Yet an insurance company is not legally obliged to insure a person nor to look favourably on someone to whom insurance has already been refused for whatever reason. 'Special terms' for those who have been tested may be set in the future. HIV+ people are unlikely to get insurance and people with AIDS are seen as uninsurable. Insurance companies say these measures are necessary for fairness to all insurees. Some doctors have suggested that reports should not be passed on to insurers, but insurance companies claim that this will put up premiums. A Private Members Bill is at present being taken through Parliament to allow patients to see insurance reports being sent by their GPs. Some companies are demanding that all employees take an HIV test because they immediately become part of their occupational care scheme. For those that are HIV+ but do not develop AIDS for years, or those who have AIDS but remain well, employment options will be unnecessarily restricted.

Finally, should testing be promoted because it encourages safer sex? Two studies on the effects of testing conflicted in their findings. One found that those tested reduced their number of sexual partners whether or not they were found to be positive. The other study claimed that those who were positive and those not tested reduced their number of partners, but those who were tested and found to be negative did not (Current topics in AIDS Vol I: the psychosocial impact of AIDS and HIV). In this case counselling alters habits as much as testing.

CONFIDENTIALITY

Questions of confidentiality arise once a test has found a person to be HIV+. DHSS guidelines issued to doctors in 1985 said: 'The strictest confidentiality must be maintained when an HIV antibody positive individual is identified. Where a person is tested for HIV infection or for its complications and it is thought to have been sexually transmitted, Health Authorities have an obligation to maintain confidentiality of information under the terms of the National Health Services (Venereal Diseases) Regulation 1974 (SI1974.9). Unless the patient has given his/her consent, personal health data relating to him/her must not be disclosed to anyone for any purpose other than the health care of that patient except where the disclosure is necessary to prevent the spread of infection.' Disclosure for other than medical/prevention reasons can carry serious consequences.

Patients may well be happy for direct care staff to be informed of their condition. However, the patient's consent where possible should be sought. 'Sloppy practices' with regard to confidentiality may be extremely counter productive - AIDS/HIV still cause a great degree of hysteria, which may directly harm the patient or their family. With a greater emphasis on infection control procedures the knowledge of a particular person's HIV status should be immaterial, since health and safety standards, if followed, are adequate to control infection. This argument applies equally to GPs and primary care staff. The primary care team may offer considerable support to the person with AIDS, but the patient's rights over 'who is to know' should still be respected. Sometimes a patient has not wanted their GP to know due to worries over other family members accidentally being informed.

Confidentiality can be broken in more than one way. One CHC gave the example of an HIV+ person who had gone into hospital for 24 hours for a minor operation, infection control procedures were implemented in an intrusive manner, which singled the patient out as 'different', and where the notes at the end of the bed also included information on HIV+ status. The whole procedure worried the family of the patient who were led to wonder if the 'experts' were taking such precautions, whether they as the patient's daily carers were at risk. A minor operation became a situation which undermined confidence.

To avoid such situations it follows that various managerial

decisions do have to be made in the light of HIV/AIDS. Questions have to be answered, like:

- * are safety precautions effective without being unnecessarily obtrusive or redundant?

- * do safety precautions deal with all special circumstances ie, surgery, laboratory, autopsy, sharp instruments, spills, anatomical waste and dressing changes?

- * is there a hospital public information policy and statement on the care of AIDS patients?

- * can the patient see the same doctor throughout all periods of treatment?

- * what happens to staff who contract HIV at work?

- * what are the discharge procedures for people with HIV/AIDS?.

With the mounting concern about HIV/AIDS, occupational health and safety standards have been reappraised. It has been found that there is often a low level of compliance with the regulations. Attempts are now being made to rectify this - but incidents of staff not wearing gloves, used needles being left on wards waiting for disposal, etc are still being reported. One nurse told the House of Commons Select Committee that there were no dangerous patients just dangerous practices. However cases of people becoming infected with HIV at work remain extremely low.

There are strong arguments against making AIDS a notifiable disease. These include the fact that in countries where sexually transmitted diseases are notifiable there are worse records in tracing partners and getting people to come forward than those who do not (P. 73 Vol II House of Commons Social Services Select Committee report on AIDS). Other reasons for making a disease notifiable do not apply to AIDS. For example no immediate health measures could be taken to prevent the disease from spreading as it could say with typhoid. Finally, it would be impossible to identify all sero-positives so notifying only those that are identified could create a false sense of security.

WHAT ARE THE NEEDS OF PEOPLE WHO ARE HIV+ OR WHO HAVE AIDS?

What are the needs of the infected individual? Many have already been discussed: the need for humane medical care, social and emotional support, and the maintenance of a person's civil rights. Various books have now been written, by people with AIDS or who are HIV+ and by those working in the field, on the needs and feelings common to people with HIV infection. Broadly speaking they are as follows:

- 1) CLEAR INFORMATION about their infection especially at the time they are informed of a positive HIV antibody test. Information may need to be repeated several times over a period of days in order to avoid the situation where facts are not absorbed due to shock.

Information should concern the disease itself and what to do about it. Information on infection control, promoting ones own health, safer sex and support groups could be given along with

help in deciding who to tell and how. Information must cater for the individual. It is wrong to quote average timetables for illness and death. To tell someone that they only have 12.5 months to live imparts a sense of hopelessness and depression when the person most needs hope, and in any event such figures are based on research averages and cannot be applied to individuals. Medical jargon should be avoided.

2) HUMAN CONTACT - a hug, holding hands maybe, warmth and the time to discuss worries, concerns, fears, anger etc.

3) ENCOURAGEMENT to fight an initial sense of doom ie. to fight the feeling of imminent death. A desire to live and fight the disease may soon replace initial despair but the management of depression and anxiety will continue to be necessary in varying degrees, for different people at different times.

Loss of employment, leading to financial difficulties, and other such changes in circumstances due to HIV infection, can cause depression and anxiety too. Anxiety needs to be identified in order to differentiate between the physical symptoms this may engender and the physical symptoms caused by HIV related illness and AIDS. The two need to be treated separately.

Overcoming Prejudice

In his book Living With AIDS David Miller (a senior clinical psychologist at the Middlesex Hospital Medical School) comments "documented experiences of people with cancer, showing that those who fight to live often have a longer and better quality of life (some even overcoming their illness completely) are mirrored to some extent in many people with AIDS. People with AIDS and HIV want to live, but some have reported that the reactions of people around them, including in some cases doctors, often encourage them to see such desires as futile!" yet "a sense of hope and a reinforcement of the will to fight for life is, for most patients I have spoken to, information of the same importance as the nature of their diagnosis and methods of infection control".

However, a patient can be tyrannised by positive thinking. When a person is exhausted by ill health there are limits on the ability and will to fight. Feelings of guilt and failure may result from other people's imposed positiveness. Clearly encouragement needs to be sensitive.

The media has concentrated on negative images of AIDS/HIV. However, people with AIDS/HIV have reacted in a positive manner by directly challenging such stereotyping. They have emphasised 'living' with AIDS rather than 'suffering' from it. Yet ability to fight disease, anxiety etc also depends on the reaction of others, as David Miller explains "HIV is not something to fear - it is something to fight. But to fight it effectively, everyone affected - patients, (para)medical staff, and carers (lovers, spouses, families, friends, work colleagues) - must be clear about what this phenomenon means on a social, medical, practical and emotional level. And they must learn to communicate this

knowledge effectively. For so many of my patients, fears aroused by their diagnosis or knowledge of infection have been matched by their fears about the reactions of those around them. It is most important that our management of this infection and its disease be not clouded by intolerance, prejudice or fear. AIDS is a disease, and HIV is an infection, in which all 'victims' are innocent". Since some people have lost their livelihood, home and friends through being HIV+, the anxiety due to anticipated social rejection is real.

PARTICULAR NEEDS OF HAEMOPHILIACS

The testing of donated blood and the heat treatment of blood products are essential for a reduction of HIV spread among haemophiliacs in particular and through blood transfusions in general. These precautions have been undertaken and it is thought that the rate of transmission through these routes in the future will be negligible.

However the effects of HIV infection among haemophiliacs should not be ignored. Many haemophiliacs became infected with HIV through contaminated Factor 8 (a blood clotting agent used in treatment for haemophiliacs). Imported Factor 8 was primarily responsible for infection. Haemophiliacs now need considerable reassurance about the medical treatment for their condition, and there are of course particular problems associated with their original illness, eg the provision of dental care.

There are also many young haemophiliacs infected with HIV. A conference in Newcastle in 1986 were told that of 104 10-14 year olds tested, 68% were HIV+, rates were similar for 15-19 year olds but less among younger children. The DES has given clear guidance recommending that HIV+ children attend school as normal. However, in schools where no teaching on HIV/AIDS has taken place this may create difficulties for the child. Some thought also needs to be given to home tutoring of children who become ill. Evidently the parents of these children also face many difficult questions, such as when to inform the child they are HIV+, talking about sex etc, as well as caring for them if they become ill.

SUPPORT NETWORKS

Support networks for all those with HIV/AIDS are extremely important. The services offered by voluntary groups vary. The following list is not exhaustive.

- * FACTS (The Foundation for AIDS Counselling, Treatment and Support) provides medical support outside of hospital for those who do not want to be treated by their GP, as well as providing support to GPs and others in the care of their HIV seropositive patients.

- * London Lighthouse offers a variety of services including, when the building is completed, residential care. It will have 24 beds and plans to offer continuing care from the time a person first realises they are HIV positive. It also plans to provide a home support service throughout London to enable people who are

HIV+ or have AIDS to live independently at home.

* Frontliners are a group of people who have AIDS or ARC, who meet fortnightly for social support which breaks down feelings of isolation and to work on projects. The emphasis is on living with AIDS and helping others to do the same.

* Body Positive is a support group for people who are HIV+ allowing people to help each other combat possible feelings of isolation and powerlessness. They also offer over the phone counselling, hospital visits and training weekends for people who are HIV+.

* Black Communities AIDS Team offers support to Black people who are HIV+ or who have AIDS, and hope to set up a Black buddies scheme. They provide information to the ethnic minority community in a variety of languages, and also provide information to organisations about dealing with AIDS within the ethnic minority communities.

* The Terrence Higgins Trust, as well as being the centre for a variety of support activities, has also been a powerhouse of information and publications on HIV/AIDS. The Terrence Higgins Trust also runs a Buddies scheme offering one-to-one support for people who are HIV+ and their families.

Setting up a support network is not easy. Peoples' trust has to be gained and sensitivity is needed in advertising the group's existence. The Buddy group run from the Terrence Higgins Trust has 400 buddies. Selection procedures are undertaken and training given. Similar voluntary support services will be necessary for those with HIV/AIDS throughout the country. Some initial support for these projects may be needed from statutory bodies along with premises in which to meet privately.

Voluntary support groups or self-help groups bring positive benefits for the individual from working with others in the same situation. They also arise in order to fill gaps left by statutory medical and social services. However, they may also be instrumental in guiding service provision in many boroughs and health districts. The voluntary nature of self-help and support groups needs to be respected, in order to avoid unreal and possibly damaging expectations being placed upon them. On the other hand, statutory bodies need to recognise the essential work voluntary groups are carrying out and provide the necessary finance and resources. Even the Terrence Higgins Trust, which plays a fundamental role in HIV/AIDS education and in supporting those infected, still finds finance a major worry.

A wide network of locally based telephone helplines has been established. Attempts are being made to form a national co-ordinating body. Helplines are extremely important first points of contact as the incredible number of calls received by the Terrence Higgins Trust and the national AIDS helpline make clear. However, they are not a substitute for face-to-face support for body positives and those close to them. Telephone helplines and personal support services should both be made available.

It is understood that the National AIDS Trust has been set up to promote and co-ordinate voluntary sector AIDS/HIV work. However

there seems to be some doubt as to what this body is presently doing. Public coverage of their work would be useful.

SUPPORT SERVICES AND TERMINAL CARE

The majority of those who are HIV+ or who have AIDS are young - between 18-45. This is a group in the population who society are unused to connecting with death or long term illness. Many may be living alone without informal care support. Moreover, many aspects of AIDS or AIDS related complex such as prolonged diarrhoea, are extremely disabling. The provision of a community laundry service funded jointly by the Local Authority and DHA which could wash soiled sheets etc, can make the difference between being able to cope at home or not. Respite care and meals on wheels may both be needed. A person may have been forced to leave his/her home either due to prejudice or severe illness. Housing for those with HIV or AIDS where a person has security of tenure is needed. One project which plans to offer accommodation is London Lighthouse, based in an area with one of the highest levels of AIDS. This project is now widely accepted by a once hostile community, although in a rural scottish area a similar project failed to get off the ground due to local opposition. Local Authorities need to consider adding AIDS to their medically at risk criteria for priority housing.

Hospice care for those with HIV/AIDS is limited. Some hospices are reluctant to take AIDS patients because of fears over funding and due to a perceived difficulty in introducing young terminally ill people into a predominantly elderly setting. In fact at work, in leisure and at home young and old live side by side often benefitting each other by their presence. Hopefully more hospices will start to accept those who have AIDS. Some form of adequate government backing must be assured for new hospices being set up by voluntary organisations as more hospice type houses seem likely to be needed in London and major cities.

WHAT CAN CHCS DO?

As one CHC put it "Ideally action should be taken in advance of need, so this is a reason for CHCs keeping themselves fully informed and ensuring that appropriate provisions are made".

CHCs can play an important role in supporting good health care, and education programmes. They can also assist people with complaints about treatment. Some CHCs have been heavily involved in such work. In 1985 Central Manchester helped set up the Manchester help-line services. Croydon, Wandsworth, Brent and Tower Hamlets have run seminar days on AIDS (Tower Hamlets have written their seminar up in pamphlet form, including a large section on problems involving the worried well). North Lincolnshire worked with voluntary groups and the local health education department to run a series of public education seminars on AIDS. Paddington and North Kensington, along with Bloomsbury and Riverside CHCs have regular meetings with voluntary groups working in the area of HIV and AIDS. They are now embarking on a quarterly newsletter 'HIV News' to bring together information and

expertise from the statutory and voluntary sectors throughout the three districts. Harrow CHC have surveyed HIV anti-body testing and counselling in North West Thames via the CHCs in the region.

Exeter and District CHC have set up a special interest group on AIDS/HIV for members. Their terms of reference were:

"To comment on the implementation of Exeter Health Authority's policies on AIDS having sought local views (so far as is practicable) of people with AIDS; those who are sero-positive and those concerned they may have been at risk; and having consulted the Authority's AIDS task force, the Exeter AIDS forum and any appropriate voluntary organisation."

In line with this the group has identified their first objectives as being to: (a) determine the nature of provision of services by the Health Authority, (b) find out what other organisations exist, what they offer and whom to contact, (c) obtain the views of those who are HIV+ or who have AIDS in order to identify what their requirements are, and (d) look at what counselling services are available. The Exeter group have now produced a report which amongst other things calls for an increase in staff and resources for health education, increased access to counselling services and a properly funded future for the drugs project. They would be happy to let other CHCs have copies of the report.

For those CHCs who are working in this area, a possible checklist of issues to cover would include:

- 1) DISTRICT HEALTH AUTHORITY - is there a DHA strategy? Is there a DHA working group on AIDS/HIV? What actions and activities have they undertaken? Who is involved, and, in particular, are people who are HIV+ or have AIDS involved?
- 2) TESTING - does testing always involve pre and post test counselling? Is there a district agreement on who should do counselling and what standards apply? Have GPs been involved in this decision? Is self referral available?
- 3) TRAINING - which groups of health care workers receive training? How were training standards decided? Has it been effective, ie do patients feel happy with their care?
- 4) EDUCATION - is the health education unit over stretched in terms of resources and time due to extra HIV/AIDS work? Are posters etc about HIV/AIDS in evidence in public places? Are women adequately but sensitively informed about HIV in ante-natal clinics? Is there a DHA policy on education for drug injectors? Does the Local Education Authority have a policy on teaching about HIV/AIDS?
- 5) CARE - are care plans being developed for community and hospital care? Does this include joint planning or joint funded posts with the local authority? Are there sufficient staff trained in the various specialities needed to treat AIDS patients? Will the DHA be obtaining Zidovudine? Is adequate and varied terminal care available?

- 6) VOLUNTARY GROUPS - are there voluntary groups working on HIV/AIDS in the district? What services do they offer, how can they be contacted? Do they need assistance, ie use of CHC offices for meetings? If drug misuse services are provided by the voluntary sector are these adequately funded?
- 7) RESOURCES - are sufficient resources available for the above? If not, what gaps in services are appearing? What pressures are being felt?

CONCLUSION

"I think it is only fair at the outset to make the point that additional central funding for AIDS was never intended to reflect the full cost to health authorities of providing AIDS-related services".

Tony Newton in a letter to a CHC

Caring for people with AIDS is expensive, although estimates of the cost of health care for those with AIDS vary. The latest figures for 11 months care in the community combined with one month hospital care were put at £21,858 or £27,055 if Zidovudine is prescribed for each individual. Within this the hospital costs account for some £5,600 (Deirdre Cunningham and S F Griffiths BMJ 10.10.87 p922). This estimate is much greater than earlier estimates.

The Government has announced extra monies of around £7 million to be earmarked for 1987/88 HIV/AIDS work in the regions most affected, and £50 million has been allocated for all DHAs for 1988/89. As the number of people with AIDS increases, a large amount of this extra finance could be taken up by Zidovudine.

There will be an inevitable need for extra resources in future years. Even if the spread of infection is rapidly curtailed, there are a considerable number of people who are already HIV+ and who will need treatment. In some districts the numbers are considerable and money must be targetted to these. In any event HIV/AIDS is a new illness which needs to be recognised in all aspects of health care provision and there will be a major cost in respect of training and diagnostic arrangements, as well as treatment. Extra finances will be needed if this is to be fully achieved. At a time when many DHAs are having to cut services, extra finances for HIV/AIDS work will only come with increased overall funding of the NHS.

At the same time Local Authorities would like to see extra financial allocations made to them in recognition of their role in the care of those ill with AIDS and infection control. Only limited extra money has so far been made available by central Government. This leaves local authorities unable fully to carry out their essential caring work, and also means that not enough is being done in providing training and information to local authority employees.

Of course much of the work developed in relation to AIDS/HIV infection will have a wider use. For example improved counselling skills and better ways of communicating with patients about their condition and terminal care can be used positively in other areas of health work. Similarly community housing units for those with AIDS need not be designated specifically for this group but could include units for the elderly etc. Concern about infection control has already led to measures which will not only restrict the spread of HIV but also of Hepatitis B. The integration of HIV/AIDS into other areas of health care is necessary and can be beneficial.

There is a great need for both national and local co-ordination. The Government has given a substantial sum to the Health Education Authority for its AIDS programme and the work proposed is welcome. It is important, however, that the HEA is now given the opportunity to co-ordinate AIDS work at a national level and encouraged to move quickly on the various initiatives proposed.

Inevitably, of course, most work on AIDS/HIV infection have taken place at local or grass-roots level. Liaison between health and local authorities and with the voluntary sector at that level is also of great importance. Special jointly-funded AIDS Liaison posts may be helpful in this.

It is important to avoid complacency, much may already appear to have been done about AIDS/HIV. However the long-term reality of caring and supporting a substantial number of people with AIDS has yet to be fully addressed. This will have to be done against a background of continuing popular mis-information and prejudice. Although some of the initial hysteria may have disappeared, there remains the potential for a very authoritarian response. This will not be in the interest of anyone, least of all people with AIDS or who are HIV+, their carers and those who are close to them.

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SOURCES OF INFORMATION ON AIDS

* The HEA has a resource list of books, leaflets, posters, videos etc produced on AIDS, free of charge from the resource unit - send an S.A.E. The HEA also produce AIDS UK which is a quarterly epidemiological briefing on AIDS and HIV in the UK

* AIDS PREVENTION is a newsletter produced quarterly and distributed to all HEUs. Back copies can be obtained by sending an SAE to Islington Health Education Department, Royal Northern Hospital, Holloway Road, London N7 6LD. For the current issue ask your local HEU. The newsletter has a section on local and national initiatives plus a resource section.

* AIDS NEWSLETTER - 45.00 per annum (20 issues) is available from the Bureau of Hygiene and Tropical Diseases, Keppel Street, London WC1E 7HT.

* The AIDS LETTER - 12.00 per annum (6 issues) available from Royal Society of Medicine, 1 Wimpole Street, London W1M 8EA

* The TERRENCE HIGGINS TRUST, BM AIDS, London WC1N 3XX (including newsletter)

* IMMUNITY a registered charity for HIV education and research. Work includes co-production of a leaflet for prostitute women. Address: Immunity, BM Immunity, London WC1N 3XX

* FACTS a registered charity providing medical treatment, counselling and support. Particularly willing to provide information/share expertise with GPs in the diagnosis/care of HIV+ patients. FACTS, 25 Melbourne Way, Bush Park, Enfield E1 1XG

PATIENT'S BILL OF RIGHTS

Reproduced from AIDS: a strategy for nursing care by Robert Pratt

1. The right to quality health care in an atmosphere of human dignity without regard to age, ethnic or national origin, sex or sexual orientation, religion or presenting illness.

2. The right to receive emergency medical and surgical treatment.

3. The right to considerate dignified and respectful care by all health care workers, regardless of the patient's physical or emotional condition.

4. The right to be informed of the name, title and function of anyone involved in their care.

5. The right to receive upon request an explanation of their current medical condition in language that they understand.

6. The right to give or decline true informed consent and to participate in the choice of treatment. If consent for treatment is not given, the right to be informed of the likely medical consequences of their action.

7. The right to privacy to an extent consistent with providing dignified medical and nursing care.

8. The right to confidentiality.

9. The right to be informed and to participate in their discharge planning.

10. The right to refuse participation in research projects.

11. The right to receive, upon request, a consultation and/or care and treatment from another appropriate physician on the staff other than the one assigned to them.

12. The right, both as patient and citizen, free from restraint, interference or coercion, discrimination or reprisal to voice grievances and complaints and to recommend changes in policies and services. This implies the patients have access upon request to senior nurse managers.

13. The right to expect visitors to be treated with courtesy and respect.