DEPARTMENT OF HEALTH AND SOCIAL SECURITY

CARING FOR PEOPLE WITH AIDS IN THE COMMUNITY

Report of a conference held at the Institute of Education
University of London on Wednesday 25 March 1987

Edited by Dr Sandra Williams

King Edward's Hospital Fund for London

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Foreword

Over a thousand people in this country have now been diagnosed as having AIDS, and over half of them have already died. Whatever our success in educating people how to avoid infection with HIV, sadly we shall see thousands more cases of AIDS among those who are already infected. These will be mostly young people, who will need care and support in the face of an often debilitating, and ultimately fatal condition.

The development of a network of services and support for people with AIDS is a challenge for voluntary agencies, for the National Health Service and for local authorities. There is a consensus that services should, as far as possible, be provided to enable people to be cared for in their own homes. The task now is to develop appropriate services on the ground.

Different agencies have much to learn from each other. And we can all benefit from experience overseas. It was in order to share knowledge and widen understanding that the Government called a conference of key people last March to consider the provision of services in the community for people with AIDS. It was a valuable day, and we are grateful to all who took part. We are also indebted to the King's Fund for agreeing to publish the proceedings. I strongly commend anyone who is concerned with the development of services for people with AIDS to read this report of the conference.

Rt Hon Tony Newton OBE MP
Minister for Health

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Opening address

Rt Hon NORMAN FOWLER MP Secretary of State for Social Services

The Secretary of State began by welcoming delegates to the conference. He thanked those who had come to give keynote speeches, to chair seminar groups or to act as rapporteurs at the final session. He was particularly grateful to Dr George Rutherford who had come to share his experiences of care programmes in San Francisco.

Mr Fowler then went on to describe the considerable progress made by this country in developing a four-part strategy since the AIDS threat had become evident:

1 Public health measures had been taken, such as the screening of blood donations;

2 A major public education campaign had been directed at informing people how to avoid infection and was now entering a new phase, aimed at reaching high risk groups like drug misusers and encouraging local initiatives to complement the national campaign;

3 Proposals from the Medical Research Council had been agreed for a directed programme of research into vaccines against HIV infection and into therapeutic drugs for those with AIDS;

4 Services were being developed for those who were infected or who had the disease itself.

The purpose of convening this conference was to focus on the fourth element – the development of caring services – in order to see if delegates together could find a way of developing the most effective form of care for AIDS patients who did not require acute hospital care.

Mr Fowler warned delegates that however successful the public education campaign was, the size of the problem would grow. He referred to the conclusions of a conference which he had convened earlier in the week, which had focused on predicting future trends in the spread of HIV infection and AIDS. Although cautious about making forward predictions, the consensus view at this conference had been that over the next few years numbers would continue to rise steadily.

Emphasising the value of international cooperation in the struggle against AIDS, Mr Fowler mentioned that he had recently visited the United States to discuss respective national responses. There were three points about the American experience which he wanted to bring to the attention of delegates. First there was the extent to which the response to AIDS had come from the whole community, not just health care workers. Second it was clear that a 'continuum of care' was needed, ranging from hospice care at one end of the spectrum, to being able to stay at home at the other. Third it was apparent that successful care programmes had developed out of experimentation and had not necessarily worked perfectly first time around. Although he was aware that any patterns of care developed here must be appropriate for this country, he reminded delegates that there was much to learn from the experience of other countries.

In developing patterns of care for this country Mr Fowler emphasised that a number of central issues needed careful thought, and he pointed out that some of these issues had been allocated for discussion in the seminar groups. He listed, for example: finding the most effective role for hospitals as a 'resource' for care programmes outside hospital; examining the role of the hospice; thinking about the relationships between those who provide direct care to AIDS patients and those, like GPs and community nurses, who already have an important role in health care outside the hospital; considering how best to draw on voluntary support; and looking at how to manage, coordinate and monitor new care programmes effectively.

To provide a background for these discussions, Mr Fowler expanded on the series of practical measures, together costing around a quarter of a million pounds, which the Government was taking centrally to help the development of care programmes. These six measures focused primarily on staff training, on setting up pilot projects and on coordinating forward planning and service provision. They included:

1 Funding a fellowship, tenable for three months, in each of the 14 health regions for a nurse to study and formulate ideas for the nursing practice for those infected or who have AIDS but are not in hospital, and for reports of these studies to be published as a set of collected papers.

2 Funding, for one year, two part-time training appointments for general practitioners in each of the three Thames Regions which were treating the majority of AIDS patients. This would provide the opportunity for some GPs to gain direct experience in the care and treatment of AIDS patients by taking sessions in the hospitals, under the supervision of hospital doctors.

3 Establishing a pilot scheme for an AIDS Regional Advice and Support Centre which would be community-based, would serve as a focal point for education and support for families and others sharing the care of patients in their homes, would be run jointly by the health and local authority and would have close links with voluntary bodies.

4 Planning a unit in London to meet the need for training hospital specialists and GPs in the clinical management of AIDS patients, and looking at the possibility of establishing a counselling training unit in the Midlands (on the same lines as the two units already operating in Bolton and Paddington, for which funding had been doubled) for health care professionals.

5 Reviewing the wider needs of nurse education, (the allocation to the English National Board for this had been doubled) and, in consultation with the Board, funding workshops in each of the health regions to increase senior nurse managers' knowledge of the management of AIDS and HIV infection in the community and the education needs of their staff.

6 Examining social services care and support for AIDS patients, including staff training needs, through a working group led by the Department of Health and Social Security. Advice on the implications of AIDS for the NHS would be provided by an informal working group also led by the Department, but mostly made up of members of the NHS.

Mr Fowler had listed these initiatives to emphasise the importance he attached to developing care services for AIDS patients outside hospital. He favoured caring for AIDS sufferers in the community not because it was a cheap option or an easy option, but because he believed it to be the right approach and, moreover, the approach preferred by those needing care. He advised delegates that the shared objective in the months and years ahead must be to develop statutory and voluntary services which, wherever possible, enabled AIDS patients to be cared for in their own homes.

KEYNOTE SPEAKERS

The San Francisco experience

GEORGE RUTHERFORD Medical Director of AIDS Office, San Francisco Department of Public Health

Dr Rutherford expressed his hope that by sharing San Francisco's considerable experience of dealing with AIDS and the other clinical manifestations of HIV infection, he might help delegates plan their own out-of-hospital care systems for AIDS patients. He began by reviewing some of the epidemiology of AIDS in that area.

Epidemiology of AIDS in San Francisco

Using a series of slides he showed that there had been over 3,000 cases of AIDS diagnosed in San Francisco and that (based on the mathematical modelling of the epidemic curve) there would be 4,485 cases diagnosed by June 1988. Using these projections he also estimated that there would be 1,449 living AIDS patients by June 1988.

He looked at AIDS cases by transmission category and suggested that in several respects AIDS in San Francisco more closely resembled the demographics of AIDS in northern European countries than it did New York. In the United States as a whole, gay and bisexual men comprised 74 per cent of cases and heterosexual drug users comprised 17 per cent of cases, whereas in San Francisco gay men comprised 97 per cent of AIDS cases and they were a fairly homogeneous group.

Dr Rutherford described how in San Francisco they had assessed the acute and chronic care needs of their patients. Through interviews with random samples of living AIDS patients' physicians and through hospital discharge by diagnosis data, they knew that on any given day approximately 10 per cent of all living AIDS patients in San Francisco would be hospitalised and that up to another 10 per cent of living patients would probably be in need of subacute, intermediate or skilled nursing care or hospice services. Additionally, for every 10 hospitalised AIDS patients there would be about one ARC patient in need of acute or chronic care. Therefore they estimated they needed bedspace to hospitalise up to 22 per cent of all living AIDS patients, half in acute care and half in chronic care, at any one point in time.

Subacute care and support services

Dr Rutherford then went on to discuss the complex system of interrelated subacute and support services, which he saw as the hallmark of San Francisco's response to the AIDS epidemic. He said this type of care was designed to be medically appropriate, psychosocially supportive, culturally sensitive and cost effective. It aimed to minimise unnecessary use of acute care facilities and to maximise the potential for patients to be cared for outside the acute care setting.

He identified subacute, intermediate and skilled nursing care as slightly different cases of licensed health care in settings which provided constant monitoring by nursing staff of patients needing hospitalisation, but not acute care. This service could be provided through freestanding institutions like nursing homes, or as part of an acute care hospital. Typically AIDS and ARC patients admitted to these facilities would have diarrhoea, dehydration, or dementia and would be admitted directly from an acute care inpatient unit. Dr Rutherford said San Francisco had less than 25 beds for this type of acute rehabilitation and that expansion of these services was their highest chronic care priority in the coming year.

Moving on to discuss home health care, he said that this was provided primarily through the successful in-home hospice programme, which brought hospice care to a patient's home, rather than delivering it in a hospice building. He described the hospice services as multidisciplinary and fitted to the needs of the individual patient in the terminal phase of their illness. Admittance to the hospice usually followed final hospitalisation, and Dr Rutherford quoted the average daily census in 1986-87 as 63 patients and the length of their stay in the programme averaged 57 days.

He explained that in-home hospice services were frequently provided in a variety of housing programmes available for AIDS patients as well as in their own homes. He further mentioned that in-home nursing and medical assessments of AIDS and ARC patients were undertaken by public health nurses and, experimentally, by physicians and psychiatrists. This enabled patients to remain at home and only visit their physician when a treatable condition was diagnosed.

Housing

San Francisco's experience had shown that housing for AIDS and ARC patients was sometimes required and Dr Rutherford went on to describe the three types of housing needs he had encountered: short-term emergency housing for patients in fairly good health while they looked for more permanent accommodation; long-term housing for those capable of living cooperatively without constant staff supervision; and long-term housing for those less fitted for cooperative living, such as drug abusers or the ambulatory mentally ill.

He sketched out the two housing programmes currently available: the San Francisco AIDS Foundation's Emergency Housing Program and the Shanti Project. The Emergency Housing Program houses patients in a programme-managed facility for up to one week and assists in finding housing. A disproportionate number of its users are chronic substance abusers and are ineligible for other AIDS housing programmes. The Shanti Project provides low-cost, long-term housing in 11 donated houses for 44 AIDS and ARC patients and promotes cooperation, emotional stability and residents' independence. Shanti staff do not live in or provide meals, although home health care and practical and emotional support services are available. Dr Rutherford added that a 21-bed residential treatment programme for AIDS and ARC patients with substance abuse problems and a hotel for homeless AIDS and ARC patients ineligible for other housing programmes were also being developed.

Practical and emotional support

Drawing attention to the practical support moderately to severely ill patients needed to maintain themselves at home, Dr Rutherford outlined the range of activities provided by volunteers under a programme of the Shanti Project. Additionally he mentioned a food bank operated for poorer AIDS and ARC patients by the San Francisco AIDS Foundation.

He also described the range of emotional support services available. These encompassed crisis intervention, psychotherapy, support groups and peer counselling groups for AIDS and ARC patients and support groups for family, lovers and friends. Once again the Shanti Project was singled out as providing one of the more innovative emotional support services.

Social services, legal referral and advocacy

Focusing on social services advocacy, Dr Rutherford told delegates that acute care hospitals, subacute facilities and home health care agencies all provided this service for their patients, typically as they entered the terminal phase of their illness. The San Francisco AIDS Foundation dealt disproportionately with poorer patients and with those with substance abuse problems, and provided social services advocacy earlier on in their disease.

He added that free or reduced-cost legal services to AIDS and ARC patients and their partners was provided by two private organisations. Furthermore, the San Francisco Human Rights Commission dealt with complaints of discrimination against AIDS or ARC patients as defined by the city's AIDS anti-discrimination ordinance.

Subacute care and entry points to support systems

Pulling together the threads of his presentation, Dr Rutherford concluded that systems of subacute care could be broken down into three broad categories: medical and nursing care (including subacute, intermediate and skilled nursing care, home health care and in-home assessments), mental health services and social services. He saw the first two groups as particularly closely related to hospital inpatient and outpatient care and used slides to show delegates the schematic relationship between inpatient, outpatient and community-based medical, nursing and mental health services.

He then went on to show how and when these services fitted into the patient's clinical course and described the efficient movement of patients between services at different times during their illnesses.

Costs of subacute care and support services

Discussing the costs of subacute care and support services, Dr Rutherford said the real point was that even in the face of the relatively high cost of subacute, intermediate and skilled nursing care, community-based care was substantially less expensive than the alternative of hospital inpatient care.

Recommendations

Summing up, Dr Rutherford said that San Francisco's problem was how to develop further its system of out-of-hospital care to meet an expanding caseload, which increasingly included intravenous drug users, minorities, women and children. He saw the audience's problem as where to begin this process. He was unsure how far San Francisco's network of services was translatable to an area with a less concentrated gay population, but he believed the concept of home health care could be tried here. He recommended starting with out-of-hospital nursing care and volunteer-based practical and peer counselling support services, on the basis that other social services and mental health services would follow. Key factors in this evolution would be dedicated community-based service organisations who could recruit, train and supervise volunteers.

QUESTIONS

In the discussion that followed Dr Rutherford's speech, Mr Fowler sought confirmation that in San Francisco the sharing of drug equipment was not one of the major problems so far as AIDS was concerned. Dr Rutherford agreed this was the case. He added that the clinical course of the 12 per cent of cases in San Francisco who were both gay men and intravenous drug users more closely resembled that of gay men who were not intravenous drug users, than of heterosexual men who were intravenous drug users. He thought San Francisco might be an anomaly in the United States in that there was a large percentage of white middle-class gay patients around which support services could grow up.

Dr Charles Farthing, who works with AIDS patients at St Stephen's Hospital in London, asked Dr Rutherford to clarify further what he meant by subacute care. Dr Rutherford said he perceived subacute care as inpatient care with an emphasis on nursing care for a patient convalescing from an acute hospitalisation who did not need acute care medical services, but did require constant nursing services and was too ill to be able to participate in his own care.

These patients typically remain in subacute care for a period of a few weeks and are discharged to home (and, if appropriate, to in-home hospice care) or, if chronically debilitated with little hope of improvement, to skilled nursing facilities. As there is a shortage of skilled nursing beds, many patients who require skilled nursing care will be cared for in high acuity-level, more expensive subacute care beds. The aim was to move these patients into the more chronic care institutions, but Dr Rutherford said the shortage of chronic care, nursing-home type beds meant it was unlikely that acute beds could be turned over fast enough to meet the demand.

Dr Farthing said there seemed to be a terminology problem here because in Britain hospices would provide that subacute care. In reply Dr Rutherford attempted to distinguish hospice care from subacute care. He saw the latter as a higher level of care than would be provided in a hospice, perhaps involving continuous intravenous medication, and that the aim of subacute care was convalescence or rehabilitation rather than terminal care.

Professor Eric Wilkes asked Dr Rutherford to explain why people did not die at home among a young middle-class population. Dr Rutherford clarified that about 60 per cent of patients in San Francisco did die at home with the services of in-home hospices. Others died unexpectedly in acute care hospitals or required a level of care beyond that which was available through the hospices. Professor Wilkes was uncomfortable using the word hospice here because it seemed to mean different things to different people.

Dr Pinching from St Mary's Hospital, Paddington, wanted clarification as to how much the formidable voluntary sector in San Francisco – which would not necessarily be available in this country – had contributed to managing the caseload. He also wanted Dr Rutherford to recommend a strategy for linking together the statutory hospital and local authority services and voluntary services. Dr Rutherford was unable to provide the figures for the cost of voluntary services, but to give some perspective he said that Shanti had around 600 volunteers working for it at any given point in time and a budget of $3 million per year. These people worked eight hours a week, giving a total of 200,000 hours a year of free services. These services were not inexpensive to run as people had to be paid to recruit volunteers, to train them and to supervise them. As to how to get organisations to cooperate, Dr Rutherford said that in San Francisco they were in a position to insist on cooperation because they paid them. He explained that Shanti received 60 per cent of its funding from the Department of Public Health, which was also the statutory authority for the San Francisco General Hospital. He admitted that without this lever it would be difficult to ensure cooperation. He added that getting community-based organisations to grow up from scratch was a problem. Shanti had been an existing organisation for cancer patients and other patients with terminal illness, which had responded to the AIDS epidemic.

Picking up on the issue of continued care, Ms Barbara Young asked how long patients would spend in hospital when this was available. Dr Rutherford reiterated the point that most patients died at home, but that on average they spent about 20 days in the course of their disease in hospital. He added that it was becoming increasingly difficult to meet the growing demand for 24 hour a day hospice care in the home. With the opening of a traditional residential hospice in February (the Coming Home Hospice) it was likely that more severely ill patients would be moved to the traditional hospice-type facility in the final weeks of their illness.

Mr Herbert Laming wanted further information about prevention and about predictions for the future. He asked whether Dr Rutherford was planning for a continued increase in the demand on services, or for a tailing off which would affect the level of service required.

Referring to research done on the natural history of HIV infection and on the percentage of patients infected who would eventually develop AIDS, Dr Rutherford said that in San Francisco they were anticipating there would continue to be a huge number of cases. Correspondingly, services would need to grow way into the future.

The shortage of chronic care beds was a real problem. He thought it unlikely that HIV transmission could be stopped easily and expected that in San Francisco ongoing transmission was likely to be through intravenous drug users and their sexual partners. He also alluded to the problem that services which had been tailored effectively for the white middle-class gay community were unlikely to be appropriate for other groups, such as the poor innercity populations. He added that two kinds of facilities were being considered for intravenous drug users: a modified detoxification treatment unit; and what amounted to an hotel for AIDS and ARC patients who had a subacute illness, were mentally ill or homeless and who were ambulatory.

Models of care in the hospital and community

MICHAEL ADLER Professor of Genito-Urinary Medicine, Middlesex Hospital

Professor Adler began by reminding delegates that as a hospital physician he was not directly involved in caring for patients in the community, but he was acutely aware of the importance of community services for his patients. He urged delegates to consider not just the 'AIDS sufferers' identified in the conference title, but also those with HIV infection, some of whom had physical, psychological, social and occupational problems that required as much care as those patients with AIDS. He congratulated Mr Fowler for mounting a comprehensive and unique public health campaign, but nevertheless agreed with Dr Rutherford that the best that could be hoped for was a slowing down of the epidemic.

In his talk he covered three areas: the effects of HIV and AIDS on the hospital service; some epidemiological and general questions with relevance to service planning; and an overview of the different approaches which could be used to provide care within the community.

Effects of HIV and AIDS on the hospital service

Professor Adler said that the estimated median incubation period from infection to AIDS was five years and could be longer. Once diagnosed, patients could live for a number of years. After a patient had developed AIDS each bout of acute illness would require hospitalisation and would weaken the patient further. Using slides Professor Adler showed that the median survival rate varied with the presenting manifestation of the disease.

He informed delegates that nearly 80 per cent of the cases in the UK had been looked after in the four Thames Regions, and particularly in St Mary's, St Stephen's and the Middlesex Hospitals. He used the case load of AIDS patients at the Middlesex Hospital to illustrate the common problem of an increasing case load which is expensive and eats into other acute services. This had increased from the first case seen in 1983 to a total of 89 cases by the end of 1986, with a projected cumulative total of 445 by the end of 1988. Professor Adler said that the Middlesex Hospital had recently opened a new ward dedicated to AIDS with 12 beds, but that it was already outgrowing this facility. This shortage of beds acted as a spur to cut each patient's length of hospitalisation, but Professor Adler said there were other reasons, not least patients' preferences, for care outside the hospital setting.

Focusing on the cost of care for patients, Professor Adler said that at the Middlesex they had estimated the lifetime costs of inpatient and outpatient care for their first 30 patients and had found total costs of about £7,000. Although this study showed that basing calculations on those who died tended disproportionately to select those with short survival time, he did not think it could be assumed that costs of care would rise proportionately to survival times.

Care requirements would vary according to the stage of the illness and also the diagnostic category. As about 80 per cent of hospital costs related to inpatient and room charges, Professor Adler pointed out that a reduction in length of stay by developing community care or outpatient based care could substantially reduce the cost of hospital care.

Epidemiological and general questions relevant to service planning

Turning to service planning, Professor Adler said it was important to consider the future size of the problem. He said they had calculated that by the end of 1988 there would be an average bed need of 334 inpatient beds nationally, the majority of these being in inner

London where beds were currently being reduced. The annual cost of these beds would be approximately £15.5 million.

Professor Adler admitted that these calculations were limited. He argued that good epidemiological and mathematical models were needed in order to predict more accurately what would occur for the rest of this century, and to avoid planning services in a vacuum. He also thought it was vital for planning services to look at the natural history of progression of HIV infection and the size of the spectrum. Epidemiological data suggested that anywhere up to 35 per cent of individuals infected with HIV would progress to AIDS, but this was likely to be an underestimate. He explained that the spectrum of infection with HIV was wide, ranging from totally well, asymptomatic individuals through to patients with full-blown AIDS, and that it was important to have accurate assessments about the proportions in each group at any one time and about movement between groups. He raised the further issue that the introduction of Retrovir (AZT) and other treatments could alter both the size of the spectrum and the natural history of AIDS, and could have implications for the costs of care.

On a more general level Professor Adler raised the issue of whether, apart from the anxiety and hysteria surrounding the infection, HIV infection and AIDS were really special and different from other medical problems and required special facilities. He raised the possibility that the need for this conference illustrated that the National Health Service, local authority and community services were not good at working together, regardless of AIDS. In this respect he thought the Griffiths overview of community care was very timely.

Professor Adler told delegates that he was concerned about the 'backlash phenomenon' of AIDS, whereby certain groups in the health service felt their problems were being ignored and that AIDS was attracting all the money and the publicity. He thought this backlash could be attenuated to some extent if community and terminal care services were also examined with a view to making them work more efficiently, so that all client groups, regardless of condition, would benefit. He speculated that if such an examination came up with the right answers there would be no need to think about AIDS as a separate issue, since the service would deliver the goods as it would do for all other patients.

His final question on service planning, which he thought important for Mr Fowler to consider, was whether the objective was to save money or reallocate money. He asked whether the goal was to save money by reducing expensive hospital care, or whether that saving would be redirected into community services. He saw a danger in assuming that the San Francisco model could be recreated easily in the UK. With a welfare state and the NHS he did not think it a safe assumption that community services here would be largely underwritten by voluntary donations and volunteer labour as they had been in San Francisco. As to whether savings from a reduction in bed days would bring with it a shift of resources from hospital to community, Professor Adler had no answer; but he said that the precedent of mental handicap and mental health, where there had been a shift to community care without a shift in resources, did not augur well for AIDS.

Overview of approaches

Professor Adler then went on to look at the array of approaches that could be adopted for looking after patients with varying degrees of HIV infection and AIDS. He prefaced this review with the remark that community services would work only if primed by an extensive educational programme directed towards those who were expected to do the work.

He proposed that an antibody-positive but well person should be monitored regularly, either in general practice or in outpatient departments of genito-urinary medicine. Wherever possible, when symptoms developed, the patient should be cared for in the community or in an outpatient department. The transition from antibody positivity to AIDS may be heralded by an acute opportunistic infection or tumour. The first episode should normally involve hospitalisation, since the diagnosis of AIDS was dependent on accurate clinical and laboratory diagnosis. Convalescence could be at home under the supervision of a GP, or a day care centre, which could be community or hospital based.

When a subsequent acute infection occurred, Professor Adler suggested that the patient could be managed in a series of ways: by the GP and his team, by a hospital team in a day centre, or by a hospital based home care team which could go into the patient's home and provide back up for the GP. He also discussed the possibility of setting up a network of hostels for patients who were too ill to live at home but who were not ill enough to be in a hospital or terminal hospice. Finally he talked about the general shortage of terminal care facilities and made it clear that he did not feel it was necessary to set up terminal care homes specifically for AIDS patients. He argued that an examination of hospice facilities within the UK was required so that more places for all types of patients could be found. In areas treating many AIDS patients a complementary approach would be to develop terminal home care teams, to enable those who wished to die at home to do so. He added the observation that not all AIDS patients died slowly and some would be unsuitable for terminal care facilities. Currently a significant proportion of acute hospital beds were also used for terminal care of those who died in hospital as a result of acute or complicated infections.

Professor Adler concluded his speech by encouraging delegates to develop a series of different models of care, which could be evaluated in the tradition of classical medical care studies and would help identify the most efficacious, acceptable and cheapest form of care. In this context he described in detail the type of hospital-based home care team or AIDS support team that he and his colleagues wanted to develop at the Middlesex Hospital. This team would intervene at different points in the disease progress and would provide the link between community and hospital and hospice care. He said that the NHS and local authorities in the UK offered the same infrastructure of community services as now existed in San Francisco. The challenge was to make them work.

The role of nursing

SUSANNE OXLEY Senior Nurse, Infection Control, Westminster Hospital

Ms Oxley began by saying that she was pleased to share with delegates the experience she had gained working with AIDS individuals during the past three years. In her capacity as Senior Nurse, Infection Control, one of her major tasks had been identifying care for people with infectious conditions. She believed strongly that a system similar to that operating in San Francisco could be instituted in Britain. She reminded delegates that they represented the wide range of care services that needed to respond cooperatively to the AIDS problem and said that in her talk she would focus on the role of nursing in this capacity.

She emphasised that an important aspect of the role of nursing was that it focused on the person as an individual and responded to needs on an individual basis. She expanded on the aims of community nursing in meeting people's needs by quoting a passage from the Cumberledge report. This summarised the principles of community nursing as: promoting maximum independence and autonomy of the individual, while at the same time providing appropriate support in the community; preventing wherever possible hospital admission; working cooperatively with informal carers and other health professionals and statutory and voluntary agencies to provide a comprehensive network of care; and involving people in the community, as well as field workers, in the planning and evaluation of services.

Ms Oxley said that these activities were essential for the continuity of care. They applied without exception to all individuals – healthy, sick or dying – and that AIDS and HIV infection should not present any problems that delegates were not already adept at responding to on a human and professional level. However, she was aware the problems did exist and although some of these appeared unique to AIDS, she believed AIDS simply highlighted the deficiencies in the existing health care system in relation to promoting health and well being, working in partnership with clients and providing care for young chronically sick and dying people.

She went on to discuss how a reality could be created out of the ideological principles of community nursing roles. She argued that it was important for everybody to recognise their roles throughout the spectrum of HIV infection and she believed this spectrum began with the uninfected population. Information about HIV disease and its transmission should be included in nurse training and imparted to the general public. To counteract sensational media reports it was necessary to reinforce the non-prejudicial information that HIV could infect anyone, but that it was not highly contagious and infection could be prevented.

She thought that this positive education could be provided in the variety of community settings where young people came into contact with the health care system and in health education programmes in schools. It should also continue through to providing pre-test counselling for individuals requesting HIV antibody testing and, subsequently, post-test counselling and support.

Ms Oxley's experience had shown that promoting health and independence meant supporting parents as well as the clients. In this respect she saw voluntary bodies such as the Terrence Higgins Trust and Body Positive as providing the lead in what should be a cooperative activity of assisting clients to retain a sense of power over their lives. The Westminster Hospital, among others, had developed counsellor posts in response to these needs. She viewed this support as particularly crucial during the transition from ARC to AIDS.

To meet the ever changing needs of this client group Ms Oxley reiterated that it was important to work with a model of continuity of care centred around the individual and his informal carers, with good communication between all parties, and with objectives discussed and planned as a team. She thought the setting up of community liaison posts based in hospitals would help coordinate events on admission and discharge. Home care teams working from hospitals and day centres, such as that planned at St Stephen's Hospital, could also help close the gap between hospital and community care.

Ms Oxley went on to discuss some of the problems presented by an approach which aimed to maintain patients in their own homes. For example, community nurses were not able to administer intravenous drugs which were often necessary to treat opportunistic infections and malignancies. There were also problems associated with the need for intravenous fluids and repeated blood transfusions. Furthermore, community nurses could only give drugs prescribed by a doctor and it was possible the GP might be unaware of the patient's diagnosis.

Ms Oxley queried whether the resource implications of promoting care in the community for all individuals in this country had been met. She said that in her area they had managed to achieve good continuous and terminal care in the community, particularly where good home support with continuous in-home carers had been available. However, she was aware that it could take a district nurse at least an hour per visit to care adequately for an AIDS patient at home. The resource implications were considerable, especially in the terminal stages of a patient's illness when frequent visits were required. In her area they had also successfully involved informal carers in the hospital setting. She thought this was a model for hospital care that should be moved towards.

Questioning the assumption that every client necessarily had a home to be nursed in, Ms Oxley went on to discuss the role of hospice care. She acknowledged the problems of a general shortage of hospice care. She also raised the point that AIDS presented hospices with the added dilemma of possible termination of their financial support from their largely private contributions. She thought there was perhaps a responsibility for ensuring that funding was maintained, and wished the London Lighthouse success in its mission to provide care for AIDS patients.

Finally Ms Oxley reminded delegates that they needed to work with one another and with voluntary organisations and informal carers to provide a cohesive approach to community care. She was also emphatic that professionals needed support and training in order to function effectively in caring for AIDS patients. She alluded to the fact that there were only two nursing representatives on the specialist advisory group on AIDS and concluded by asserting that nursing had a valuable, if not the largest, professional contribution to make in community care.

Planning community services

ANDREW HENDERSON Director of Social Services, Kensington and Chelsea

Mr Henderson said that he spoke as Director of Social Services of one of the three boroughs in West London, within whose boundaries well over 50 per cent (probably around 70 per cent) of the total of people with AIDS in the UK either lived or were being treated. He estimated that in the Royal Borough of Kensington and Chelsea there were probably 120-150 residents with serious health problems from AIDS or ARC and a much larger but incalculable number of people with HIV. He believed these figures would be up to 1,000-1,500 in two to three years time.

The planning crisis now

Mr Henderson argued that to some extent the use of hospital care had shielded some social agencies and the community itself from the full implications of the AIDS problem, but it was important for them to realise that they were confronted with an immediate planning crisis. Soon the hospitals would not be able to cope with increasing demands, and people not requiring active treatment would have to leave hospital whether or not they had a satisfactory place to go.

He welcomed initiatives like this conference to help make progress in identifying the most effective forms of community provision for AIDS patients, to ensure that funding was available for this provision and to evaluate and disseminate models of provision. Although pleased that the DHSS was initiating a study of the health service and community services provision in his area, he realised they would have to plan and act on data currently available.

Community care and philosophy

Mr Henderson acknowledged that AIDS was an exceptional health crisis, but stated that the problems it presented were similar to those affecting other client groups requiring community care. Moreover, his experience of working with people with AIDS showed that with adequate support they wanted to continue living in their own homes and, wherever possible, to die there too. This client group had the same rights as any other to look for the support necessary to maintain them in the community, and statutory agencies had the responsibility to respond.

Types of care

Starting from this assumption, Mr Henderson said that what was required was the well-tried prescription for community services involving a combination of individual counselling and support, domiciliary services, group and day-care support, supportive housing provision and, for some, residential respite or terminal care. The sorts of agencies involved in providing this care would be those already working together to provide community care. However, Mr Henderson qualified this by adding that a new factor was the need for education, training and continuing support for staff involved, to help them overcome their own fears and prejudices concerning AIDS. He referred particularly to the fear of catching the infection, the fear of death and also homophobia. He complimented Mr Fowler on both the Government's education campaign and on his own key role in this.

Believing that the feasibility of extending services to AIDS patients depended on the willingness of other agencies to become involved (for instance, hospices) and also on the reaction of the local community, Mr Henderson said there were lessons to be learnt here. There had to be a commitment to education and training as the means of changing staff and community attitudes towards the setting up of services for people with AIDS. There also had to be a realistic assessment of what was feasible.

Models of care in Kensington and Chelsea

Mr Henderson went on to describe models of care being developed in Kensington and Chelsea. Although he hoped these had relevance elsewhere, he reminded delegates that his area contained highly atypical social conditions, had an unusual demographic make-up and, like other inner-city areas, had a tradition of heavy reliance on hospital services and residential care.

First line care for people living at home

With family links and friends in short supply, Mr Henderson said that in his area a key factor in maintaining people in the community was in giving emotional and practical support. Domiciliary services to people with AIDS were integrated into normal service provision, but currently relied on volunteers in the workforce. In addition, the support of well-organised and trained volunteers was needed and was provided by the Terrence Higgins Trust, Body Positive, London Lighthouse and sometimes CRUSAID. The important role of counselling was undertaken by the regular social work teams although, in addition, two specialist social workers were members of the team at the AIDS Clinic at St Stephen's Hospital.

Group work and day care

Mr Henderson said there was evidence that groups or networks were more effective than individual counselling in engendering positive attitudes to living life well and constructively. In this context he described several important developments by Body Positive, London Lighthouse and St Stephen's Hospital.

Residential provision

Aware that some people with AIDS would not have a home which would enable them to stay out of hospital, Mr Henderson thought there would be a need for a variety of special housing provision, perhaps provided by trusts within the housing association movement. He pointed out that the lead time for housing projects argued for a rapid allocation of resources in that direction.

He then turned to terminal and hospice care. In his view more important than the compelling argument that hospices and residential homes were cheaper than hospitals was the fact that for people not requiring active treatment, yet who could not remain at home, some form of terminal care home was a better place to die than a hospital. Also, AIDS was taking its toll of young people. Bearing in mind both the shortage of hospice care and the specialist needs of this younger age-group, Mr Henderson said he thought that specialist hospice-type care might be needed in areas with a high incidence of AIDS.

An integrated model of care

The objective of integrating services for living with services for dying was seen by Mr Henderson as important as integrating statutory and voluntary services. His department had acquired funding for three years from a charity for an 'AIDS care organiser', whose task was to design an integrated package of care for each individual with AIDS. He singled out the London Lighthouse, which was developing residential care as the last element in the total interlocking set of services offered, as a model for both the statutory and voluntary sectors to emulate. However, this would require collaboration, and Mr Henderson pointed out that this was particularly difficult where the geographical boundaries of organisations involved were not coterminous.

Mr Henderson's concluding remarks concerned finance. He thought that if, as he hoped, the community care approach was officially endorsed by the Government, this had to be coupled with an endorsement of a system of central coordination and a fostering of local initiatives. There also needed to be a mechanism for targeted special funding, both to the statutory sector and the voluntary sector. The key for people with AIDS was to take charge of their health and of their living. The key for delegates was to rise to the challenge of planning integrated services.

QUESTIONS

In the general discussion that followed the keynote speeches, Dr Linda Benson expressed concern about the lack of resources and mechanisms for training and supporting all staff in looking after AIDS patients and sought advice on what to do about this. Professor Adler said there was a need for some sort of organisation to try to take on this role and relieve the burden from those working in the field who were currently providing training and support on on an ad hoc basis. He referred to the centres which were being set up to train counsellors and speculated as to whether this type of centre could act as a resource centre providing educational material. Ms Oxley described how Riverside Health Authority had responded to the training needs of health care workers and community care workers and mentioned the training package developed for GPs at St Stephen's. She thought the need for counselling and support had to be clearly identified and demanded.

Supporting Mr Henderson's comments about the feasibility of community care by social services departments, the Rev Nicholas Stacey drew upon the experiences of the community care project for the elderly (monitored by the Personal Social Services Research Unit at the University of Kent) to suggest that there was probably an enormous untapped resource of volunteers who could be mobilised to help AIDS patients remain at home. This point was picked up by Mr Fowler, who asked Mr Henderson whether there was still an untapped reservoir of volunteers. In reply Mr Henderson, though encouraged by the possibilities, drew a distinction between areas like Kent, which had a stable community full of potential volunteers, and London, where volunteers were not from a middle-aged settled population but were largely professionals who felt moved to do more than they were doing already. He argued that his experience with London Lighthouse showed it was necessary to have a concomitant training programme for volunteers and this needed to be costed into the use of volunteers.

In response to a question from Dr Farthing about London Lighthouse, Mr Henderson confirmed it was intended that the central Lighthouse building would provide subacute care and that Lighthouse would help and assist smaller home hospice units in the surrounding area. He explained that it was a voluntary project and was not confined precisely to the Royal Borough of Kensington and Chelsea. If funding was acquired for the residential project it could be in place within the year and the model of care would be what Dr Rutherford had described as subacute care. The cost of the building and its conversion was £3 million, towards which Lighthouse already had half a million. They had applied to the Government for further funding.

Explaining that because a higher proportion of identified seropositive individuals were drug addicts, the problem in Scotland was rather different than in Kensington and Chelsea or San Francisco, Dr Brooks of the Scottish Home and Health Department asked Mr Henderson whether he could comment on his experience of drug addicts. Mr Henderson confirmed that drug addicts were not a major feature of the problem in his part of London. He said that in so far as the general run of social and community services for drug addicts tended to be shouldered by the voluntary sector, it was likely that these voluntary bodies would play a significant role in response to AIDS. London Lighthouse would be open to drug addicts if they fitted in, but there was no experience yet to show whether this would or would not be the case.

In response to a question from Mr Fowler, Dr Rutherford confirmed that in New York drug misuse played a greater part in the transmission of HIV infection than in San Francisco. Nevertheless in New York care services had tended to grow up around gay men, and intravenous drug users were stuck in hospitals. They wanted to avoid this happening to intravenous drug users in San Francisco and he referred to the two approaches for accommodating drug users that he had described in his speech. Ms Oxley said that at St Stephen's Hospital the vast majority of the drug user population with AIDS had come from community psychiatric nursing referrals and from the drug dependency clinic. She thought that these individuals were best maintained within that specialist area where they were already receiving support for their drug abuse. Community psychiatric nurses involved in the community-based detoxification programmes had had extensive experience in AIDS counselling and provided this in individuals' homes.

Mrs Elaine Lever raised the problem of health care professionals being over-cautious in their contact with AIDS patients and thereby conveying the wrong message about the risks of infection to the non-professionals. Professor Adler took this point and used it to support his argument for an extensive training and support programme for all those people in the community looking after patients with HIV infection and AIDS.

Dr Paula Kilbane asked whether there were any epidemiological predictions about another special group that was emerging — young people with dementia — and whether there were any suggestions about how to deal with this problem. In reply Professor Adler reiterated that it was important both to describe the spectrum of infection and to keep a close watch on how the clinical picture was changing. He made no predictions but thought the care for someone with dementia would probably be very different from that required for someone with straightforward sarcoma or pneumonia.

Mr Henderson was unsure whether dementia indicated the need for a very different range of care from the social angle, but thought it was something that was particularly distressing for the people concerned and for people around them. Dr Rutherford informed delegates that the Centre for Disease Control had changed its case definition to include dementia and encephalopathies, as well as wasting, as part of the spectrum of AIDS, so that there would be very accurate numbers of how many patients presented encephalopathy. Several speakers observed that mental disability was rarely seen without the physical as well, so that deterioration was usually on both fronts.

SEMINAR GROUPS

The afternoon session began by participants dividing into six seminar groups, each of which spent the next 90 minutes discussing a particular aspect of caring for people with AIDS in the community. In the final plenary session that followed, Mr Fowler invited a rapporteur from each group to report on the key points which had emerged during discussion.

Final plenary session

Key points reported from seminar groups

Group 1 : Role of the hospital outpatient department as a bridge between hospital services and community care

Mr Fowler asked Mr Robert Pratt, Senior Nurse at the Charing Cross Hospital School of Nursing, to speak first. His group, chaired by Professor Michael Drury, had looked at the role of the hospital outpatient department as a bridge between hospital services and community care. He said their discussion had focused on two specific issues: training and the referral system.

They had been clear that the outpatient department had a role to play in facilitating training and that the educational initiative was essential. They had concluded that training should be targeted in a tailor-made fashion for each group concerned, and that the intensity of training should be directed at those areas of the country where the need was more urgent. The question of who were the appropriate trainers had been discussed because it had been recognised that clinicians would not be able to deal with everyone requiring training. The group had explored the cascade system, where there would be training for the trainers, and had looked at where this might be appropriate, for example trade union officials instructing employees throughout industry.

Mr Pratt said that although they had not got very far in deciding on the message that should result from training, they had thought it important to report back to the plenary session that messages currently promoted must include aspects of how not to acquire HIV infection, as well as how to acquire it. They thought that probably the most important aspect was that training should take advantage of well-established systems in training structures into which AIDS and HIV related issues could be built.

In addition to training, the group had also discussed the referral systems used in outpatient services and the referral systems bridging hospital services and community services. In this context they had looked at, but had not found solutions to, the difficulty of potentialising the use of the general practitioner because of the confidentiality problems which could present a barrier to using the standard system of care. They had also looked at the new links being formed between genito-urinary medicine clinics and community services, and had concluded that these should be strengthened.

It had been their view that all care should be shared between the outpatient department and the GP, that new experimental support systems should be encouraged and that all should be community-based rather than hospital-based; perhaps built on existing models and systems such as care of the elderly, maternity systems and community-based paediatric physicians.

Mr Pratt concluded by saying that the group had run out of time while considering the development of walk-in clinics. These not only offered initial pre-screening counselling and screening services, but had a central coordinating role for clients who required it, for instance, between the outpatient department, the hospital itself, community services and voluntary services.

Group 2 : Role of hospices

The second rapporteur to be called was Ms Barbara Young, District General Manager of the Paddington and North Kensington Health Authority. She summarised the key points of her group's discussion on the role of hospices, which had been chaired by Dame Cicely Saunders.

Ms Young said the group had begun by asking themselves what exactly was hospice care. The description given by some group members who were involved with hospices had fitted what was needed for care of people dying from AIDS, but there were problems in simply using the current hospice movement. The patients concerned would be much younger than the normal sufferers dying in hospices and the period of time when they would need support, from diagnosis to the first hospital inpatient admission, was comparatively long, and would need to be linked into the hospice movement. Moreover, the group had recognised that hospices were overstretched already and were unlikely to have the spare capacity to deal with this new caseload. There had also been some concern that the acceptance of AIDS patients as well as cancer sufferers might affect their traditional source of funding.

Ms Young said the group had gone on to look at what the existing hospice movement might actually provide. They had concluded that in addition to education, training and dissemination of models of care, the movement could also provide for care of the dying in hospitals and people dying at home. She said there had been some indication that if funding was made available, the traditional hospice providers would take on a separate role in caring for AIDS patients, but not in the same facility.

Following on from this, the group had considered what hospices might provide if they specifically looked after AIDS patients. Ms Young said they had thought it possible to set up special facilities in districts or areas with large concentrations of AIDS patients. But where only one or two patients at any one time needed AIDS care, the normal care facilities for the dying might have to be used. Ms Young commented that they had also discussed whether a small group living project, such as that operating in San Francisco, might be more appropriate. They had agreed that drug misusers presented particular problems and that because of their disruptive life style this group was not easily accommodated in the same facility as other patients.

In the context of looking at the interface between hospice, hospital and home care the group had considered the various reasons why the theory of the GP as the lynchpin of this often broke down in practice. Ms Young said it was clear that the idea of careful discharge planning was relevant if the GP was not keen to take on this role of lynchpin. Those involved with the hospice movement had advised that by working with GPs in individual cases it was possible to impart expertise in looking after people who were dying, and to give GPs the confidence to be more able to cope next time they had a patient in a similar situation.

Hospice at home and home care had been discussed and they had recognised the expressed wish of many AIDS sufferers to die at home. Ms Young said the group had seen the need for

Whether home teams should be hospital linked, based in hospices, or be community teams with a community focus, had been the subject of tense debate. Ms Young reported a warning against over medicalising and over professionalising the model for community care.

Finally, Ms Young said that the group had considered the question of funding. A number of people had felt that this was currently insufficient to do things that could and should be done. All the agencies represented in the group were familiar with existing models of care based on care groups. They had a clear idea about what was possible and were clear that something had to be done quickly. They simply needed the resources to get on with it.

Group 3 : Provision of housing and residential care outside hospital

Professor Eric Wilkes spoke next. He said that his seminar group, chaired by Herbert Laming, Director of Social Services for Hertfordshire had had a lively discussion about the provision of housing and residential care outside hospital.

Considering accommodation for HIV positive drug misusers, the group had thought it might be necessary to liberalise the facility policies and not insist on drug withdrawal before admittance to any extra accommodation. Focusing on the future of HIV positive children as another special interest area, they had been heartened to note that the training of foster parents in this exacting work had proved to be possible.

Before looking at special accommodation in the community for AIDS sufferers, they had tried to pin down what was so special about AIDS. They had identified the social disapproval, inaccurate information about infectivity and the different culture associated with AIDS. They had also noted the youth of the sufferers, the implications of this for bereavement aftercare and the explosive growth in numbers. They had concluded that there were valid reasons for treating AIDS as a special case, but not necessarily a problem requiring much in the way of special accommodation.

Professor Wilkes reported the group's view that sheltered housing provision should probably be normal sheltered housing, although the legal, political and administrative decisions leading to the expansion of this resource would be special. Under the umbrella of sheltered housing, there had been agreement in principle that support group living could be approved, but some disagreement as to whether HIV and AIDS sufferers should be housed separately from or integrated with other residents. Professor Wilkes said the group had decided that both approaches were necessary and would have to be tackled.

In considering whether special AIDS units could be made acceptable to the local community, the group had been heartened by the fact that good community development practice had achieved a reasonable measure of success with similar developments in other fields; for example, special headquarters in the fields of mental illness and mental handicap. However, with special AIDS units it could take a couple of years to achieve this acceptability and in some areas of London this was too long to wait.

The group had gone on to recognise that the case of AIDS belonged to the family, where there was one, and that the need for family support would have to be part of any special accommodation package, not removed from it.

Professor Wilkes said that the group had discussed the possibility of positive discrimination for people with AIDS being exercised by directors of housing on the medical grounds of vulnerability, but they had not been sure whether this would actually solve any problems. They had, on the other hand, been very supportive of special facilities such as the London Lighthouse model which, with its 26 units of accommodation, would allow flexibility and coordination in meeting the needs of AIDS cases. The group had gone on to identify a need for 24-hour nursing supervision accommodation in the community. They had thought that in some cases the easiest way to provide this would be for directors of social services to buy nursing home care from private nursing home sources where these homes were not only registered but were appropriate to these vital responsibilities.

In view of their concern that eagerness to learn from the London experience could result in the over-resourcing of premature structures elsewhere in the country, the group had thought it necessary to look closely at the scale of what provision was likely to be necessary in the major connurbations outside London. They had also been worried about the management problem of coordinating care in and between different regions, social services departments, district health authorities and special interests, including the interests of the voluntary sector.

Group 4 : Care at home: role of the caring professions

Dr Anthony Pinching, Clinical Immunologist at St Mary's Hospital, summarised the frank exchange of views his group had had on care at home and the role of the caring professions. This session had been chaired by Rosalynde Lowe, Chairman of the Health Visitors Association.

Dr Pinching began by reporting his group's unease with the term 'AIDS sufferers'. He thought many people would prefer to say 'people with AIDS' and to include by extension those people with any illness resulting from HIV. He said that in discussing the role of the caring professions, the group had first looked at the varying needs of patients and had emphasised the importance of flexibility in responding to those needs. This discussion had touched on the needs of the different risk groups, in particular intravenous drug users, children and people of African or other ethnic backgrounds.

The group had considered the relative contributions of statutory and voluntary services. Although they had agreed that existing services should be utilised rather than new ones created, they had recognised that in the short term it might be necessary to by-pass existing services that failed. Dr Pinching said that they had emphasised the need to ensure that existing services started to take up their proper role and that this depended heavily upon education, training and a sense of involvement.

They had then focused on who should plan and coordinate the services provided by the different community care professionals. Dr Pinching said that the particular problems of the inner cities had been a constant theme in their discussion. In particular, the different roles and contributions of general practitioners had been identified as a key problem. Some members of the group had argued strongly that the GP was ideally placed and trained to coordinate activities. Others had pointed out that this rarely happened, largely because patients were often unwilling to involve their GPs.

The group had moved towards a model of care which featured a key worker, who enabled liaison and cross-referral between the different elements of a broad multidisciplinary resources team. Ideally this key worker would be the GP but, particularly in inner city areas, it could be any other adequately trained community care professional. As a way forward for the future in addressing the problem of the general practitioner, Dr Pinching said that it had been suggested that some GPs could be identified as specialists in AIDS.

Keen to avoid the mistakes which they felt had already been made in funding the hospital service, Dr Pinching said the group had been unanimous that adequate funding was needed for whatever community service provision was decided upon. In this context, they had discussed the cost of staff training and the option of using paid volunteers. They had also identified a need for joint planning and joint funding, but had acknowledged the obstacles that were created by a lack of coterminosity of authority boundaries. Dr Pinching said they had concluded that a proper management structure with accountability was essential and had suggested, perhaps impertinently, that Sir Roy Griffiths might find this an interesting area to get involved in.

Group 5 : Care at home: services to patients

Dame Anne Springman, Chairman of East Sussex Family Practitioner Committee, summarised the key points of a discussion which had been about care at home, with the focus on services for patients. The chairman of this group had been Alan Morgan, Chairman of the National Council for Voluntary Organisations.

Dame Anne began by warning delegates that there would be much repetition among the three seminar groups which had discussed aspects of care at home. Her group had thought it important to define the needs of the individual patient at the particular stage of their illness, and to construct a targeted package of care on a multidisciplinary basis. They had seen practical assistance as important, but had judged friendship and support from families and voluntary organisations to be the greatest comfort.

The group had emphasised that much work needed to be done to bridge the gap between hospitals and home care, and to break down professional jealousy which created artificial barriers and impeded collaboration between services. They had also advocated advice planning models which included self help, as well as help for the client. It had been their view that people with AIDS should once again become more involved in planning for their future.

Dame Anne reported the group's awareness that much prejudice still existed and that public attitudes to people who were HIV positive or who had AIDS still required much education and sensitivity in their way of dealing with such patients. She related the group's observation that many members of the public with ordinary infections were far more of a threat to an AIDS patient than the AIDS patient was to them. She said the group had also concluded there was insufficient training or willingness to be trained in some areas of primary health care, and some members had argued that the medical fraternity were the most difficult to educate.

During discussion a variety of multidisciplinary models for care had been suggested and thought worth exploring. Additionally, the group had recommended that more advice centres should be set up, involving those with a knowledge of housing, social services benefits, home assistance and, very importantly, pastoral care. Concluding, Dame Anne said they had been unanimous in thinking it necessary to continue the education process in all the areas concerned with people willing to share good practices, while at the same time exploring new ways of relieving the AIDS problem in Britain and elsewhere.

Group 6 : Care at home: support for patients and relatives

Finally, Mr Fowler called upon Jonathan Grimshaw from Body Positive to sum up the proceedings of this discussion group, chaired by the Rev Prebendary John Gladwin, on support for patients and relatives in the context of care at home.

Mr Grimshaw said that his group had focused on some of the obstacles to providing support and had then gone on to identify some of the needs of carers and patients. Similar to other groups they had extended the definition of AIDS sufferers to include anybody with HIV infection. They had also reached the conclusion that systems or models of care developed must be flexible enough to meet the demands of individuals.

An analogy had been drawn between people who were HIV antibody positive and people with cancer, in terms of their need for counselling support; both needed counselling immediately they learned of their condition, and both cases involved issues of loss and adjustment. The group had considered support for friends and lovers as well as for patients and relatives, and had identified education and information for them as an essential element, possibly provided by GPs and community workers.

Mr Grimshaw said the group had thought that the same services were available here as in San Francisco, but that they were under-financed and to be found in a different and uncoordinated structure. GP involvement was variable and a lot of people capable of providing support, including GPs, nurses and clergy, had not resolved their own prejudices. This highlighted the urgent need for education and training.

Mr Grimshaw reported the group's general concern about the dangers of under-resourcing the voluntary sector and also their more specific stance against paying volunteers. He said they believed that resources could be better used to train volunteers in the high levels of skills needed to provide counselling and support in the home for this client group. Mr Grimshaw added that proper priming was the traditional way of funding the voluntary sector and that the group had thought the kind of model seen in San Francisco, of contracting with volunteer organisations to provide specific services, was an approach worth exploring here.

Echoing a number of points that had already been made, Mr Grimshaw described the group's view that AIDS had brought to the surface all kinds of general issues about levels and types of community care. He also said that they had emphasised the need to promote levels of awareness in the wider community without promoting anxieties, and had looked at ways of dealing with the 'worried well'. Their advocacy for more and properly funded support for carers, including doctors and nurses, had included the need to develop and impart skills based on bereavement counselling. They had also urged that the Terrence Higgins Trust should be resourced in order to disseminate their skills.

Mr Grimshaw explained that while the group had recognised the similarities between cancer patients and people with AIDS, they had also explored the differences. Additionally, they had looked at the specific problems of providing support for drug addicts with AIDS. Practical problems such as access to housing and getting benefits from the Department of Health and Social Security had also been considered.

Mr Grimshaw said the discussion had touched briefly on resources and the potential problem of a backlash associated with directing resources towards AIDS. They had concluded by exploring the idea of creating a forum to encourage closer dialogue between the Government, the authorities, the Terrence Higgins Trust, Gay Switchboard and other voluntary organisations, but had not had time to decide on the composition of that forum.

Ending on a personal note, Mr Grimshaw observed that he was probably the only HIV antibody positive person in the room and that he was pleased at the determination of the group to resolve the problems, given the resources, the strategy, the coordination and the training.

Closing speech

Rt Hon NORMAN FOWLER MP Secretary of State for Social Services

Mr Fowler thanked all those who had contributed, both from the platform and in the seminar groups. He commented that events like the conference typified the unified response from the community to the threat of AIDS, something which he had always believed was possible to achieve in this country. He was pleased that AIDS had not become an issue of party political controversy.

Summing up the day's proceedings, he said he believed that the proper starting point was the information given by Professor Adler, that in this country there had been 730 cases of AIDS to date. However, he warned against complacency, reminding delegates that there had been only 160 cases in the United States as recently as 1982. More to the point, he referred to the substantial number of people in this country known to have the virus, a proportion of whom would go on to develop AIDS and said that whatever happened in the public education campaign, a duty remained towards these people.

He said he agreed with Professor Adler that the realistic aim now was to slow down the spread of infection and to contain the numbers involved. This aim created challenges and pressures for everybody and he spoke particularly of the challenges he knew were facing his department and the pressures on those working in the hospitals.

Drawing on the conference proceedings to think about what ought to be done, Mr Fowler said he felt there was a consensus view that people with AIDS did not need or want continual hospital care. He thought there was agreement that a range of facilities and services was needed, that these services should be viewed from the patient's perspective, and that possibly the best course was care in a person's own home. In this context he supported Susanne Oxley's comment that community nurses had a crucial role to play, and indicated that he would want to see some of her points followed up. He also concurred with Andrew Henderson that some of the problems involved were illustrative of those to be found in community care generally. Above all, he pointed to the need to coordinate health services, local authorities and voluntary organisations as effectively as possible.

Encouraged by Dr Rutherford's commentary on the American experience, Mr Fowler thought it important to consider whether the voluntary contribution in this country could be tapped further. Personally he thought it could, and he said that one of the major challenges over the next few months would be to harness that contribution, and not to waste it.

One of the major themes of the day had been what kind of service to provide between the stages of home and hospital. Mr Fowler said he saw a clear need for both hospices and imaginative hostel accommodation and he accepted the message of the conference that additional hospice provision was required. A challenge for him and the Minister for Health would be to translate that message into practice.

Mr Fowler drew together a number of loose ends in the day's discussion and highlighted the difficult area of services for drug users. Tackling the issue of resources, he reminded delegates of the Government's response to date. More money had been made available for public education and research, and for treatment; the budget had been increased for AIDS and for the health service generally. He said he had heard the message from the conference that more resources should be made available to AIDS, but he extended this message to include the need for overall better use of resources. He emphasised that a vast amount of money was going into community care policies through the social security route and it was open to question whether this money was always being used in the best conceivable way in the interests of clients generally. He remarked on the importance of the current Griffiths inquiry into this area and noted that a representative of this inquiry had attended the conference. Mr Fowler said that clearly they would want to examine with Roy Griffiths what had been said.

Mr Fowler concluded by saying that a report of the conference proceedings would be made available for delegates to consider. He thought that some proposals, such as those relating to hospices and hostels, could be acted upon quickly, but that others would need further consideration. Finally, he repeated his view that community care was not an easy option or necessarily a cheaper option, but that it was the better option as far as the individual was concerned. Much had come from the conference on the need to develop community care policies generally and specifically, and he undertook to report back on future progress in this area.

Appendix I

CARING FOR PEOPLE WITH AIDS IN THE COMMUNITY

A conference held on Wednesday 25 March 1987 at the Institute of Education, University of London

PROGRAMME

Morning session

10am-1pm SPEAKER SESSION
Chairman: Rt Hon Norman Fowler MP
Secretary of State for Social Services

Opening speech
Rt Hon Norman Fowler MP

Keynote speakers

George Rutherford, Medical Director of AIDS Office, San Francisco Department of Public Health

Michael Adler, Professor of Genito-Urinary Medicine, Middlesex Hospital

Susanne Oxley, Senior Nurse, Infection Control, Westminster Hospital

Andrew Henderson, Director of Social Services, London Borough of Kensington and Chelsea

QUESTIONS

Afternoon session

2pm-3.30pm SEMINAR GROUPS

1 *Role of the hospital outpatient department as a bridge between hospital services and community care*
Chairman: Professor Michael Drury, President, Royal College of General Practitioners

2 *Role of hospices*
Chairman: Dame Cicely Saunders, Founder, St Christopher's Hospice

3 *Provision of housing and residential care outside hospital*
Chairman: Herbert Laming, Director of Social Services, Hertfordshire

4 *Care at home: role of the caring professions*
Chairman: Rosalynde Lowe, Chairman, Health Visitors Association

5 *Care at home: services to patients*
Chairman: Alan Morgan, Chairman, National Council for Voluntary Organisations

6 *Care at home: support for patients and relatives*
Chairman: Rev Prebendary John Gladwin, Secretary, Church of England Board for Social Responsibility

4pm-5pm FINAL PLENARY SESSION
Place: Jeffery Hall
Chairman: Rt Hon Norman Fowler MP

Appendix II

CARING FOR PEOPLE WITH AIDS IN THE COMMUNITY

LIST OF PARTICIPANTS

Rt Hon Norman Fowler MP	Secretary of State for Social Services
Lord Glenarthur	Minister of State for Health and Social Work, Scottish Home and Health Department
Rt Hon Tony Newton OBE MP	Minister for Health
Mrs Edwina Currie MP	Parliamentary Under Secretary of State for Health
Baroness Trumpington	Joint Parliamentary Under Secretary of State
Sir Donald Acheson	Chief Medical Officer, DHSS
Dr Sheila Adam	Specialist in Community Medicine, North West Thames Regional Health Authority
Miss M Aitken	Chief Adminstrative Nursing Officer, Greater Glasgow Health Board
Dr Jog Anand	District Medical Officer, Peterborough Health Authority
Mr Alan Barton	Assistant Secretary, AIDS Unit, DHSS
Mrs Daphne Batty	British Agencies for Adoption and Fostering
Mrs Yvonne Baxter	Chairman, Community Psychiatric Nurses Association
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Dr John Cohen	Inner London GP

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Mr Phil Green	NALGO and General Whitley Council Staff Side
Mr Jonathan Grimshaw	Body Positive
Mrs Angela Guillaume	Friends' Committee, Princess Alice Hospice
Dr David Hawkins	Consultant Physician, St Stephen's Hospital, Fulham
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Mr Henry Howarth	Pharmacist
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Mrs Helen Irwin	Committee Clerk, House of Commons Social Services Committee
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Mr W Taylor	General Manager, Lothian Health Board
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Mr Dave Tomlinson	Phoenix House
Mr Ira Unell	Senior Social Worker, Mapperley Hospital Drug Dependency Unit
Mr Bill Utting	Chief Inspector, Social Services Inspectorate, DHSS
Mr David Watters	Education Officer, The Haemophilia Society
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Ms Barbara Young	District General Manager, Paddington and North Kensington Health Authority

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