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CABINET
HOME AND SOCIAL AFFAIRS COMMITTEE
SUB-COMMITTEE ON AIDS

CARING FOR PEOPLE WITH HIV INFECTION AND AIDS

Memorandum by the Secretary of State for Social Services

This paper describes what has already been done to meet the needs of people with HIV infection and AIDS. It outlines what further work is needed to develop appropriate services, with an emphasis on care in the community, and sets out the steps I am taking to carry this forward.

THE SCALE OF NEED

2. 734 cases of AIDS have been reported in the UK, of whom 329 are still alive. 30-40,000 people are believed to be infected, some 5,300 have been tested and found antibody positive. Three quarters of cases are being treated by 3 central London hospitals. Most are resident in North and West London.

3. Most people who are antibody positive are physically well, although they may need psychological and emotional support, but some will have illnesses caused by HIV infection. Those with AIDS are likely to be unwell much of the time, with periods of acute illness needing hospital treatment. On average they only survive a year from diagnosis of AIDS. There is evidence that a few infected individuals will suffer neurological damage in advance of other symptoms. Annex 1 describes the usual clinical course of a person with AIDS.

4. At least one third of the people who are antibody positive will develop AIDS over a five year period and a substantially higher proportion over 10 years. They are likely to be concentrated in the larger cities, especially London. I understand that there is likely to be a sharp rise in cases in the East of Scotland, where significant numbers of intravenous drug misusers are infected.

CURRENT PROVISION

5. The NHS is providing the following services:

- testing and counselling in clinics for sexually transmitted diseases (and to a lesser extent by GPs)

- counselling for drug misusers, and the experimental drug equipment exchange schemes

- counselling at centres for haemophiliacs

- out-patient and in-patient care at acute hospitals for people with AIDS; and for those with other HIV related symptoms

- health care in the community by community nurses and general practitioners (although there are doubts about the willingness of some GPs to provide services to people with AIDS and some patients do not wish their GP to be informed of their illness).

6. Personal social services departments are providing:

- social work help and counselling in a NHS setting or on referral from hospitals
- organising and supporting volunteers
- home helps and meals on wheels
- assistance to find accommodation (particularly for isolated young men in London).

7. Voluntary bodies are providing befriending, counselling and practical help.

COMMUNITY CARE

8. In planning services for people with HIV infection and AIDS, we need to be guided by their wishes and preferences. This reinforces the case for developing community-based care services and preventing unnecessary hospitalisation, whilst ensuring that acute hospital services are available when needed.

THE AMERICAN EXPERIENCE

9. In San Francisco where the home care approach is most developed, the basis is a multi-disciplinary team comprising a nurse, social worker, attendant (home help) and a volunteer. Nurse support is available 24 hours a day if required and volunteers provide on average, 8 hours support per person per week. There is often a need to find or construct a supporting "family", particularly in inner cities. About 50% of patients have no formal family support.

10. Nurses undertake a wide variety of intravenous treatments. The Americans have no difficulty in finding volunteers to work with

homosexual patients, but there is less support for drug misusers who require an estimated ten times more care and effort. Only 5% of patients are in hospital at any one time. In the United Kingdom 2% of current cases are drug misusers and 90% are homosexual, but the proportion of drug misusers is expected to rise and in Scotland this group may eventually provide the majority of AIDS cases.

STEPS TAKEN

11. The challenge in the United Kingdom is to build the positive aspects of the American experience onto the strengths of our institutions. In consultation with colleagues, I am taking steps to mobilise the agencies and professions involved to develop community based services:

first, I held a conference on 25 March for key people in the NHS, personal social services, the churches, voluntary bodies and the relevant professions. There was useful exploration of the issues and the proceedings will be published.

second, I have established working groups, led by my Department, of people from the NHS and the personal social services to identify what is needed to develop services.

third, I announced at the conference a number of pump-priming schemes (listed in Annex 2). I am also considering further financial support to some pioneering hospice schemes and to voluntary bodies working in this field.

fourth, I am seeking to ensure the establishment of machinery for co-ordinating the work of voluntary bodies.

ISSUES TO BE ADDRESSED

12. It is too early to provide a blueprint for services and there will in any case need to be diversity to deal with different needs in different places. We may need to experiment with different approaches. But a number of key issues are emerging:

targetting resources. In a way which makes the most effective use of them, provides flexibility and enables statutory and voluntary agencies to work together to decide the services which are appropriate in particular cases. We need to consider how best to manage, co-ordinate and monitor any new care programmes.

- training for staff. We need to ensure staff are better informed, are not unnecessarily fearful, and learn the skills they need. I am providing central support for the training activities listed in Annex 2.

- models of care. We shall explore with GPs and other NHS staff working in the community the models of care appropriate to this country.

- volunteers. In the United States a large volunteer programme helps keep costs down and support the patient in the community. Volunteers could offer valuable respite to family carers and help to form a "family" for patients who have none available. Health authorities will be asked in their 1988/89 Short Term Programmes to give an account of the arrangements they have made with voluntary bodies and personal social services departments to harness the work of volunteers in this field.

- hospices. There are about 100 hospices in the United Kingdom, of which one third are administered by the NHS. The remainder are run by voluntary bodies. Most are believed to admit AIDS patients by arrangement with the health authority, but some do not see people with AIDS as part of their clientele. I shall be considering further with the hospice movement what role they can play in this field.

the general public. Our public education campaign has done much to dispel myths about AIDS but there is still much unnecessary fear about being near to people with AIDS. We shall have to continue our educational efforts if a community care policy is to be widely acceptable.

COSTS

13. I shall be bringing a paper to H(A) shortly on the likely costs of AIDS, so have not discussed costs in this paper nor the pressures which some of these services are under. Whilst it clearly makes sense not to treat people with AIDS in expensive acute beds, when a domestic environment could be appropriate, I believe it would be wrong to see community care as a low cost policy. Rather, the emphasis should be on providing care in a way which the patient finds most acceptable.

CONCLUSION

14. The Sub-Committee is invited:

14.1 to note the steps which I am taking to develop services for people with AIDS;

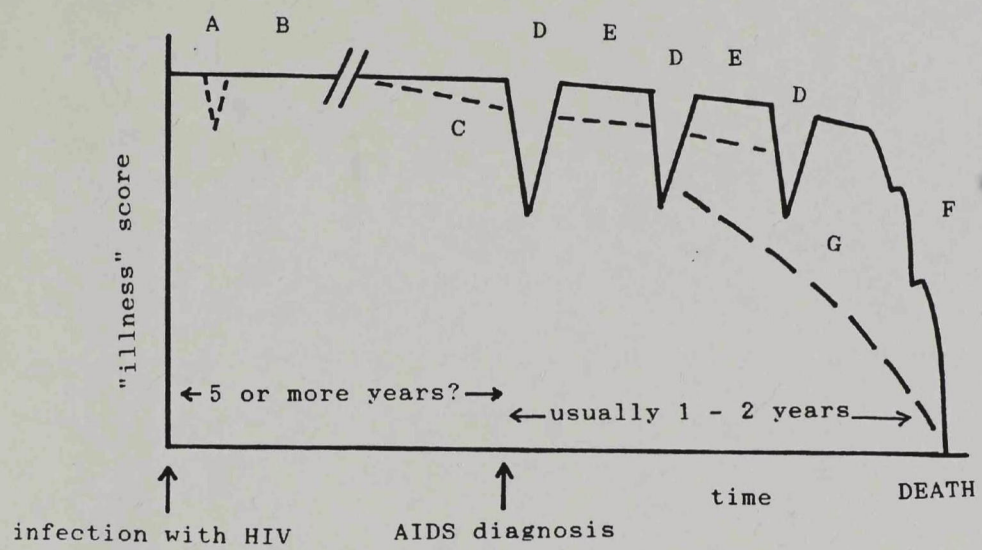
14.2 to agree that I should consider further the issues set out in paragraph 12, in consultation with colleagues, and should report again to H(A) in due course.

N F

Department of Health and Social Security
7 April 1987

ANNEX 1

CLINICAL COURSE OF HIV INFECTION IN AIDS



A: Acute "glandular fever like" seroconversion illness in some.

B: Physically well antibody positive and PGL (persistent generalised lymphadenopathy) patients. Attending outpatients regularly for counselling and follow-up.

C: AIDS-related Complex (ARC) - weight loss, diarrhoea, lethargy, fevers, night sweats. Brief hospital in-patient admissions might be needed for diagnosis. Outpatient follow-up. Some able to continue at work.

D: Serious episode of opportunistic infection or onset of cancer following which the diagnosis of AIDS is made. Requires acute hospital bed for an average 20 days per admission (current UK figures). At present about 2/3rds patients have at least 3 periods of admission, and of these, half have 6 or more spells of admission.

E: Between these episodes, some patients may be fit enough to return to the community and to work.

F: Towards the end, the patient's infections cannot be adequately treated and/or the tumours do not respond to therapy, the adverse effects of aggressive treatment become unbearable and general deterioration makes death inevitable.

G: HIV can affect the nervous system. About a third of patients have some signs of neurological damage when AIDS is diagnosed and at least 2/3rds have by the time of death. For some, HIV dementia can be a major problem leading to a steady decline. Such patients have loss of intellect and memor y and may lack control of their limbs, have difficulty in communicating, be incontinent of infected excreta and need round the clock nursing. These patients do not need the services of an acute hospital, but will block acute beds if there is no where else for them to go.

ANNEX 2 : SCHEMES TO PROMOTE COMMUNITY CARE FOR PEOPLE WITH AIDS

Showing proposed expenditure in 1987/88

1. A fellowship in each of the fourteen health regions for a nurse to study and formulate items for the nursing care of people with AIDS who are not in hospital. Their reports to be published as a set of collected papers. **(£49,000)**

2. Two part-time appointments for GPs in each of the three Thames Regions with most AIDS patients. They will gain first hand experience of the care of these patients, which they can then put into practice with their own patients and disseminate to GP colleagues. **(£32,400)**

3. A pilot scheme for an AIDs Regional Advice and Support Centre run jointly by the health and local authority, with close links with voluntary bodies. **(£80,000)**

4. The funding of the counselling training units in Bolton and Paddington is to be doubled. **(£200,000)**

5. A unit is to be established in London to train hospital specialists and GPs in the clinical management of AIDS. **(£33,000)**

6. In nurse training,the English National Board are being funded to develop and expand their AIDS course. **(£30,000)**

7. Workshops will be provided in each of the health regions to train community nurses in AIDS management. **(£60,000)**

8. A working group is examining training needs on AIDS for social service staff.