

CONFIDENTIAL - FOR PRIVATE DISCUSSION

*"Antibody status not known"*

Points emerging from Discussion

March 30th - April 13th

1. Care of Out Patients

a. It was felt that it would help the care of patients if their HIV Ab status was recorded in the notes. It was thought that the following points should be recorded, or perhaps "coded" if necessary.

- a. HIV Ab status and date of +ve or last -Ve
- b. Whether the patient knew.
- c. The date the patient was told his HIV Ab status
- d. If the patient had clearly expressed a wish not to know the Ab status this should be clearly stated too, or the HIV status recorded N/K.

We respected the problem this policy might pose to confidentiality. Possibly a coloured sheet of essential information could be filed in the notes and include HIV and HbsAg results, severity of haemophilia, inhibitor status etc.

b. The problems of providing adequate support and "counselling" of the patients and their families were discussed. Many patients do not feel they can easily get in touch with their 'contact' in the haemophilia centre and many have expressed a wish for extra support. Possible ways to deal with this were considered.

1. An open access time, eg on a weekday evening for 3 hours when appointments were not necessary and a doctor and member of the nursing staff would be available in the annexe for

discussion or to discuss queries by phone. Such an arrangement might evolve into a sort of "support group" but we did not feel that the patients would welcome or use one if it was plainly advertised as such.

ii. An extra haemophilia clinic to supplement the Tuesday pm clinic so that haemophilia patients could be allowed at least 30 minutes appointment time rather than discuss their anxieties and feelings in the sometimes pressured atmosphere of MOPD. I am quite happy to try such a clinic on a Monday or Friday morning and would aim to hold it in the annexe. This would mean the annexe would need at least an examination room and blood taking equipment.

iii. It was felt that the haemophilia Society could provide extra contact with some patients and Sheila and Andy Cowe would be very helpful in advising us.

iv. It was thought patients should be seen in an environment that allowed discussion of AIDS related problems at least every 6/12 and that formal recall should exist for this - in other words, if problems had not been aired in MOPD an additional appointment should be offered.

v. We felt that informal counselling and support provided through the centre should not be underrated. Some people may resent formal "stiff" counselling sessions and their choices should be respected and recorded.

c. Confidence: We acknowledge that confidence and trust in the team are undermined by conflicting stories and different views on the significance of results. We felt it was very important to

have a clear 'party-line' on main pieces of information such as:

- i. the likelihood of Ab +ve patients developing AIDS
- ii. the significance of ARC
- iii. the significance of Robert's tests. (The question of the "Cardiff Train" and "black list" show how quickly confusion can arise).
- iv. What symptoms to report
- v. What precautions to take in social activities and in the home.

We all felt that honesty with each other and the patients, is very important. Patients need to be aware of the changing attitudes and advances in HIV research, so it is important for us all to keep up to date with the press, the journals, and with scientific rumours. The weekly meetings are important for this.

d. GPs: Although we felt that in many instances the patient could be helped by his GP being fully aware of his HIV status, on balance it was felt that, while the patient remained well and independent, more was to be lost than gained from imparting such information to GPs.

e. Ways of giving help and support to families of haemophilia sufferers were considered, and it was thought that an evening 'group' may help in this respect also.

## II. Care of Inpatients

i. It was felt that if at all possible the patient should be aware of the diagnosis. What they know should be clearly recorded too. It was thought that concealing information from patients allowed a minefield of fibs to develop.

ii. Nursing problems were dealt with at some length. We all thought that continuity of nursing care was very important. We felt that the patients would ideally need to be "specialised" and that this should be done by ward nurses and not agency nurses. It was suggested that Miss Taylor be invited to any relevant meetings about patient care.

iii. Patients should be looked after in a side room on ward 23, without barrier nursing or isolation.

iv. Families must be allowed opportunity to be alone and undisturbed despite "specialling".

v. It was felt that we should think carefully about the necessity of daily blood tests and/or invasive investigations in patients who were terminally ill.

vi. It was considered very important that policy decisions about treatment and discussion about continuing or ceasing it should be aired together with the nursing staff.

vii. We discussed the place of home treatment and care and agreed that one objective was, in most circumstances, to aim for home. However this would depend on the wishes of the patient and his family.

### III. Domiciliary Care of Ill Patients

i. We presume that manpower could be a major stumbling block to

caring for weak or ill patients who need a lot of general nursing and support at home.

There were several problems in this sphere. The major one being a threat to confidentiality if community care became necessary. We thought that it may be appropriate to ask the patients permission before notifying their GPs and thus mobilising district nurses and health visitors. Billie or Michelle should be able to visit patients 1-2 weeks. As long as this is sufficient no further action need be taken. If extra nursing care is necessary then either -

- a. the patients GP and health visitor will become involved.
- or
- b. The patient will return to ward 23.
- ii. OT involvement. May be necessary to help us get the patient home.
- iii. Medication should be provided by us
- iv. Return to hospital should be possible whenever the patient requests it.
- v. All intercurrent infections must be treated in hospitals.
- vi. Clear advice must be given to patients and their families about coping with:
  - Blood spillage or staining
  - Diarrhoea/vomiting
  - Treatment of infections .

#### IV. Post Mortem Support

- i. We envisage an expanding need in this area and felt that

Billie or Michelle might not be able to cope with a heavy commitment to bereaved families although that would be our ideal.

ii. Stuart McGregor has very kindly offered his services as a counsellor and he may be very helpful in this context. It was felt his presence at our meetings might be helpful.