



National Health Service in Scotland  
Management Executive

St. Andrew's House  
Edinburgh EH1 3DG

Dear Colleague

**PROVISION OF HAEMOPHILIA TREATMENT AND CARE**

**Summary**

This guidance sets out the background to haemophilia treatment and care, highlights the particular features and requirements of patients suffering from haemophilia and related conditions, and reminds NHS purchasers of the considerations which they will need to take into account in order to secure continuity of access to comprehensive treatment and care for these patients. A description of the services provided by the types of haemophilia treatment centre is contained in the Annex.

**Action**

Health Boards will need to have regard to the considerations set out below in contracting for services to provide haemophilia treatment and care.

**Background**

The Haemophilic Condition

The haemophilic population in the United Kingdom comprises a group of patients whose medical management is both complex and costly. Some of the complexity arises due to the rarity of the condition, its lifelong nature, its variable severity, and the fact that patients do not appear "ill" in the accepted sense of that term. It may not always be understood that the lack of prompt, appropriate treatment may lead to prolonged hospitalisation and the misuse or even on occasion the wastage of expensive blood products.

Evolution of the Present Mode of Patient Referral

HC 76(4) set out the arrangements for haemophilia treatment and care through Reference Centres, Haemophilia Centres and Associate Haemophilia Centres.

Haemophilia patients have built up relationships with a chosen Centre for various reasons, and the Centre may not be within their home Board. Haemophilia patients have tended to refer themselves direct to a particular haemophilia

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**Addressees**

For Action:

General Managers,  
Health Boards

Chief Executives, NHS  
Trusts

Chief Executives  
Designate, NHS Trusts

For information:

General Manager  
Common Services Agency

General Manager, State  
Hospital

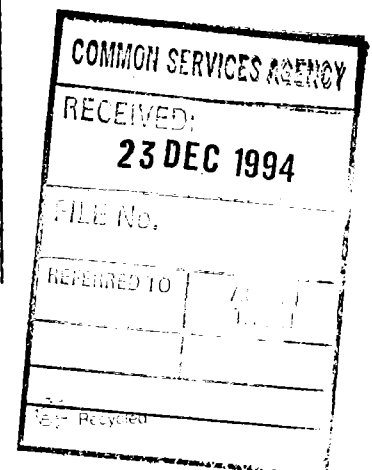
**To be copied to:**

Unit General Managers  
for action

**Enquiries to and further  
copies from:**

Mr G Wildridge  
SOHHD  
ME 3/2  
Room 279  
St Andrew's House  
EDINBURGH  
EH1 3DG

Tel: 031-244-2433  
Fax: 031-244-3487



treatment centre, and have in many cases, though not universally, by-passed customary consultation with the general practitioner because of the specialised knowledge required for their treatment.

### Considerations

Health Boards will need to take into account in contracting for services for haemophilia patients that there are a number of particular considerations in securing the aim of access to comprehensive care:-

- \* variability and severity of the haemophilic condition;
- \* complexity of the condition which may require a diverse and complex range of services. Given the nature of the condition, the amount of treatment required by individual patients will be **unpredictable**;
- \* expertise in treatment of haemophilia patients is not uniformly available across the country;
- \* the need for ease of access to supplies of blood products to support home treatment programmes;
- \* the prevalence of HIV, which is a significant problem in this group of patients, and the need for treatment and counselling for HIV infected haemophilia patients;
- \* individuals may need little more than review and access to blood products, but more sophisticated treatment will be required in many cases. As far as possible Boards should plan for this through the contracting process in consultation with professional advisers. Purchasers are encouraged to contract for low volume services wherever possible, rather than rely on extra contractual referrals.

### Contracts

Contracts should ensure that each patient has access to the services required to provide comprehensive care and will need to incorporate quality standards.

Treatment can be provided by 2 types of haemophilia treatment centres, Comprehensive Care Centres and Haemophilia Centres, according to the services and facilities which they provide. The Annex gives details. Comprehensive Care Centres in Scotland are in Glasgow and Edinburgh.

Access to the services required to provide comprehensive care can be secured either through contract with a single Comprehensive Care Centre, or through contracts with a Haemophilia Centre and with a Comprehensive Care Centre for those services not available at the Haemophilia Centre.

The way in which access to these services is achieved will depend upon local facilities and the needs of individual patients. Contracts should secure access to comprehensive care on a planned basis. In view of the unpredictability of need and the potentially large cost involved, simple block contracts would not be an appropriate form of contracting for haemophilia care. Purchasers are encouraged to move towards more sophisticated block or threshold contracts which will take account of these

considerations in contracting for haemophilia treatment and care, and to increase their use of cost and volume and cost per case contracts.

### Medical Audit

As part of the contracting process, Health Boards will be seeking to obtain quality and cost effective services for their haemophilia patients. The UK Regional Haemophilia Centre Directors' Organisation has prepared a scheme of Medical Audit which will play an important role in enabling all haemophilia treatment centres to maintain the highest standards of care.

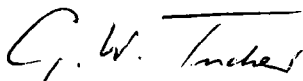
### Professional Enquiries

The professional contact point for enquiries from medical staff about the contents of this circular is:

Dr A Keel  
Scottish Office Home and Health Department  
Medical Services Division  
Room 102  
St Andrew's House  
Regent Road  
EDINBURGH  
EH1 3DG

Tel: 031-244-2799

Yours sincerely

  
G W TUCKER

ANNEX

**HAEMOPHILIA TREATMENT CENTRES**

Haemophilia treatment centres are of 2 types according to the services and facilities which they provide. These are described below.

**1. Services Provided by a Comprehensive Care Centre**

A Comprehensive Care Centre normally provides treatment for 40 or more severely affected (less than 0.02 units clotting factor present per ml of plasma) patients per year and needs to be able to provide all the following facilities:

1.1 a clinical service provided by experienced staff for the treatment of patients with haemostatic disorders and their families at short notice at any time of the day or night;

1.2 a laboratory service capable of carrying out all tests necessary for the definitive diagnosis of haemophilia and all common inherited haemorrhagic disorders, including the identification and assay of the relevant specific haemostatic factors. Further, capable of monitoring therapy and carrying out preliminary testing for inhibitors;

1.3 where appropriate and indicated, to conduct in collaboration with other haemophilia treatment centres, the further investigation or relatives of patients with haemophilia or other haemostatic disorders;

1.4 an advisory service to patients and close relatives on matters specific to haemophilia. Advice should also be given to general practitioners as appropriate;

1.5 maintenance of satisfactory quality control and assurance for all laboratory tests offered in relation to clinical services, by laboratory accreditation through CPA (UK) Ltd, or equivalent; by establishing appropriate internal procedures; and by participation at the appropriate level in the UK National External Quality Assessment Scheme in Blood Coagulation (NEQAS), or other relevant approved external quality assessment schemes;

1.6 maintenance of medical records; records must be maintained of all treatment administered and all adverse reactions reported. Special medical cards are to be issued and a register kept of all patients attending the centre;

1.7 counselling in privacy of patients and their relatives;

1.8 participation in appropriate clinical audit;

1.9 where appropriate, to provide advice on and organisation of home therapy programmes either individually or in collaboration to other haemophilia treatment centres;

1.10 the provision of prophylactic treatment programmes for patients with haemophilia and other haemostatic disorders;

1.11 24-hour advisory services to Haemophilia Centres and support to such Centres as appropriate;

1.12 a specialist consultant service for all surgery including orthopaedic and dental, for infectious disease (such as HIV and hepatitis) and paediatric care, and for genetic, HIV, and social care and other counselling services;

1.13 a reference laboratory service for Haemophilia Centres. The services should also include the diagnosis of atypical cases, genotypic analysis, the assay of inhibitors and other haemostatic factors, the diagnosis of hereditary platelet disorders, the supply of assay standards and reagents, and when requested, advice and recommendations concerning analytical procedures;

1.14 education facilities for medical staff, nurses, MLSOs, counsellors and other personnel as required in order to promote optimal comprehensive care of patients;

1.15 co-ordination of meetings and undertaking research programmes, including the conduct of clinical trials and to establish and participate in suitable local and National programmes of clinical audit.

## **2. Services Provided by a Haemophilia Centre**

It would normally be expected that a Haemophilia Centre would provide services (1.1 to 1.9) above