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HEALTH CIRCULAR

HC(76)4



DEPARTMENT OF HEALTH AND SOCIAL SECURITY

To:
Regional Health Authorities)
Family Practitioner Committees) for action

Area Health Authorities)
Boards of Governors) for information

February 1976

HEALTH SERVICES DEVELOPMENT
ARRANGEMENTS FOR THE CARE OF PERSONS SUFFERING FROM HAEMOPHILIA AND
RELATED CONDITIONS

Summary

This circular encloses a memorandum which sets out revised arrangements for the care of persons suffering from haemophilia and related conditions; lays down revised criteria for the designation of haemophilia centres; and asks Regional Health Authorities to review, in the light of these criteria, centres at which treatment is at present available to patients.

1. On 5 March 1968 a memorandum was circulated to hospital authorities, under cover of HM(68)8, listing centres which had been designated for the diagnosis, treatment and registration of persons suffering from haemophilia and related conditions and describing the functions of these centres. Following a review, which was carried out in consultation with the Directors of the present Haemophilia Centres, some alterations to the existing arrangements have been worked out and agreed and these are incorporated in the revised memorandum attached as Appendix 2.

Criteria for Designation as Haemophilia Centres

2. To qualify for designation, Haemophilia Centres must be able to provide clinical treatment to patients at short notice at any time of the day or night and be capable of undertaking assays of specific coagulation factors as part of their diagnostic and therapeutic procedures. With the introduction of new therapeutic agents the prospects of haemophiliacs reaching active adulthood have considerably improved and Haemophilia Centres should therefore be able to provide a wider advisory service than hitherto to haemophiliacs and their families particularly in the fields of preventive medicine and dentistry, education, employment, genetic counselling and social medicine.

Associate Centres

3. Centres which were designated in 1968 but which do not fully meet the new criteria may nevertheless, to avoid inconvenience to patients already registered with them who live or work nearby, continue to be recognised for the purpose of giving emergency treatment. These centres will be known as Associate Centres. Each will be linked with a convenient designated Haemophilia Centre so that together they will be in a position to offer patients a full therapeutic, diagnostic and advisory service.

Reference Centres

4. The introduction of new therapeutic agents, accompanied by the growth in experience of the treatment of haemophiliacs, has led to changes in the role of the three centres which were designated in 1968 as Special Treatment Centres. Although it is no longer necessary to refer the majority of patients to them for surgery these Centres, and a few others, have during recent years developed an advisory role towards individual Haemophilia Centres, and it has been decided that this role could usefully be officially recognised and further developed by designating them as Reference Centres and describing in some detail their functions.

Other facilities in the United Kingdom

5. As it is important that patients and Directors of Haemophilia Centres should be aware where treatment for haemophilia is available in the United Kingdom, haemophilia centres in Wales and Northern Ireland and regional haemophilia centres in Scotland have, with the agreement of the Welsh Office, the Department of Health and Social Services, Northern Ireland and the Scottish Home and Health Department respectively, also been included in the list of centres in England (attached as Appendix 1). The organisation of haemophilia centres in Scotland differs from that in the rest of the United Kingdom in that each centre provides the whole range of services for its area.

Action

6. Regional Health Authorities are asked to review, in consultation with the appropriate Reference Centre, the list of centres in England at which treatment is available to patients in the light of paragraphs 2 and 3 above and to inform the Department by 30 April 1976 which Centres are to be designated as Haemophilia Centres and which are to be known as Associate Centres.

7. Family Practitioner Committees are asked to send a copy of the attached FPN and Appendix 1 for information to all general medical and dental practitioners on their lists and to the Local Medical and Dental Committees. Enough copies are being sent separately.

8. The Department (HS2B) will continue to supply the Special Medical Card (Haemorrhagic States) and the booklet "Notes on the care of patients with hereditary haemorrhagic disorders".

From:

HS2B Division
Hannibal House
Elephant and Castle
London SE1 6TE

GRO-C

H1/H7/14

Further copies of this document may be obtained from DHSS Store, Scholefield Mill, Brunswick Street, Nelson, Lancashire
B89 0HU Tel: (0282)62411/2

**NATIONAL HEALTH SERVICE
GENERAL MEDICAL AND DENTAL SERVICES
ORGANISATION OF HAEMOPHILIA CENTRES**

Summary

1. This Notice advises general medical and general dental practitioners of the revised arrangements for the care of persons suffering from haemophilia and related conditions; the Appendix lists the centres at which treatment is available in the United Kingdom.

Background

2. The arrangements under which centres are designated for the diagnosis, treatment and registration of persons suffering from haemophilia and related conditions have been in existence since 1968. Following a review which was carried out in consultation with the Directors of the present Haemophilia Centres some alterations have been agreed; the new arrangements are described in the succeeding paragraphs.

Haemophilia Centres

3. The functions of these Centres are to provide:-

(i) a laboratory service able

(a) to carry out the tests, including the identification and assay of specific coagulation factors and anti-coagulants necessary for an exact diagnosis to be made

(b) to monitor coagulation factors and anti-coagulants during treatment

(c) in collaboration with the appropriate Reference Centre (see paragraph 7 below) to investigate relatives of patients with haemophilia or related conditions.

(ii) a clinical service for the treatment of patients at short notice at any time of the day or night

(iii) an advisory service to patients (and, in the case of child patients, to their parents) on matters of concern to them such as preventive medicine and dentistry, education, employment, genetic counselling and social medicine. Advice should also be given to general practitioners about the emergency treatment of haemophilic patients on their list and the procedure for securing these patients' admission to hospital when required including what the patient should do to obtain ambulance transport in an emergency.

4. A record of all patients to whom haemophilia cards are issued should be maintained at each Haemophilia Centre including at least the following information:-

Name, address and telephone number of patient
Date of birth
Diagnosis
Mother's maiden name
Maternal Grandmother's maiden name
Name, address and telephone number of general practitioner
Name of consultant in charge of the case

Associate Haemophilia Centres

5. Centres which were designated in 1968 but which do not fully meet the new criteria laid down for designated Haemophilia Centres (see paragraph 3 above) may wish to continue to provide emergency treatment to haemophiliacs living or working nearby and registered with them. These centres will be known as Associate Haemophilia Centres. Each will be linked with a convenient designated Haemophilia Centre so that together they will be in a position to offer a full therapeutic, diagnostic and advisory service to haemophiliacs and their families.

Reference Centres

6. In 1968 the centres at Oxford, Manchester and Sheffield were designated as Special Treatment Centres where special skills were available to patients requiring major surgery. At that time management during and after surgery was the most difficult aspect of the treatment of haemophilia. This is no longer the case because the management of patients undergoing surgery has become easier as a range of therapeutic materials have become more widely available. Today the emphasis in the treatment of haemophilic patients is on the early day-to-day care on demand and this treatment must be provided at all centres.

7. However, although it is no longer necessary to designate centres for the specific purpose of carrying out surgical treatment there are administrative and other advantages to be gained in designating some centres to be Reference Centres, to which Haemophilia Centres can look for guidance and support. The centres currently so designated and the areas which they broadly cover are:-

St Thomas' Hospital)	London, the South East and
The Royal Free Hospital)	East Anglia
The Churchill Hospital)	Oxford, Wessex, the South West, the
Oxford)	Midlands and Northern Ireland
The Royal Infirmary)	
Manchester)	
)	The North West, North Wales,
)	Trent and Yorkshire
The Royal Infirmary with the)	
Children's Hospital, Sheffield)	
The Royal Victoria Infirmary)	The North of England
Newcastle)	
University Hospital of Wales)	South Wales
Cardiff)	

8. The functions of these Reference Centres are:-

- (i) to provide a 24-hour telephone advisory service to Haemophilia Centres and Associate Haemophilia Centres and to support them particularly during holiday periods
- (ii) to provide a specialist consultant service for surgery and for orthopaedic, dental, paediatric and social care for those Haemophilia Centres and Associate Haemophilia Centres wishing to use such a service
- (iii) to advise on and organise when called upon home therapy and prophylactic therapy for haemophilia patients
- (iv) to provide a reference laboratory service for Haemophilia Centres and Associate Haemophilia Centres including the diagnosis of atypical cases, the assay of antibodies and the supply of assay standards and reagents
- (v) to provide education facilities for doctors, technicians, nurses and others as required in order to promote optimum care of patients and a comprehensive laboratory diagnostic service
- (vi) to ensure close co-operation between the Haemophilia Centres, Associate Haemophilia Centres and the Regional Centres of the Blood Transfusion Service
- (vii) to co-ordinate, as necessary, the allocation of available therapeutic materials to Haemophilia Centres and Associate Haemophilia Centres
- (viii) to co-ordinate statistics collected by Haemophilia Centres and Associate Haemophilia Centres
- (ix) to co-ordinate meetings and research programmes.

9. Regional Health Authorities have been asked to review the list of centres in England at which treatment is at present available to patients, as shown in the attached Appendix, and to inform the Department which centres are to be designated as Haemophilia Centres and which are to be known as Associate Haemophilia Centres. As it is important that patients and others should be aware where treatment for haemophilia is available in the United Kingdom, haemophilia centres in Wales and Northern Ireland and regional haemophilia centres in Scotland have also been included in the list. The organisation of haemophilia centres in Scotland differs from that in the rest of the United Kingdom in that each centre provides the whole range of services for its area.

10. The Department (HS2B) will continue to supply the Special Medical Card (Haemorrhagic States) and the booklet "Notes on the care of patients with hereditary haemorrhagic disorders".

January 1976

APPENDIX 1

CENTRES AT WHICH TREATMENT IS AVAILABLE TO PATIENTS SUFFERING FROM HAEMOPHILIA AND RELATED CONDITIONS

ENGLAND

Alton	Dr P G Arblaster Treloar Haemophilia Centre Lord Mayor Treloar Hospital Alton Hampshire	GRO-C
Birmingham	Department of Haematology The Children's Hospital Ladywood Middleway Birmingham B16 8ET	GRO-C
	Dr J Stuart Department of Haematology Queen Elizabeth Hospital Edgbaston Birmingham B15 2TH	GRO-C
Bournemouth	Dr D Stern Department of Pathology Royal Victoria Hospital Shelley Road Boscombe Bournemouth BH1 4JG	GRO-C (9 am - 5 pm weekdays Ext GRO-C At other times please ask for doctor on call for Haemophilia Control)
Bradford	Dr R L Turner Haematology Department The Royal Infirmary Bradford BD9 6RJ	GRO-C Ext GRO-C
Bristol	Dr G L Scott Department of Haematology Bristol Royal Infirmary Bristol BS2 8HW	GRO-C (9 am - 5 pm weekdays Ext GRO-C At other times please ask for Sister-in- Charge of the Accident and Emergency Department)
Cambridge	Dr D G Chalmers Department of Haematology Addenbrooke's Hospital Hills Road Cambridge CB2 2QQ	GRO-C Ext GRO-C (At night and at weekends please ask for the Duty Haematologist)
Carlisle	Dr A Inglis Department of Pathology Cumberland Infirmary Carlisle CA2 7HY	GRO-C (Hospital switchboard will contact relevant member of team on duty)
Coventry	Dr N K Shinton Department of Haematology Coventry and Warwickshire Hospital Stoney Stanton Road Coventry CV1 4FH	GRO-C

Darlington	Dr A E S Mustafa Memorial Hospital Darlington	GRO-C (Hospital switchboard will contact relevant member of team on duty)
Derby	Dr D A Winfield Royal Infirmary Derby	GRO-C
Exeter	Dr J O P Edgcumbe Department of Pathology Royal Devon and Exeter Hospital Exeter EX1 1PQ	GRO-C Ext GRO-C
Hull	Dr C G L Raper Department of Pathology Kingston General Hospital Beverley Road Hull HU3 1UR	GRO-C
Leeds	Dr L M Swinburne St James' Hospital Leeds LS9 7TF	GRO-C
Liverpool	Professor A J Bellingham Liverpool Royal Infirmary Pembroke Place Liverpool L3 5PU	GRO-C
London	Professor J W Stewart Bland-Sutton Institute of Pathology The Middlesex Hospital Mortimer Street London W1N 8AA	GRO-C (At night and at weekends please ask for the Duty Pathologist).
	Dr R S Mibashan Haematology Department Royal Postgraduate Medical School Hammersmith Hospital Du Cane Road London W12 0HS	GRO-C Ext GRO-C (At night and at weekends please ask for the Haematology Registrar on duty).
	Professor P L Mollison Department of Haematology St Mary's Hospital Praed Street Paddington London W2 1NY	GRO-C Ext GRO-C
	Professor J G Humble Haematology Department Westminster Hospital Dean Ryle Street London SW1P 2AP	GRO-C
	Professor R M Hardisty Department of Haematology The Hospital for Sick Children Great Ormond Street London WC1N 3JH	GRO-C Ext GRO-C (At night and at weekends please ask for the Resident Assistant Physician).

London
(continued)

Dr G C Jenkins
Department of Haematology
The London Hospital
Whitechapel Road
London E1 1BB

GRO-C

Dr Katharine M Dormandy
The Haemophilia Centre
The Royal Free Hospital
Pond Street
London NW3 2QG

GRO-C

(After 5.30 pm and at weekends please ask for the doctor on call for the Haemophilia Centre).

Professor T A J Pranker
Haematology Department
University College Hospital
Gower Street
London WC1E 6AU

GRO-C

Dr P Barkhan
Department of Haematology
Guy's Hospital
London SE1 9RT

GRO-C

(At night and at weekends please ask for the Resident Pathologist)

Professor W M Davidson
Haematology Department
King's College Hospital
Denmark Hill
London SE5 8AF

GRO-C

Dr C A Holman
Haematology Department
Lewisham Hospital
High Street
Lewisham
London SE13 6LH

GRO-C

Professor G I C Ingram
Department of Haematology
St Thomas' Hospital
London SE1 7EH

GRO-C

Ext GRO-C

(At night and at weekends please ask for the doctor on duty for Haemophilia)

Professor P T Flute
Haematology Department
St George's Hospital
Blackshaw Road
Tooting
London SW17 0QT

GRO-C

Manchester

Dr I W Delamore
Department of Clinical
Haematology
The Royal Infirmary
Manchester M13 9WL

GRO-C

Dr D I K Evans
Department of Haematology
Royal Manchester Children's
Hospital
Pendlebury
Nr Manchester M27 1HA

GRO-C

Margate	Dr H Sterndale Isle of Thanet District Hospital (Margate Wing) St Peter's Road Margate Kent CT9 4AN	GRO-C
Middlesbrough	Dr R E Potts Middlesbrough General Hospital Ayresome Green Lane Middlesbrough Teesside TS1 5JE	GRO-C (Hospital switchboard will contact relevant member of team on duty)
Newcastle	Dr P Jones Royal Victoria Infirmary Newcastle upon Tyne NE1 4LP	GRO-C Ext GRO-C (At night and at weekends please ask for Ward 8 (children) or Ward 13 (adults))
Nottingham	Dr T E Blecher Dr E A French Haematology Department The General Hospital Nottingham NG1 6HA	GRO-C Ext GRO-C or GRO-C (At night and at weekends please ask for the doctor on call for Haematology)
Oxford	Dr Rosemary Biggs Dr C Rizza Oxford Haemophilia Centre Churchill Hospital Oxford OX3 7LJ	GRO-C Ext GRO-C (After 5.00 pm and at weekends please ask for the doctor on call for the Haemophilia Centre)
Portsmouth	Dr J R O'Brien Central Laboratory St Mary's General Hospital (East Wing) Milton Road Portsmouth PO3 6AG	GRO-C
Sheffield	Professor E K Blackburn Dr J S Lilleyman Dr F E Preston Dr H T Swan Departments of Haematology The Royal Infirmary Sheffield S6 3DA and Sheffield Children's Hospital Sheffield S10 2TH	GRO-C (At night and at weekends please ask for the doctor on call for the Haemophilia Centre)
Southampton	Dr Morag Chisholm Royal South Hants Hospital Fanshawe Street Southampton SO9 4PE	GRO-C
Sunderland	Dr A MacKenzie The Royal Infirmary Durham Road Sunderland Co Durham SR2 7JE	GRO-C (Hospital switchboard will contact relevant member of team on duty)
Whitehaven	Dr P J Whitehead West Cumberland Hospital Hensingham Whitehaven Cumberland CA28 8JG	GRO-C (Hospital switchboard will contact relevant member of team on duty)

WALES

Cardiff

Dr A L Bloom
Department of Haematology
University Hospital of Wales
Heath Park
Cardiff CF4 1XW

GRO-C

(After 5 pm and at weekends please ask for the House Physician to the Haematology Department)

NORTHERN IRELAND

Belfast

Professor M G Nelson
Department of Haematology
Royal Victoria Hospital
Grosvenor Road
Belfast BT12 6BA

GRO-C

SCOTLAND

Regional Haemophilia Centres

Aberdeen

Dr Audrey A Dawson
Haematology Unit
University Medical Buildings
Foresterhill
Aberdeen AB9 2ZB

GRO-C

Ext

GRO-C

Dundee

Dr G R Tudhope
Wards 5/6
Ninewells Hospital
Dundee DD1 9SY

GRO-C

Ext

GRO-C

Edinburgh

Professor R H Girdwood
University Department of
Therapeutics
The Royal Infirmary
Edinburgh EH3 9YW

GRO-C

Ext

GRO-C

Dr S H Davies
Department of Haematology
The Royal Infirmary
Edinburgh EH3 9YW

GRO-C

Ext

GRO-C

Glasgow

Dr C R M Prentice
Department of Medicine
Royal Infirmary
Glasgow G4 0SF

GRO-C

(If not available ask for the Receiving Physician)

Inverness

Dr I A Cook
Regional Blood Transfusion Centre
Raigmore Hospital
Inverness IV2 3UJ

GRO-C

MEMORANDUM ON THE FUNCTIONS OF HAEMOPHILIA CENTRES

1. In the memorandum attached to HM(68)8 a description was given of the functions of a number of centres, known as Haemophilia Diagnostic and Registration Centres, which were designated for the diagnosis, treatment and registration of persons suffering from haemophilia and related conditions. It has been decided to make some changes in the existing arrangements and these are described in this memorandum.

HAEMOPHILIA CENTRES

2. The functions of these Centres are to provide:

- (i) a laboratory service able
 - (a) to carry out the tests, including the identification and assay of specific coagulation factors and anti-coagulants necessary for an exact diagnosis to be made
 - (b) to monitor coagulation factors and anti-coagulants during treatment
 - (c) in collaboration with the appropriate Reference Centre (see paragraph 6 below) to investigate relatives of patients with haemophilia or related conditions
- (ii) a clinical service for the treatment of patients at short notice at any time of the day or night
- (iii) an advisory service to patients (and, in the case of child patients, to their parents) on matters of concern to them such as preventive medicine and dentistry, education, employment, genetic counselling and social medicine. Advice should also be given to general practitioners about the emergency treatment of haemophilic patients on their list and the procedure for securing these patients' admission to hospital when required including what the patient should do to obtain ambulance transport in an emergency.

3. A record of all patients to whom haemophilia cards are issued should be maintained at each Haemophilia Centre including at least the following information:

Name, address and telephone number of patient
 Date of birth
 Diagnosis
 Mother's maiden name
 Maternal Grandmother's maiden name
 Name, address and telephone number of general practitioner
 Name of consultant in charge of the case

ASSOCIATE CENTRES

4. Centres which were designated in 1968 but which do not fully meet the new criteria laid down for designated Haemophilia Centres (see paragraph 2 above) may wish to continue to provide emergency treatment to haemophiliacs living or working nearby and registered with them. These centres will be known as Associate Centres. Each will be linked with a convenient designated Haemophilia Centre so that together they will be in a position to offer a full therapeutic, diagnostic and advisory service to haemophiliacs and their families.

REFERENCE CENTRES

5. In 1968 the centres at Oxford, Manchester and Sheffield were designated as Special Treatment Centres where special skills were available to patients requiring major surgery. At that time management during and after surgery was the most difficult aspect of the treatment of haemophilia. This is no longer the case because the management of patients undergoing surgery has become easier as a range of therapeutic materials have become more widely available. Today the emphasis in the treatment of haemophilic patients is on the early day-to-day care on demand and this treatment must be provided at all centres.

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The Churchill Hospital)	Oxford, Wessex, the South West, the
Oxford)	Midlands and Northern Ireland
The Royal Infirmary)	
Manchester)	The North West, North Wales,
)	Trent and Yorkshire
The Royal Infirmary with the)	
Children's Hospital Sheffield)	
The Royal Victoria Infirmary)	The North of England
Newcastle)	
University Hospital of Wales)	South Wales
Cardiff)	

7. The functions of these Reference Centres are:

- (i) to provide a 24-hour telephone advisory service to Haemophilia Centres and Associate Centres and to support them particularly during holiday periods
- (ii) to provide a specialist consultant service for surgery and for orthopaedic, dental, paediatric and social care for those Haemophilia Centres and Associate Centres wishing to use such a service
- (iii) to advise on and organise when called upon home therapy and prophylactic therapy for haemophilia patients
- (iv) to provide a reference laboratory service for Haemophilia Centres and Associate Centres including the diagnosis of atypical cases, the assay of antibodies and the supply of assay standards and reagents
- (v) to provide education facilities for doctors, technicians, nurses and others as required in order to promote optimum care of patients and a comprehensive laboratory diagnostic service
- (vi) to ensure close co-operation between the Haemophilia Centres, Associate Centres and the Regional Centres of the Blood Transfusion Service
- (vii) to co-ordinate, as necessary, the allocation of available therapeutic materials to Haemophilia Centres and Associate Centres
- (viii) to co-ordinate statistics collected by Haemophilia Centres and Associate Centres
- (ix) to co-ordinate meetings and research programmes