THE INFECTED BLOOD INQUIRY

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The Bulletin

"The Essentials of Haemophilia Care"

LAUNCH OF NEW BLUEPRINT FOR HAEMOPHILIA CARE

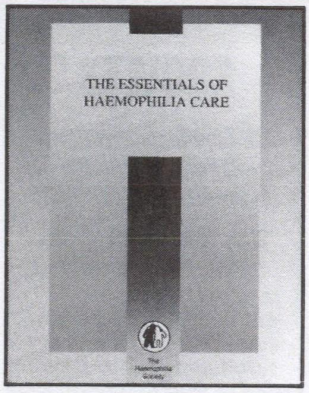
The NHS reforms have provided an opportunity to set out a detailed standard for the care of all people with haemophilia in the UK. Under these reforms, local health districts are now responsible for purchasing the care which all people with haemophilia will receive.

This care is normally provided at present by hospitals in health districts outside that where the individual lives, and so it has been necessary to explain to District Health Authorities (DHAs) what they should be buying and where that care should be provided.

The intention is to ensure that patients continue to receive the best possible care at the Centre of their choice, and to seek to improve the standard provided to all patients everywhere.

The Society's document, "The Essentials of Haemophilia Care" has been produced in order to assist DHAs in their new task. The paper describes in some detail the services, in terms of treatment and care, that a person with haemophilia has the right to expect. The paper goes on to give guidance on how DHAs should go about contracting for these services. The document contains a foreword by Dr. Elizabeth Mayne, Chairman of the Haemophilia Centre Directors' Organisation, commending it to the DHAs.

It has been circulated to all District Health Authorities, Haemophilia Centres, Society Groups and the medical media. The document is available from the Society office, free of charge to all members, and we have summarised its main provisions on page 10.



VERY WELL DONE GRO-A

GRO-A

GRO-A has done swimmingly in raising funds for haemophilia.

Nine-year-old GRO-A was sponsored by friends and family to swim an entire mile, forty-eight lengths of Crosby swimming baths.

GRO-A's mum, GRO-A was very pleased with his efforts. "Swimming is one of the few sports that GRO-A can do," she said. "He really enjoys it. He has to avoid playing rugby, cricket and football because he could get hurt. When I last took him to the hospital he saw a poster advertising fund-raising for a kidney dialysis machine, and he decided he would like to swim to raise money for the local branch of the Haemophilia Society."

Cheered on by family and friends GRO-A completed his target of forty-eight lengths in just thirty-eight minutes.

Proceeds from the swim, which so far total £185, will be donated to the North West and North Wales branches of the Society.

READERS WRITE

Articles in the last issue of The Bulletin on the purity of blood products elicited a considerable response from our readership. A selection of the letters and the Society's position on product purity appear on pages 6 and 7.

In this issue

A MERRY CHRISTMAS TO ALL OUR READERS

A BLUEPRINT FOR FUT

INTRODUCTION

The theme of the proposals can be summed up by part of Dr. Mayne's foreword. She says "Medical experience of the condition can be sparse and expertise tends to be concentrated in large Regional Centres. It may not always be understood that the lack of prompt, appropriate treatment may result in crippling deformities in those patients who are affected most severely. Prompt treatment may enable such patients to receive a good education and attain gainful employment, thus avoiding their becoming a burden on the 'benefit' resources of the taxpayer."

The core proposals seek to ensure that these needs are met within the structure of the specialist regional reference Centres, working with smaller more local Haemophilia Centres, which together, are able to offer every person with haemophilia a full comprehensive range of services.

Haemophilia care can appear to be very expensive. However, it is a false economy to provide haemophilia care cheaply. The availabiliy of sufficient supplies of safe blood products is cost effective in the long term. Safer and purer blood products can reduce the possibility of viral infections such as hepatitis and HIV, thus reducing future health care costs. Similarly the availability of sufficient blood products would allow more extensive use of prophylactic treatment which would greatly reduce the likelihood of joint damage and hence reduce the need for expensive hospital treatment and major surgery at a later date. There would also be savings resulting from less dependence on social security disability benefits. The reduced disability and improved quality of life would of course also enable the person with haemophilia to make a further contribution to society.

STANDARDS OF CARE AND TREATMENT

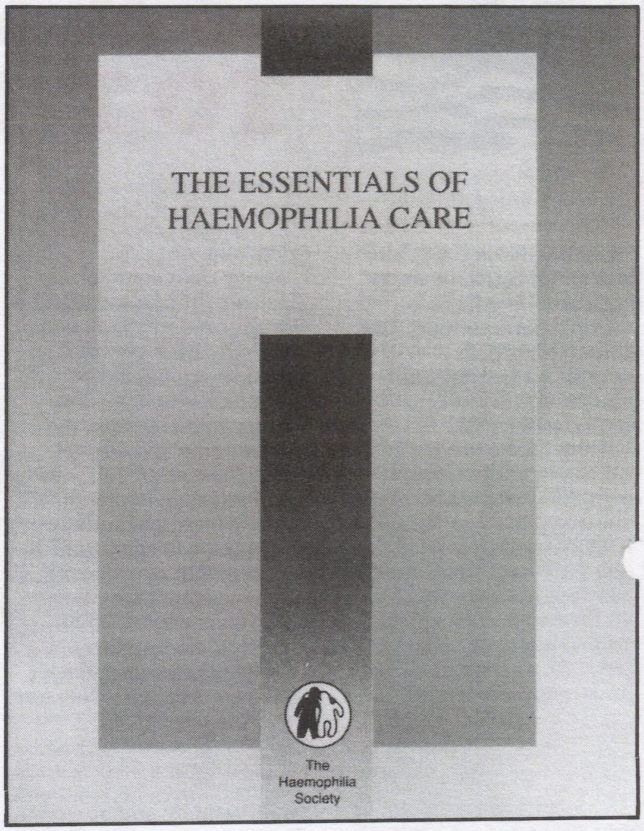
COMPREHENSIVE CARE

It is essential that all people with haemophilia have access to a comprehensive care service that takes full account of the diverse and complex range of services that they may need. Comprehensive care is best delivered by a core team consisting of a designated haemophilia consultant, a haemophilia nurse, a social worker and a physiotherapist. In addition, there should be access to a paediatrician, an orthopaedic surgeon and other specialist services.

Successful haemophilia care is achieved as a result of a partnership between the patient and the haemophilia care team. People with haemophilia rapidly become expert in their own care, and their views must be listened to and respected by those caring for them. Similarly, the patient has a responsibility to co-operate and comply with procedures indicated by the haemophilia team.

TESTING

All Centres must be able to provide laboratory facilities that can carry out all the tests necessary for diagnosis and the identification of factors such as inhibitors. Facilities should also be available for the testing of potential carriers. These tests should be backed up by a full genetic counselling service, providing opportunities to discuss family planning and enabling informed decisions to be made.



DIAGNOSIS

For the person with haemophilia, and in many cases their parents the diagnosis is the beginning of a long term relationship with the Centre and its staff. At this stage there are a number of services that should be offered:

- — A full explanation of the implications of living with haemophilia
- — A full medical examination
- — A special medical card
- — Explanation of the treatment regime
- — Details on how to use the services on a 24-hour basis
- — Details on the other services available
- — Vaccination against hepatitis B
- — Testing of other family members
- — Appropriate background literature
- — Information on educational and support groups.

TREATMENT

It is essential that people with haemophilia have access to a clinical service for the management of bleeding episodes and other medical emergencies by experienced staff at short notice and at any time of the day or night.

People with haemophilia should be given the opportunity of receiving home treatment, being provided with adequate supplies of blood products to meet their needs and with the minimum of disruption.

Blood products should be made available solely on the basis of the clinical needs of the patient, not the price of the product or other budgetary constraints.

To enable patients to be on home treatment, the Centre will provide training and facilities for the patients. Patients must be able and willing to accept responsibility of completing records of treatments and attending review clinics.

URE CARE

REVIEW AND FOLLOW-UP

It is essential that people with haemophilia should be regularly reviewed and followed up. This is particularly important where there are additional complications such as HIV and liver disease. In general this should be at least twice a year, with those with additional complications being seen at least four times a year.

Each review should include:

— A full medical review and examination
— A full laboratory assessment
— Assessment of joint function
— Access to social worker and counselling services.

OTHER FACILITIES

The Haemophilia Centre itself needs to be accessible for people with walking difficulties, with adequate convenient car parking facilities, and facilities for patients and other family members who may have travelled a long way in order to visit the centre.

HIV TREATMENT

The document lays out proposals for the treatment of HIV and haemophilia, in particular that there must be access to specialist HIV care in conjunction with the care of haemophilia. In many cases, the Haemophilia Centre has developed excellent HIV facilities, but where HIV treatment is separate, there must be adequate liaison with the haemophilia team.

CONTRACTS AND DELIVERY OF CARE

It will be the responsibility of local DHAs to contract where services are provided for people with haemophilia living in their area. The Society believes that there should be a Reference Centre in each region that would itself provide the full range of services but would also work with and support the smaller Centres in providing comprehensive care for each haemophilia patient wherever they lived in the region. Patients would be expected to register with the Reference Centre but would be able to negotiate how their treatment was to be managed and where the different elements would be provided.

There are certain principals that we believe the DHAs should follow:

— DHAs should not contract for haemophilia services with a local provider unit unless it can provide a comprehensive care service and treats a minimum number of haemophilia patients each year
— DHAs should allow patients access to the centre of their choice and fund their treatment accordingly
— DHAs should fund contracts so that clinicians are free to make purely clinical decisions of the type and quality of product prescribed
— DHAs should ensure that each of their haemophilia residents has access to the fuil range of services.

CONCLUSION

The NHS reforms do pose a potential threat to the existing system of haemophilia care, but all the indications are that those in the DHAs who are responsible for contracting haemophilia services are welcoming the Society's initiative in providing a standard that they can apply to Haemophilia Centres. This provides a valuable opportunity to ensure that a uniform standard of top quality comprehensive care is provided to all people with haemophilia in the UK.

"The Essentials of Haemophilia Care" is available free, from the Society's office.

IN PRAISE OF PROPHYLAXIS

My son GRO-A was diagnosed as having haemophilia at 13 months when he started to walk and was getting bad bumps and bruises.

We were lucky. In spite of having severe haemophilia he had very few joint bleeds, and mostly minor bleeds into muscles.

These often seemed to mend themselves with a little care. The importance of immediate treatment was not pressed home upon us. Indeed we were told that treatment would stop a bleed that was continuing but that if the bleed had already stopped then treatment wouldn't help the recovery. Thus in most cases treatment seemed to be unnecessary and often resting seemed preferable, particularly when the alternative, a very lengthy visit to the local hospital, didn't always result in treatment. The doctors who saw us were often, understandably in such a small centre, unfamiliar with haemophilia cases.

We felt we were doing very well. GRO-A had perhaps half a dozen injections a year and the six monthly clinics pronounced him fit.

However, by the time he reached seven he was beginning to get more problems. His right ankle, although not always painful, was often puffy. He had a prolonged bout which immobilised first one leg, then the other. We were regularly urging caution and his learning to ride a bike was constantly postponed because of his ankle.

THEN I WENT TO ST THOMAS'

Meanwhile I was learning home treatment but a lack of continuity and consistent practice of the staff prompted me to ask for tuition from the centre at St Thomas' Hospital in London.

It was there that I first met the notion of prophylaxis. It was hard to come to terms with. From half a dozen injections a year to three a week was a big leap.

However, my feeling of 'doing well' was shattered by learning that his ankle was developing a real weakness that needed attention and as a result, quite unknown to us, the development of his right calf muscle was affected -- it was a good few centimetres smaller than his left.

A TRIAL PERIOD

We agreed, reluctantly, to a trial period of prophylaxis, at least to try and overcome the problem with his ankle. Initially it was very hard, both doing the injections, and also justifying both to ourselves and our son that they were necessary.

Gradually it became more of a routine. GRO-A did more and more of it himself. Almost imperceptibly we realised that we had stopped constantly advising caution. He hadn't needed to rest his leg or use a wheelchair for a long time. He learned to ride his bike. He began to play cricket and kicked a ball about in an easy way with his friends. An occasional problem, usually attributed to a specific fall or knock, surprised his friends who no longer thought of him as someone with a problem.

He is now eleven and does the injections himself. Prophylaxis has made all our lives easier. We worry less, are less cautious. GRO-A does anything he wants to do (apart from football). He has few bleeds, the ankle is still not 100% but is less of a problem. If we had begun with prophylaxis he wouldn't have even that to deal with.

Furthermore we know we are preventing future problems. His muscles and joints are not being undermined by bleeds.

My only wish is that we had begun prophylaxis sooner.

GRO-A Kent