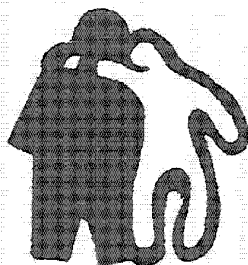


THE HAEMOPHILIA SOCIETY



HAEMOPHILIA TODAY

SEMINAR REPORT MANCHESTER 1978

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HAEMOPHILIA TODAY: AN INTERDISCIPLINARY APPROACH

REPORT AND CONCLUSIONS OF A SEMINAR FOR SOCIAL WORKERS AND OTHER PROFESSIONAL GROUPS HELD AT THE ROYAL INFIRMARY, MANCHESTER ON 23rd NOVEMBER 1978

Conclusions and Recommendations

The arrival of concentrate has brought a greater degree of medical security. With the resolving of some medical problems it is now possible for medical staff to give more time to considering other aspects of care.

Haemophilia Centre staff, Disablement Resettlement Officers and Careers Officers have an added responsibility to work together closely to educate the public and employers concerning what people with haemophilia have to offer to the community.

The Haemophilia Centre should be able to provide all the information the haemophiliac requires, discuss the implications of the condition with his family, and give families the emotional support which they need. Continuity of care through individual members of the Haemophilia Centre staff is important.

Home therapy provides prompt and early treatment, thus removing the long journey, the long waiting periods, and general frustration.

Parents of children benefit from home visits by Haemophilia Centre staff, and Social Workers. Treatment of emotional problems as well as social problems can be dealt with.

Haemophilia involves frustration and uncertainty when bleeds occur, often pain, embarrassment, and some conflict.

The question of stress reaction is of vital concern. It was suggested that the problem of emotional regression in adults is one that deserves more attention from the various specialists.

Competent parents tend to produce competent children and a confident child with haemophilia is able to reassure those he meets about his disability. The building of parental confidence is the responsibility of the Haemophilia Centre caring team, together with the family doctor, health visitor and local Social Services Department.

Where possible, Special Schools should be used as a temporary resource only.

A vital rôle of the Haemophilia Centre is providing a link between the community services and hospital services, particularly concerning such areas as education, employment, housing etc. There is an evident need to stimulate Local Authorities to provide the necessary services and to provide the necessary information and knowledge concerning haemophilia.

HAEMOPHILIA TODAY: AN INTERDISCIPLINARY APPROACH

Report of the Seminar for Social Workers : November 23rd 1978

Chairmans Introduction: Mrs Vicki Stopford is Research Social Worker to the Haemophilia Society.

Mrs Stopford welcomed delegates and hoped all would have an opportunity to exchange ideas in discussion both during the session and informally between sessions. She commented on how the Haemophilia Society greatly values the feedback which these Seminars give - a feedback which allows a better understanding of the problems that agencies experience when assisting people with haemophilia.

Mrs Stopford introduced the Speakers Panel as follows:- **Dr Delamore** is the Director of the Haemophilia Centre at the Manchester Royal Infirmary. This Centre is a main Reference Centre and therefore acts in a supervisory and advisory capacity and has links with Centres in the surrounding area. The Haemophilia Centre provides the main focus of support and help both medically, practically, and emotionally for the person with haemophilia, his family, and as a resource and information point for other hospital and community agencies. Dr Delamore's department deals with the whole field of haematology and its many specialisms. **Alex Shaw** is a nursing sister attached to the Haemophilia Centre at the Royal Manchester Children's Hospital. She is in a comparatively new appointment with the Centre, but has been involved both with the daily running of the treatment from the Centre and notably with the Home Therapy Programme. Home treatment has revolutionised the lives of people with haemophilia and their families and has demanded extra resources from community agencies. **Mrs Jean Lovie** is a Medical Social Worker attached to the Haemophilia Centre at the Royal Victoria Infirmary, Newcastle upon Tyne. She is based within the Unit itself where a special emphasis on a team approach to daily treatment is encouraged. The Social Worker at the same time is, by virtue of her specialist knowledge, able to offer information and support not only to colleagues in other hospitals and area based departments, but also to other professional agencies. **Mr GRO-A** is Chief Educational Psychologist with Stockport Metropolitan Borough and lectures within the University. He also has haemophilia and is therefore in a good position to describe how this has affected his own life.

In conclusion, Mrs Stopford hoped that the seminar would facilitate a better understanding of haemophilia overall and provide a forum for discussion of, and solutions towards, its problems.

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THE ROLE OF THE HAEMOPHILIA CENTRE WITHIN THE HOSPITAL AND COMMUNITY SERVICES

Dr I.W. Delamore is Director of the Haemophilia Centre of Manchester Royal Infirmary

Haemophilia is a rare disorder occurring in about 3 or 4 per hundred thousand, and at present there is about 3½ thousand known cases in this country. Dr Delamore described, with the use of slides, how Factor VIII is missing, or abnormally affected, in haemophilia and likewise Factor IX in Christmas Disease. Haemophilia is inherited in a sex positive manner and thus, Dr Delamore explained, in the case of a female, one of her sex chromosomes is responsible for carrying haemophilia such that when she marries, half of her daughters will be carriers and half of her sons will have haemophilia. Likewise the haemophilic man will produce daughters who are all carriers. This is important as the detection of carriers raises various social problems.

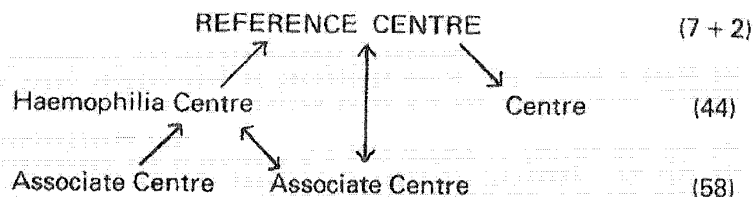
One main problem for the haemophiliac is that joints become affected by the bleeds resulting in physical deformity and severely impaired mobility. Dr Delamore explained how bleeds can occur anywhere in the body. They may occur in muscles as well as in joints. Fortunately cerebral head bleeds are rare, although it is one of the major causes of death. Dental problems bring their own difficulties but very close links are maintained with the dental department both in the preventative capacity and treatment rôle. It is very important for patients to be seen regularly by the dentist.

Dr Delamore described how in 1968 Haemophilia Centres were reorganised into Associate, Diagnostic and Reference Centres. Before this, Oxford, Sheffield and Manchester were three Special Treatment Centres. In 1974 it was decided to make changes in the arrangements of Centres. Centres should exist first of all to provide a service to carry out all the necessary investigations including the identification of the specific coagulation factors concerned, monitor coagulation factors and the effect of treatment, and investigate the relatives of patients with haemophilia and relative diseases. The second function is to provide a clinical service which includes provision of medical treatment at any time of the day or night and at short notice for patients with haemophilia. Thirdly provision of an advisory service for patients and their parents who might be concerned about dentistry education, and employment, and so on and provide a counselling service through the Social Services Department. Advice is offered also to general practitioners or anybody else who might be concerned with the management of haemophilia. Records of medical patients to whom haemophilia cards have been issued are made at the Haemophilia Centre and include all the necessary personal details of patients.

The new category allows for Associate Centres who have been designated as suitable Haemophilia Centres for the provision of an emergency service for patients but are linked to Diagnostic Centres so that together all the necessary facilities are provided. The Special Treatment Centres were changed to Reference Centres and were expanded to seven in number. These are

St Thomas' and the Royal Free Hospital in London, Churchill Hospital Oxford, The Royal Infirmary's of Sheffield and Manchester, The Royal Victoria Infirmary in Newcastle, and the University Hospital of Wales at Cardiff. There are two main Centres in Scotland; one in Edinburgh and one in Glasgow. The advantage of the more numerous Associate Centres is that patients do not have to travel so far to get treatment.

Diagram A



There are 44 Haemophilia Centres in England and 58 Associate Centres. Associate Centres in particular, are growing all the time. The Reference Centres are expected to have special skills and provide every facility that the patient with haemophilia might need, for example a 24 hour telephone advisory service for both the patient and Haemophilia Centre or Associate Centres in the region, a special consultancy service for surgery, orthopaedic surgery, dental care, paediatric and social care, and to keep medical records and statistics. Together with a wide range of ancillary services, they must advise and organise such things as home therapy, prophylactic therapy where necessary, and to provide a reference laboratory service. Dr Delamore outlined how they are expected to ensure close co-operation between all working sectors in their particular region, and co-ordinate the availability of the necessary out-patient therapy material. One great problem is the shortage of Factor VIII replacement therapy with which to treat patients.

A working relationship is maintained with other appropriate departments within the hospital. These include close links with the physiotherapy department, the orthopaedic surgeons, and Social Services Departments. Dr Delamore noted how the Centre is indebted to Mrs Anderson who attends to the social needs of the patient. She is linked to the Department of Haematology but not all her time can be spent on haemophilia. The Centre also holds regular review clinics where patients on home therapy are seen and also patients who have not been for treatment for some time, so that progress can be properly assessed.

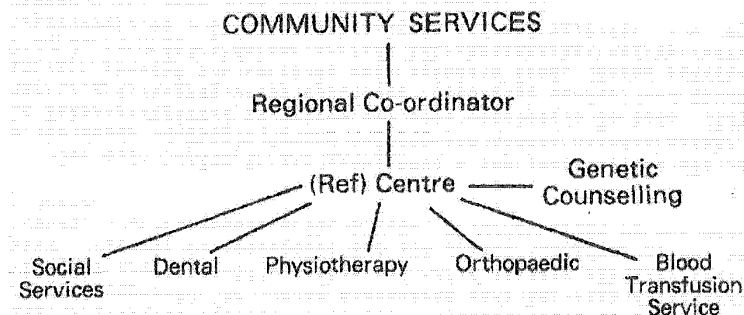
Dr Delamore stressed how very important the link must be with the blood transfusion service. In Manchester, there is in fact a joint consultant between blood transfusion and haematology. Although he spends nearly all his time in the haematology department on haemophilia, he has a special responsibility to see that replacement materials are present and supplied in

regular quantities, and takes a special interest in the blood transfusion service. Dr Delamore suggested that the key organisation in solving the shortage of treatment products must be the Blood Transfusion Service.

Genetic counselling is another extremely important aspect and Dr Delamore commented on how many patients now receive genetic counselling. However in common with other Haemophilia Centres, Dr Delamore felt that Haemophilia Centre staff, are, in many cases in a better position to provide the genetic counselling themselves. Dr Delamore firmly believed that the Centres should be able to provide all the information the patient requires, discuss the implications of the condition with families, and give them the emotional support which they need. The ability to predict carrier status is being perfected all the time, but at the moment prediction is only made on the basis of the likely chances of a female being a carrier. Dr Delamore suggested that the Social Worker has a vital rôle to play here since she has the experience and skill for family counselling.

A vital rôle also is between the Community Services and the Hospital Services concerning areas such as education, employment, housing and so on. Dr Delamore commented on the need to continually stimulate Local Authorities to provide the necessary services and, like many patients, Centre staff were frequently distressed by the ignorance of some of the people who have to dispense these services.

Diagram B



A scheme first thought of in the London area, is the employment of a regional co-ordinator who can either be a trained nurse or Social Worker. Her first duty is to visit patients on Home Therapy, which Dr Delamore felt was a very important rôle. She is also able to provide the important link between the Centre and all the Community Services which are available to the patient. Dr Delamore would like to see a regional co-ordinator in the Manchester region, but negotiations have so far been unsuccessful with the National Health Service. Such schemes often have to be supported by a charitable body such as The Haemophilia Society.

For some time it has been possible to provide pre-natal sex testing but it is very difficult for a mother to make a decision as to whether to have an abortion performed or not. Further research may be able to offer a different technique whereby blood from the foetus can be obtained and the clotting factor level measured. Recent results in Cardiff have been very encouraging and it may be possible shortly to say if a baby suffers from haemophilia or Christmas Disease. The Haemophilia Centres, particularly the Reference Centres, have an obligation to develop techniques within their rôle of research. Other research procedures under consideration include the detection of hepatitis and its long term affect.

Hepatitis is carried in blood products and Dr Delamore noted that a very high percentage of patients being treated for haemophilia and Christmas Disease are proving after all to be infected by one type of hepatitis or another. A great deal more work in assessing the severity of hepatitis needs to be undertaken, possibly to develop an immunisation against hepatitis or in developing ways of making blood products safer. Reference Centre Directors meet together 2 or 3 times a year to discuss these problems and reassess working parties. One area under discussion is the development of Factor VIII antibodies. This situation is one where patients, when repeatedly treated with blood products, develop antibodies against the product and thus become increasingly difficult to treat.

In conclusion the complexities of haemophilia are ever increasing. Patients demand, quite rightly, increased resources from an already over-stretched National Health Service. Haemophilia Centres must make sure that the resources available are properly co-ordinated and brought to the very best use for each individual patient. In this way there will be less waste and the general outlook and management of patients with haemophilia will improve.

[Summarised]

HOME THERAPY - A CHANGING EMPHASIS FOR BOTH THE FAMILY AND COMMUNITY SERVICES

Mrs Alex Shaw is the Nursing Sister attached to the Haemophilia Centre, Royal Manchester Childrens Hospital.

Mrs Shaw commented that as she works in a children's hospital, this talk would mainly apply to home therapy for children.

All haemophilia centres provide a 24 hour cover but Mrs Shaw stressed that continuity of care through individual members of staff is important. Because of changes of staff for training purposes etc, children have been reluctant to seek early treatment but with home therapy the continuity is provided by the patient's parents.

Home therapy is the treatment of children at home by their parents or, in the older patients, by themselves. This is called self therapy. Ten years ago giving parents the responsibility of performing venepuncture and treatment on their children away from the hospital was unheard of. Parents are however eminently capable of performing venepuncture on their children as long as they are competent, taught correctly and follow the rules.

A Home Therapy programme began about five years ago with children up to the age of 16 or 17 years. Out of about 104 haemophiliacs registered, 22 are on home therapy with another 6 in training. Ten of these 22 patients are very severely affected i.e. less than 1% clotting factor activity.

Previous to the commencement of home therapy, many of these children had frequent bleeds which meant numerous visits to the hospital for treatment, disrupting the day and night for the family. Mrs Shaw described how night visits seem the worst and the patient is fractious, sleepy and often in great pain. Not infrequently, parents are also bad tempered and sleepy because of long journeys and waiting periods, worry, and the fact that probably siblings also have had to be brought along. This state of affairs has often led to discord in the family, particularly between the parents. Home Therapy does not necessarily cut down the number of bleeds but Mrs Shaw emphasised how the number of visits to hospital had been greatly reduced. Noticeably, bleeds tend to increase when a child starts school and as he gets older and more boisterous, the number of visits have increased.

Mrs Shaw described how Home Therapy provides prompt and early treatment, cutting out all the long journeys, the long waiting periods and general frustration. It also saves the amount of Factor VIII concentrate used, therefore cutting the cost, as a small dose of Factor VIII or IX stops the bleed early. The more blood that is allowed to enter a joint or muscle, the greater the subsequent damage to the surrounding tissues and so the period for recovery is lengthened and repeated doses of blood product is needed to stop the bleed. Patients for Home Therapy are selected on the capability of parents, or the child himself after the age of 12 years, the co-operation of the child, the severity of the disease, the number of bleeds and the

availability of Factor VIII concentrate. Severely affected patients are given priority as this is the group who have frequent bleeds, particularly into the joints.

Apart from the child benefiting, the family also benefits. Mrs Shaw pointed out that although Factor VIII should advisably be stored in a fridge, this Factor VIII concentrate can, if necessary, be stored in a cool room for up to six months. Therefore, the family as a whole can go further afield, taking more adventurous holidays, even travelling abroad etc. Each family is given a full protocol on home therapy and treatment records are produced by the parents of patients.

Mrs Shaw emphasised the importance of haemophilic children on home therapy maintaining a link with the centre. Home Therapy is not the end point in treatment and there will be occasions she noted, when the staff at the centre must be contacted. It is of great importance that these children have regular check ups and that patients on home therapy are seen every six months or more frequently at a multi-disciplinary review clinic. Here they are seen by the Haematologist, Rheumatologist, Dentist and Physio-therapist.

Children on Home Treatment are able to have early treatment which usually allows an immediate return to school and obviously a normal period of schooling leads to better career and job prospects. It is usually policy, Mrs Shaw noted, for the department to try and keep children with haemophilia in ordinary schools. Mrs Shaw pointed out that although many schools are very co-operative, for example allowing wheelchairs and crutches to be used by the children when necessary, there are still many who will not accept the responsibility of a haemophilic child in an appliance of any sort, nor are many school buildings suitable. Mrs Shaw suggested that many schools could usefully be visited by Centre staff to give talks on haemophilia, its problems, and use of Home Therapy.

Special Schools obviously need to cater for a wide spectrum of handicaps but Mrs Shaw felt that this sort of environment may limit future prospects for a well controlled intelligent haemophilic child. Children attending a special school still have to attend a Haemophilia Centre for treatment. Treatment is generally not provided at these schools. Mrs Shaw emphasised the need for Heads and teachers to be advised concerning the nature of haemophilia as it is usually left to the parents to explain their child's problem.

Mrs Shaw explained that her job as a nurse in the Haemophilia Centre is to provide care in the hospital and continuity for the patient, but she also goes out on home visits. A follow up visit in the same week as Home Therapy commences is important and then approximately every 3 to 4 months. In the meantime if there are any problems, parents can ring the centre.

Mrs Shaw commented on how parents and children enjoy these home visits as they seem more relaxed and co-operative in their home environment. Treatment, technical problems as well as social problems are discussed. Mrs Shaw emphasised the importance of a link with Centre staff and Social

Workers, particularly the Social Worker in the hospital. She is able to provide both information on attendance allowances and other financial benefits, and most important of all, help and support with family social problems. Mrs Shaw commented on the high incidence of family breakdown, and help is also needed in providing rehousing where necessary, installation of telephones which are essential for all patients on Home Therapy, and help with schooling problems.

The Director of the Centre has ultimate control and everyone concerned with the haemophilic child works closely with him.

Mrs Shaw suggested that one of the main disadvantages of Home Therapy is the abuse of the materials used. For example, non-attendance at clinics, abuse of joints, and laterly in the much older patient, drug dependence. If these do occur, the patient is immediately withdrawn from the Home Therapy Programme.

In the main Mrs Shaw concluded that Home Therapy gives the patient and his family a greater amount of freedom and independence, less joint problems and disabilities. He is a more viable candidate for career assessment and job training, and has a greater opportunity to lead a normal life.

[Summarised]

SOCIAL WORK CONTRIBUTION IN A MULTI-DISCIPLINARY APPROACH TO TREATMENT

Mrs Jean Lovie is the Medical Social Worker attached to the Haemophilia Centre, Newcastle upon Tyne.

The meeting was reminded that haemophilia is a chronic disorder and that the haemophiliac has to learn to accept and live with his handicap. It was suggested that with a short term illness all families energies can be directed towards the sick child. With a chronic disability the economic, emotional, social and educational needs of all the family have to be met besides those of the affected child. It is not in his best interests if his needs are the focal point within the family.

Those unfamiliar with haemophilia were reminded that Haemophilia for the sufferer involves:

1. frustration - uncertainty of when bleeds may occur.
2. often pain if there was a delay in obtaining treatment.
3. embarrassment, uncertainty of public response.
4. for some the conflict of having to decide whether to appear as normal with a hidden disorder as with deafness.

In the past before the availability of concentrates a disrupted education and bleeds over the years had left many haemophiliacs with damaged joints and little to offer academically when trying to find work. Some haemophiliacs after long periods of hospitalisation and broken family ties had appeared to lack confidence when forming friendships and close relationships. Others had appeared aggressive, prone to risk take. The arrival of concentrates had brought a greater degree of medical security and the chance for a freer life style. With the resolving of some medical problems it was possible for medical staff to give more time to considering other aspects of care. It was possible to suggest to parents other ways of raising their children where the child can find his own limits safe in the knowledge that where bleeds occur, treatment can be given.

It was pointed out that having raised the haemophiliac's expectations Centre Staff, Disablement Resettlement Officers, Careers Advisory Staff had an added responsibility to work together closely to educate the public and employers as to what haemophiliacs had to offer to the community.

It had been observed that confident parents tend to produce confident children and that a confident child with haemophilia is able to reassure those he meets about his disability : he tends to be more ambitious and establish the limits placed upon him by his handicap more realistically compared with a child who has been over protected and is timid. This child can become resentful or prone to risk take.

It was important to understand that the initial response by parents to over-protect or guard is a natural loving response. Parents however provided with medical information as to how bleeds can be treated can soon see the possibility of and advantages of a freer family regime.

The building of parental confidence is a task that is the responsibility of all the Haemophilia Centre caring team and the family doctor, his health visitor and local Social Services Department.

It is important from the start to:

1. establish a relationship with parents which can be described as a partnership with staff and parents on an equal footing.
2. regard the family as the functioning unit. The child is a child within the family. Carrier testing makes the concept of family care even more important.
3. involve both parents : each has a part to play in caring for the child.
4. help parents understand that they have direct access to the hospital at all times in respect of the haemophilia and their family doctor for other aspects of care.

Parents :

1. may need help in coming to terms with haemophilia.

They may require support when expressing and sharing the anger, sadness, anxiety, sometimes guilt they feel. Once this has been done they are better able to absorb the medical information available through the centre.

2. learn, through coming to the Centre on a day to day basis to seek treatment for their child.
3. quickly absorb medical information if it is presented in a clear way.

The speed with which parents begin to relax and come to terms with the Haemophilia appears to depend upon 6 factors :

1. their previous experience of illness
2. the way they normally cope with stress
3. previous experience of haemophilia
4. intellectual capacities
5. degree of isolation in the community - nearness of family and friends
6. success in forming relationships to date

Parents learn from the medical Director; the nursing staff and their health visitor.

There is a place for the social worker in:

1. meeting families as soon as the diagnosis is confirmed. A home visit helps establish the link between hospital and home and enables hospital staff to understand more clearly how parents are placed and what their specific difficulties may be.
2. helping parents cope with the hospital setting; arranging accommodation where parents may be staying in or near a hospital, encouraging parents to bridge the gap for children between home and hospital by bringing photographs, toys from home.

3. inviting health visitor, Social Services Department staff to the Centre with families to learn more about treatment.
4. organising discussion groups for mothers or couples where they can share ideas, difficulties.
5. referring families to the help available from the Haemophilia Society.
6. where appropriate introducing parents with a haemophilic child to other parents similarly placed.
7. acting as liaison between Centre Staff and outside agencies eg. Department of Health and Social Security etc.

There appear to be a number of advantages in maintaining a continuous link with families. This may be confined to Review Clinics but the number of interviews, home visits increased if needs arise. It is forceable that social work intervention may be necessary when certain milestones in the child's development are reached:-

1. when he starts school or playgroup
2. when the parents start on home therapy. There can be initially some anxiety with the break with the hospital setting for treatment.
3. when he transfers schools
4. when carrier testing occurs
5. when the youngster leaves school and some liaison with the Careers Advisory Service appears to be required

Further discussion with families can be useful when behaviour/learning/ or schooling difficulties are reported. A change in the amount of Concentrates used may indicate a bleeding phase, delay in seeking treatment, additional anxiety within the home, or risk taking.

The understanding of problems is a team responsibility. A Social Worker may bring interviewing skills but social aspects of care are the responsibility of all the team. A team approach has the advantage of greater flexibility in care. Finally it was suggested that this approach to the work might be applied to other chronic disorders also.

[Summarised]

LIFE WITH HAEMOPHILIA : A PERSONAL COMMENT

Mr GRO-A who has haemophilia is a GRO-A

Mr GRO-A began his talk speaking from his professional point of view. He suggested that whenever we deal with client groups the more concrete the concepts offered to the patient the greater the chances are that the patient is likely to retain the concepts, and therefore the better the chances are that he would do something about following advice from Doctors, Social Workers, Psychologists, and Haemophilia Centre Nurses.

Another phenomenon of interest is the clinical situation where doctor interviews patient, clinician interviews client etc. and Mr GRO-A noted that there is a kind of dominance about this whether we like it or not. One of the expressions of this kind of relationship is that when a question is asked it will almost certainly be formalised particularly if the question is asked by somebody in a white coat. It is not probable however that the answer bears much relation to the truth. On one investigation, for example, it was discovered that only about 25% of parents were adequately able to tell to the nearest ounce the birth weight of their child. So this is a problem facing all kinds of clinics. It is thus important to be aware that the situation will inevitably arise where false information, with the best will in the world is likely to be given. There does not seem to be many ways of overcoming this other than emphasising the continuing link between patient, client, clinician, doctor and so on. It is obviously made much easier when the patient or client is able to talk to somebody he has normally talked to on several other occasions.

Mr GRO-A commented that in his experience, self exposure can go a little too far. Many haemophiliacs become quite disconcerted when asked questions such as, 'How long have you had haemophilia?'

Mr GRO-A felt that the question of stress resistance in human beings was of vital concern. If any large group of humans are actually put in a position of stress and their tolerance levels measured, one would tend to find that, in time, a distribution curve inevitably results. Most of us, by definition fall in the middle and our resistance to stress has an average reaction point. There are people who are unfortunately at either end of this distribution. It is easy to recognise people at the bottom of the distribution curve where we usually have some 'neurotics'. Mr GRO-A suggested that the people at the top end should be called 'astronauts', as they seem to be the only group of people who are measurably quite extraordinary in their ability to resist stress!

Work on stress or anxiety emotionality leads to a rather interesting theory along the lines of the 'neurotic' versus 'stable' and the 'introvert' versus the 'extrovert' type of human personality. Mr GRO-A felt it was in this grey area of 'patient' and 'professional' that medicine had somehow lost out along the way. He noted that it is almost a psychological truism to know that extroverts have a much higher rate of arousal than do introverts. It follows that extroverts will respond to stress provoking anxiety, provoking arousal

stimuli at a much later point in time than do introverts and Mr [GRO-A] suggested that pain comes under the general heading of anxiety stress arousal provoking stimulus. There is considerable experimental evidence to demonstrate that 'introverts' have a very much lower pain threshold than 'extroverts'.

Mr [GRO-A] commented on the discussions he had had recently with several medical people who have had experience working for the World Health Organisation particularly on medicine and its application, and emphasised that there was a great deal to be learnt about the control of pain using methods other than the rather overwhelming one of deadening the whole of the central nervous system in order to eradicate what may be a specific pain in a very specific spot.

Mr [GRO-A] commented on the little amount of study directed towards adult sufferers and the surprisingly large amount of attention given to children particularly in relation to the area of emotional regression. Mr [GRO-A] felt that the problem of regression in adults is one that deserves much more serious attention from the various specialists.

Mr [GRO-A] has been very interested in the development of treatment of haemophilia in the last ten years. Looking back over the last 42 years in retrospective terms, the development of treatment facilities and the understanding of the haemophilic condition has improved in a relatively short space of time. Mr [GRO-A]'s first conscious awareness of hospital treatment was of lying on one bed, with his father lying on another bed a few feet away, and a rubber tube being passed mysteriously from the crook of his father's arm to the crook of his own arm. This was his first memory of a transfusion. Also of being wheeled into an operating theatre for what was optimistically called a 'cut out' but should probably more accurately have been called a 'cut up'. Another clear memory of hospital treatment was one of being dragged very reluctantly to the Manchester Royal Infirmary for his very first period of treatment. Instead of being wheeled off to the operating theatre in order to receive the original 'cut down', he was extremely delighted to find that a slight prick in the arm followed by a bottle of red liquid suspended above his bed was all that was now necessary! That was something like only 15 years ago. At this moment in time, we have only to rush to the nearest fridge (whether in the members bar, at work, or in one's own home) in order to find a parallel kind of relief.

Mr [GRO-A] discussed how extremely lucky he was to have lived in an area which in the early post war days prides itself on its specialist education, and its early detection of children that were handicapped who may have otherwise been prevented from attending either mainstream or special school education because of that kind of handicap. Mr [GRO-A] firstly received home tuition and was then allowed to attend an ordinary school. This meant getting ordinarily beaten up at ordinarily regular intervals! He commented on meeting for the first time someone that in his experience is very rare, and that was the head teacher who did not imagine that haemophilia automatically equalled a spontaneous flow of blood from every orifice.

Provision of special education in the foreseeable future is heavily emphasised by the integration of handicapped pupils of any kind into mainstream education. Mr [GRO-A] emphasised that wherever possible, special schooling should only be used as a temporary resource.

[Summarised]

FILM: HOME INFUSION: NEW FREEDOM FOR HAEMOPHILIACS**GRO-A**

With the introduction of anti haemophiliac clotting concentrates, the treatment of people with haemophilia has been changed dramatically. Bleeding episodes can now be treated with relatively small amounts of concentrates, instead of the large volumes of blood or plasma previously required. Most people with haemophilia can now be treated on an outpatient basis, but this form of treatment still has disadvantages such as long trips to hospital, time consuming record checks, and unfamiliar faces for the children especially. These experiences may discourage proper visits to the hospital when treatment is required. The film showed how the advantages of a carefully organised and physician supervised programme of infusion of clotting concentrates by the patient or his family within the home can change the lives of people with haemophilia. A seven year old boy who resented being infused on an outpatient basis was shown to readily accept Home Treatment administered by his parents. Similarly, a business man who has 'No time to be a haemophiliac' explains how the Home Treatment programme allows him to travel extensively.

The film showed how another boy, now being treated on an outpatient basis, carries out all the preliminary preparations for infusion before being able to administer the clotting concentrate himself and subsequently move on to Home Treatment in the near future. Dr. GRO-A author of the film - and a person with haemophilia himself - demonstrates the procedures for self administration.

The need for record keeping, contact with prescribing physician, as well as precautions necessary were also explained in the film.

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Vicki Stopford
Research Social Worker
The Haemophilia Society
January 1979