KING'S FUND
PROJECT PAPER

CARING FOR CHILDREN IN HOSPITAL

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Some thoughts and suggestions
from those living and working
in the ward situation

compiled by

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FOREWORD

The King's Fund Centre has, in recent years, done a notable service for children and those who care for them by holding a series of meetings on the welfare of children in hospital, some of which I had the privilege of attending. This service has now been enhanced by the preparation and publication of this handbook which brings together in a most readable way the essence of the comprehensive, sometimes controversial, discussions.

The handbook correctly and repeatedly emphasises the intensely emotional quality of the child's experience on being admitted to, and kept in hospital; discussions among professionals, parents and voluntary bodies are apt also to be emotional, but the handbook has a refreshingly objective and commonsense approach. The compiler has produced a volume which is easy to read and understand and from which professional jargon has been eliminated. Many good ideas and standards of practice contributed by participants at the meetings are incorporated and most of them can be effected without awaiting ideal accommodation or unrealistic increases in staffing. At the same time the deficiencies in our present provisions for children, especially those in long-stay hospitals, are fully explored so I hope that the handbook will be read by administrators as well as by teachers and learners.

There is much to be done before we can be satisfied with the care that children receive in hospital and the last words have certainly not been written on this subject. With the challenge in mind, and supported by the favourable reception which I am sure will be given to this handbook, I hope that the King's Fund Centre will continue to promote active and productive interest in this important area of hospital care.

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APPENDICES

INTRODUCTION

This project paper is the result of a series of small informal meetings held quarterly at the King's Fund Centre during 1971-3 to consider various aspects of the care of children in hospital and, in particular, to discuss ways of meeting the emotional needs of the child in the ward.

The ideas and opinions put forward in these pages are those expressed by staff and parents living and working in the ward situation. They are not claimed to be a comprehensive review of the subject nor to provide a definitive guide to the care of children in hospital, but it is hoped that the paper will be of help in at least three ways. Firstly, as background information for nursing officers and administrators who have to make the decisions on policies and procedures that will help - or hinder - the ward staff in their efforts to meet the emotional and physical needs of children in hospital. Secondly, as guide material for tutors and clinical instructors who need to keep in touch with the thinking of their colleagues on the service side in order to prepare their students adequately. Thirdly, as an introduction to the care of children in hospital for those coming into the situation for the first time - medical students, nurses in training, social workers, play leaders, teachers and others.

The series of meetings started as a result of a suggestion from a paediatric ward sister that nurses from different parts of the country should get together to look at progress and problems in the implementation of the Platt recommendations on unrestricted visiting of children in hospitals. The meetings later developed to include others, professional and non-professional alike, with an interest in the care of children in hospital and led on to discussions of many non-medical aspects of the problem.

A small number of paediatric ward sisters regularly attended a majority of the meetings and were joined on each occasion by a changing group of staff nurses, nurses in training, health visitors, social workers, paediatricians, teachers, play leaders, child psycho-therapists, clinical psychologists, general practitioners, parents and representatives of voluntary organisations, notably the National

CONTENTS

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2 VISITING AND 'ROOMING-IN'

Association for the Welfare of Children in Hospital. Mrs Hazel Edwards, Nursing Officer at the Centre, convened the meetings, which were also attended by observers from the Royal College of Nursing, the Department of Health and Social Security and, on two occasions, from the General Nursing Council.

The meetings were unstructured. Participants were invited to introduce themselves and to explain their particular interests and concerns. Discussion was then allowed to develop from the points raised and avenues explored as they arose throughout the day. After about six meetings the more general problems - visiting, 'rooming-in', communication, play, nurse training - had been discussed at some length. Subsequent meetings attempted to look at single problems in more detail. Topics such as baby battering, the care of the terminally ill and the rights of the handicapped child were each introduced by a speaker, and in one instance by an ex-patient, and were then followed up in informal discussion as on previous occasions. The difficulties described and the ideas and suggestions put forward at these meetings were recorded by Mrs Shirley Hardy and Mr Neil Rhind and their reports form the basis of this project paper.

Unstructured multi-disciplinary discussion meetings of this nature at the Centre have proved to be a most valuable way of breaking down barriers between those working in hospitals and in other services, between different professional groups, between professional workers and volunteers, and between grades within a single profession. They have helped participants to identify their basic problems in patient-care and to work together to solve them. At a time when the Department of Health has urged hospitals to provide in-service training for paediatric ward staff and to include community workers, it is possible that such discussion groups might form a useful part of the programme. The staff of the King's Fund Centre are always prepared to offer help towards the establishment of such local groups and would welcome information on their findings.

1 PREPARATION FOR THE HOSPITAL EXPERIENCE

The care of children in hospital is a team effort involving hospital staff, parents and the young patients themselves. Children cannot be treated as mini-adults; their care creates problems that will not be encountered elsewhere in the hospital but it also brings great rewards. Many children face illness with tremendous resilience and gaiety, and paediatric wards can be very happy places in which to learn the art of teamwork.

Like any other patients, no two children are the same. They come from different homes and the ability of each one to cope with his stay in hospital, whether this is expected or unexpected, depends on the emotional and environmental influences which have surrounded him from birth as well as on what he encounters in the hospital itself. A family with good relationships with the general practitioner, stability and common sense, and the support of relatives and friends is likely to take even an emergency hospital admission in its stride; but some families cannot cope and these parents may react by neglecting their children, by telling them lies or, indeed, by over-reacting leading to tensions between parents, patients and staff.

General preparation

Health care workers cannot transform non-stable, non-supportive families into stable, supportive ones, but they can help to educate and prepare parents both for the possibility of hospital admission in general and for a specific admission where this is expected. An attempt to offer general preparation is important because 50 per cent of children can expect a stay in hospital before their eleventh birthday and because this may have to be an emergency admission, allowing no time for specific preparation. The purpose of this general preparation should be to educate the small child about what goes on in hospitals and to show parents how they can support their child should he have to go into hospital.

General preparation can be carried out in a number of ways. Many excellent books and leaflets are now available (see bibliography) for both children and parents and these should be widely available in school and public libraries; so too, are slides and filmstrips. Voluntary organisations, notably the National Association for the Welfare of Children in Hospital (NAWCH) visit schools and mothers' groups with such visual aids and offer to advise and share experiences.

General practitioners and health visitors are key figures in this educational process. They can advertise the facilities available at local hospitals, through their clinics and surgeries and in personal contacts with parents. They can possibly exert personal pressure for better facilities by not sending patients to hospitals without free visiting or parents' accommodation where this choice is available. Many hospitals have mothers' accommodation which is not used because parents either do not know of its existence or do not understand its importance. The mass media, and particularly television, through programmes such as General Hospital, play an important role in breaking down public fear of hospitals and in emphasising modern methods of care.

Planned admissions

Preparation for a specific hospital admission can be built on to this general educational framework; for a planned surgical experience this is usually comparatively simple. Most are short and fall into a known pattern which can be described to both mother and child. It is most important, however, that planned admissions once planned, should take place. It is devastating for both parents and child if all the necessary domestic arrangements are made and the child geared up for the 'great day' only to be told at the very last moment that no bed is available.

Children who come in as planned admissions will have previously been seen in out-patients and the consultant or registrar will have had an opportunity at that time to prepare mother and child for the procedure involved. It has been found helpful in many hospitals for them to be invited to visit the paediatric ward to see the accommodation, meet the sister and discuss any problems which may arise. This creates an opportunity not only to calm a child's imagination about the forthcoming experience but also to show parents how they can help. Parental ignorance or embarrassment about their proper role can greatly increase the inevitable emotional upheaval to the child. This verbal preparation should be reinforced by written information handed out at the Clinic, or sent by post with the date of admission. Such material might consist of a leaflet giving details of ward arrangements for the parents, which enourages them to spend as much time at the hospital as possible, and a colouring book or comic strip about hospital life for the child. Such information should always be available in the languages of local immigrant groups as well as in English.

Emergency admission

Emergencies are more difficult and must be dealt with on an ad hoc basis, remembering that a mother may have particular feelings of guilt in these cases and so be less able to help her child.

The preparation process continues even after a child's admission and this is particularly important in emergency cases. Staff have to remember to offer the necessary explanations and reassurance during the approach to surgical or other traumatic procedures. Even with planned admissions, the ward staff cannot rely on parents having taken opportunities for proper preparation. Some mothers are too ignorant, emotionally upset or afraid of communicating their own fear to attempt this task themselves. In any case some children have no confidence in what their parents tell them because they have been let down by them in the past. Ward staff therefore, have to recognise the sort of preparation a child needs at each stage and try to meet this need.

Support in the ward

Preparation in the pre-operative period should be possible even in wards with a rapid turnover of short-stay surgical cases. Acting-out is one useful approach. One hospital provides miniature uniforms in which children can dress up and enact the events that have happened or are about to happen. Besides being therapeutic, this helps the staff to get clues as to whether the children are under or over-estimating the information which has been given to them. Children can often understand but still not evaluate their experiences and need very comprehensive explanations of apparently simple procedures, for example, why the blood taken for tests does not need to be replaced. It can also help to reveal their unnecessary fears, for example, of death or amputation, which might arise out of the child's knowledge of the hospital experience of relatives.

Full preparation for hospitalisation should cover the emotional as well as the physical aspects of the experience, and skilled social workers and health visitors can play an important part in helping mothers with this emotional preparation and continuing support. This is particularly relevant in the case of prolonged medical investigations and treatments. Staff must be honest with parents and admit when they have difficulty in reaching a diagnosis. This is a particularly anxious and unsettling situation for parents and one which creates a need for considerable support from the staff if parents are to help their child through the experience.

Each child's reaction to a stay in hospital is different but experience indicates that children are more likely to be damaged by emotional neglect during this time than by any physical experience. The three-year old child who has been badly injured in a road accident will remain quite cheerful provided he is supported by his parents and treated as an individual by the nursing and auxiliary staff. It is important for staff to learn from the child: since no two children are the same, caring staff will learn different things from children undergoing the same operation or treatment.

Accident and emergency department

The accident and emergency department will often be a child's first experience of hospital and arrangements there can make or mar his ability to cope with what follows. These departments are often far from well equipped to deal with children, who may be upset by the sights and sound of injured adults, and who can equally upset those adult casualties. Children may be separated from their parents for necessary procedures because staff feel that this will save time and avoid distress, or because the parents have to look after their other children. The ideal could be separate accident and emergency facilities for children as recommended in HM (71)22 staffed by people with the time and understanding to keep a child and its parents together during treatment, and possibly a creche for siblings. Until this is possible a clerk/receptionist, voluntary worker or social worker/nurse could be employed in the department to speed the flow of patients and to give advice, assistance and sympathy to patients and parents.

2 VISITING AND 'ROOMING-IN'

The principle of free parental visiting of children in hospital has now gained general acceptance and has, in some hospitals, been in operation for many years. Completely free visiting - that is, allowing parents to stay with their children throughout the whole 24 hours - has produced a number of problems, but the majority of professional staff working in this field and parents are agreed that the advantages to the children, especially the very young, outweigh these disadvantages.

Certain problems can arise out of the constant presence of parents in a ward. These are often due to thoughtlessness or insecurity on the part of the parents and can largely be solved if they are guided as to how to behave. A father might, for example, visit in the evening and wake his own child and other children who then become distressed because their own parents are not there: the need to avoid situations like this can be explained. Some mothers appear to spend their whole day gossiping with other parents rather than participating in ward activities with their children This is usually their reaction to being placed in an unfamiliar environment and can be solved by offering them something definite to do in the ward and a place away from the ward where they can talk through their mutual problems over a cup of tea.

Arrangements for siblings

The wish of mothers to bring a large number of siblings into the ward is one of the most difficult problems for ward sisters. While it is desirable for siblings to be able to visit and keep in touch with the child in hospital, and while they are likely to gain reassurance from such visits which will stand them in good stead should they later be hospitalised themselves, most wards do not have the space or facilities to accommodate large numbers of extra children. Their presence, especially during the school holidays, only serves to distract their parents from the needs of the patient and to disrupt the work of the ward. The result may be noise levels which frighten the younger patients and a risk of wrong feeding or other mistakes because the staff cannot supervise all that is going on.

It is important that parents should not be prevented from visiting a child in hospital because of the needs of their other children and also that the siblings should not feel rejected in favour of the sick child. Some hospitals allow mothers to bring one sibling into the ward at a time, but it is preferable to offer creche or playgroup facilities for siblings within the paediatric department or the hospital as a whole, or to make arrangements for home helps or voluntary workers to care for the siblings in their own homes, where this is acceptable to the parents. A visitors' creche is a great asset to a hospital, not only for the paediatric wards but also for mothers visiting other wards or attending out-patients or the accident and emergency departments.

'Problem' parents

Ward staff will be able to identify a number of groups of 'problem' parents. There are those who accuse hospital staff of harming their child, an attitude that cannot be made worse by encouraging free visiting. There are some who seem to be unable to cope with the ward situation, although it has to be remembered that even the most sensible person can become emotionally unstable when her own child is in a worrying or distressing condition. Others are distressed by certain treatments, such as lumbar punctures or post-operative recovery but wish to remain with their child throughout. If, however, parents can be made to feel like welcome participants in the care of their child rather than forced intruders, then they are likely to respond to the atmosphere, respect the sister's judgment and leave the ward if advised to do so.

Occasionally nurses see children who are quite happy in the security of ward life but who become distressed at visiting times. This is clearly a situation which needs further examination; so too does the case of the child who is not being visited at all. This may simply involve practical problems at home which can be solved with the help of the hospital social worker, the organiser of voluntary services or outside voluntary bodies, or it may reflect emotional problems or neglect and the parent's own need of professional help from the social work or pscyhiatric services.

Specialist wards

Where restrictions have to be placed on free visiting, these should be based on the needs of an individual child rather than applied to a whole category of patients and should be advisory rather than mandatory. In practice, most complaints from parents about restrictions on visiting refer to children being nursed in specialist surgical wards which are not specifically planned to meet the needs of children and which have different visiting arrangements from paediatric wards. Children nursed in these specialist wards are not only more often separated from their parents but also more often nursed with adults and without adequate play facilities.

The restrictions on visiting are, apparently, sometimes due to the attitude of the surgeon, sometimes to that of the sister and sometimes hard to establish due to buck-passing between the two. Many of the specialist conditions are very distressing to a child and the mother's presence, if she is properly prepared for the experience, usually helps rather than hinders recovery. For example, a mother can be advised not to wake her child after surgery as this will increase his pain. A child without his mother in the pre- or post-operative period may appear quieter than the child with support, but is, in reality, probably the more frightened and distressed.

'Rooming-in'

Provision for mothers to stay overnight or to 'room-in' at the hospital follows logically from the acceptance of completely free visiting. The ease with which this can be arranged and the amount of need for such accommodation depends very much on the design and age of the hospital, its catchment area, and the case-load it covers, but something can always be found where staff are agreed on the importance of the mother's presence. Facilities vary from separate parents' suites to cubicles to camp beds and chair beds for use in emergencies, but in many cases hospitals have accommodation which is not used. This suggests a need to educate parents to use the facilities which are already provided.

While children benefit from the support of their parents during their hospital experience, it has to be remembered that a 24-hour vigil at the child's side is an unnatural experience for the mother. Mother and child are not normally cloistered together throughout the day without other distractions so that, if the mother is to make a positive contribution to her child's recovery, she needs to be encouraged to leave the ward to go shopping, to see the rest of her family or, at least to take meals and fresh air. Cubicles can be particularly isolating, although obviously necessary in some cases, and an ideal solution would be to provide a separate parents' suite adjacent to the ward or a mothers' common room in conjunction with cubicles. Most of the difficulties seen by ward staff as arising from the presence of mothers in the ward can be solved if the mothers are clearly shown what they are expected to do in this alien and unnerving environment. Staff are obviously too busy to explain all this individually but a detailed leaflet about the ward can make things clear to most parents. It should cover ward organisation, the way in which parents can help their child, practical do's and dont's, for example, about distribution of sweets to the children, and facilities available, such as arrangements for meals, washing, hair washing and telephoning.

Free visiting has been accepted because the effects of maternal separation on a child have been so clearly demonstrated by James Robertson of the Tavistock Clinic and others, but it leads to a special work situation for staff, and particularly nurses, on a children's ward. In a busy short-stay surgical ward with heavy operating lists it is undoubtedly tempting for staff to feel that they have not got enough time to deal with parents and that the presence of mothers makes more work for already hard-pressed nurses. A more careful look at the situation, however, suggests that a few minutes spent showing mothers how they can help do not increase the physical work load and that a mother makes no greater emotional demand on a nurse by her presence than she does when shut out of the ward imagining all the terrible things which might be going on or happening to her child.

3 COMMUNICATION IN THE WARD

The normal problem of staff/patient communication in hospital takes on an additional dimension in a children's ward. The staff there have to relate both to their young patients, with all the particular skills that are involved and to the parents who are often so anxious and distressed that they are unable to take in the information being given to them or to express their needs and fears.

Talking to parents

It is essential that staff should put across all the information needed by parents and child and that they should do so accurately. Parents have a right to truthful information, in both the acute and the long-stay situation, presented in a form which they can understand. Putting this over is not always as easy as it might seem. Distressed parents can be told of something again and again and still not take it in because of their anxiety. They may make it difficult for staff to relate to them, perhaps by appearing to be unnecessarily aggressive in the ward, and staff should make allowance for this because the hospital is, for the parents, an alien environment and part of a stressful situation. Some mothers are afraid of hospitals because of bad experiences dating back to their own childhood and others find it hard to cope with the unnatural situation of staying in the hospital with their child even though this is what their parental instincts urge them to do.

For all these reasons the onus has to be on the ward staff to provide information and not on the parents to ask for it, and this can be tackled on a number of levels. Medical and other information on the child's condition should be provided by the appropriate specialist and parents need to know that this is coming from the most reliable source.

The opportunities for communication between parents and the medical staff have to be well catered for. It is not very satisfactory for parents if, for example, they are allowed in the wards at all times except during the doctor's round and are given no opportunity to see him. When meetings do take place it is essential that parents are able to discuss their child's condition fully and frankly with the doctor, as much because it is unkind to raise unrealistically false hopes for parents as because it is essential to win their trust. This applies equally to acute illness and to the development of long-term handicap. Parents may not be able to accept or absorb all the information at once but what they are told must be truthful and appropriate to the situation and this makes staff teamwork essential.

The need for teamwork

Some anxious parents claim that they have not been told anything about their child's condition when staff know that this is not, in fact, the case. Others are seen to seek information from the most junior member of the ward team, perhaps the motherly, but untrained, nursing auxiliary. Such problems can be overcome by staff teamwork.

Junior members of the team must be made aware of their responsibility not to make comments which are open to misinterpretation by parents but to pass on requests for information and expressions of anxiety to senior staff who can deal with them more appropriately. Senior nursing staff, medical social workers, and others have to be kept informed about the medical information which has been given to parents so that they can repeat and reinterpret this for them. Parents are likely to find it easier to understand and accept what is often distressing news when they hear it for the second, third, fourth or fifth time, and when it is rephrased for them.

The great majority of doctors try to provide information in words which parents can understand but there may be situations in which this reinterpretation process is particularly important. These may arise with non-British doctors whose English is not clear or who have only a limited grasp of local customs, with immigrant parents who present similar problems but from the other side of the desk, or where there is a rapid turnover of junior doctors who do not stay in paediatrics long enough to understand the particular communication problems involved or to develop the necessary skills to deal with them.

A number of practical steps can be taken to aid communication. The ward should include a small room for quiet and private interviews. Parents should be welcomed properly when they bring their child to the ward. Their initial impression is very important, and can set the tone for the success or failure of the whole stay. Time has to be taken to make parents feel at home and to see that they have all the necessary information about the ward to produce this effect.

A printed leaflet is particularly helpful as it both saves staff time by covering all practical questions, and is available for continuing reference if information is not absorbed at first hearing. It also ensures that there is an agreed and consistent set of rules and regulations for parents. Nothing is more distressing for them than to be told to do something by one member of staff and then to be 'reprimanded' for doing it by another.

The provision of a paediatric ward counsellor has been found to be very useful in a number of hospitals in the USA, although there is no likelihood of such a formal post developing in this country in the near future. The counsellor is someone with a nursing or social work qualification, or perhaps a well-informed volunteer, whose primary job is communication. She can handle much of the welcoming procedure, provide practical information on ward arrangements and, where suitably trained, provide the necessary reassurance and support concerning medical and other procedures. This has proved to be a great help to busy nurses, and is a role which is often forced upon the ward play leader when there is nobody else to undertake it.

Communication should be maintained up to the point of discharge and beyond. Most parents find it helpful to take home clearly written instructions about diet, drugs or any other special problem together with the name and telephone number of any member of staff designated to help with further enquiries.

4 EDUCATION, PLAY AND LEISURE

Children remain children even when in hospital and so have a continuing need for education, play and leisure time activities. These three are closely related and essential to the patient's restoration to good health. All these aspects are first and foremost the responsibility of the nursing staff by reason of their concern for the whole child thoughout the 24 hours. As a result, the many other tasks the nurses have to perform, usually under pressure, and the very limited place that can be given to play therapy in the nurse training schedule, they need allies and expert help.

Teaching in the ward

The Department of Education and Science requires that teaching must be provided for children who are in hospital for more than three weeks; this is usually interpreted to mean that children who are in hospital for less than three weeks do not need education. Some children's wards which always have a number of children staying for more than three weeks can establish a permanent teaching group with a regular teacher, and this teacher is often able to absorb some of the shorter-stay children into her group. Some wards are visited by a teacher on an intermittent basis, when they have children who fall within the requirement; education is then less of an integral part of ward life and shorter-stay children may have to be excluded. In fact, even short-stay patients benefit from education while they are in hospital, although it may be disguised as play, and where no teacher is provided the nurses have to look elsewhere for help.

Children in hospital also benefit from continued contact with their school outside. A regular ward teacher can maintain this contact, but where none is employed, it is helpful if the nursing staff can inform patients' schools about any child admitted in the hope that a teacher will visit, bringing in books to read and any other work that can be continued on the ward.

Ward play groups

In the younger age groups the borderline between education and play completely disappears and the nursing staff again benefit from the presence of an expert in the ward. Hospital authorities have been encouraged for a number of years to make provision for organised play and increasingly are being persuaded of its value.

The play leader is important because she is a regular factor in the wards, whereas the nurses come and go with their shifts. She has the time to organise complicated and often messy play and the skill to encourage children to work through their sometimes distressing hospital experiences in their play. Her first concern must be able also to absorb the occasional visiting sibling into her group. As well as catering for a primary need in children, the play leader is able to pass on her skills to others, including the trainee nursing staff, and parents who may later have to cope with a child in bed at home.

Help from volunteers

Teachers and play leaders, where provided, usually work school hours although the need of children in hospital for play and leisure activities continues throughout their day. It would be helpful if their hours could be more flexible, but generally the nursing staff have to look for other allies at evenings and weekends. They can encourage visiting mothers to take an interest in, and play with children other than their own and they can welcome outside volunteers.

Volunteers are most likely to meet a real need where the hospital employs a paid coordinator of volunteers - someone with a specific responsibility to recruit, train, support and supervise voluntary workers. This is important because volunteers are likely to become discouraged if they are not properly used and organised, and a coordinator can match volunteers to jobs that need doing in wards where they are welcome. Volunteers can add greatly to the daily lives of children in hospital, but their placement and function must be carefully considered. There is no reason why a ward should accept help from, say, a group of young people, where this will involve the sister in spending more time supervising the volunteers than in caring for her patients. In a properly organised scheme, however, such problems should not arise. Plans would be made in advance of any volunteers coming to the ward for them to work, say, under the supervision of the playleader, and to ensure that they understand the need for reliability and continuity in any job they undertake.

Help with play and leisure activities for children in hospital is most likely to come from two age groups - young people and the 'granny' generation. Young people can be contacted through schools, youth clubs and organisations, and older people through the uniformed voluntary organisations, local councils of social service or volunteer bureaux. Regular visitors can be particularly valuable in long-stay children's wards where the contact with family and community is much reduced and sometimes completely lost. The volunteers can bring the outside world into the hospital as well as help hard-pressed staff to provide a rich variety of experiences for the children. They should be encouraged to stimulate the interests of the patients rather than to become mother substitutes, although deep relationships sometimes develop between a volunteer and a handicapped and possibly rejected child.

5 NURSE STAFFING AND TRAINING

A trainee nurse's spell of paediatric experience gives her an opportunity to appreciate a number of special skills, namely how to provide for the physical and emotional needs of children and how to approach the parent/child relationship. All nurses spend a minimum of eight weeks looking after children during their SRN training but this is only long enough to give them an introduction to what is involved. Many students come to this allocation with no previous experience of the care of babies and small children and have to overcome their nervousness at handling them, often in the presence of parents, before they can go on to find the satisfaction that paediatric nursing can offer.

The emphasis on child care

For this reason, participants at the King's Fund Centre meetings suggested that more students should gain part of their initial paediatric experience caring for well children in a day or residential nursery and that accent should be placed on the correct approach to child care and the need to support parents as the best way to get through to, and help the child.

This approach places a heavy teaching burden on the ward sister, but the skills of communicating with parents, understanding the reasons for their anxious and perhaps difficult behaviour, and of providing the right sort of support are the real essentials that the students have to learn. Students have to understand, for example, that while the mother can meet most of the feeding and handling needs - skills which they want to acquire - the mother needs the nurse's skill and observation on her child's condition. Where students are encouraged to appreciate the mothers' presence they are less likely to 'leave them to get on with everything' and to withdraw their support where it is needed as well as where it is not. Mothers need to be assured that they can call trained help at all times.

Children's nurse training

If the initial experience with children offers nurses the chance to learn the right approach to child care and mother/child relationships, the RSCN course can provide the necessary time to learn medical facts and handling skills. The RSCN qualification can still be taken as a three-year training on its own, as a three-year and 8 months comprehensive training leading to an SRN and RCSN qualification and as an 18-month or 13-month post-registration training. For those wishing to become enrolled nurses it is possible to do 18 months of the 24-months training period in a children's hospital.

There is a shortage of trained sick children's nurses, perhaps because of the number who drop out during training - girls find that nursing children is not the same as liking children - and perhaps because of a fear that the specialist nurse is hindered on the ladder towards promotion. Overall, the children's nurse is subjected to considerable demands. She is expected in many cases to be a parent substitute as well as a nurse and inevitably has to work in a complex emotional environment. Children, even more than adults, need exceptional care, thought and delicate handling, and, though small in size, they cannot be treated as small-sized adults. In long-stay wards, the nurses have a particular childcare responsibility, and the present training pattern does not altogether meet those needs. It was suggested at the meetings that the present nursing teams should be replaced by teams of non-nursing care staff led by a RSCN nurse, and that the RSCN training should include more about the care of the multiple handicapped child and the development of the normal child.

In-service training

DHSS Staff Training Memorandum 59/72 which has been sent to all health authorities and hospitals with children's wards, encourages the development of in-service training schemes to include all those concerned with caring for children in hospital and in the surrounding community. Some hospitals have already started study sessions and seminars with guest speakers, films and open discussions involving health visitors, school teachers and others. A meeting on the subject of battered babies, for example, might include the casualty department, police and NSPCC and involve a study of the subject in depth laying the stress on communication and teamwork. Such sessions are proving very valuable; they are leading to improvements in community liaison, providing useful updating for social workers, midwives, and other community workers and expanding hospital nursing staff training.

Case assignment

In-service training might also prove a useful preparation for the introduction of case assignment on children's wards. This system provides each child with a prime contact who establishes a relationship with the real mother, provides physical and emotional care in her absence, takes over the mother's role in a skilled nursing context and acts as a boundary keeper helping other members of the staff to approach the child tactfully and discreetly. Such an arrangement is obviously to the advantage of patients, provided it is flexible enough to allow child and parents also to express their own natural preferences, and is in accord with the best principles of child care. Unfortunately it is not in operation in many hospitals. This is usually attributed to the practical problems involved, such as shift times, internal rotation of night duty, rapid turnover of nurses and staff shortages, although these can usually be overcome if the will to do so is there, but another reason may be the fact that the involvement created by case assignment can be very painful to the nurse. It demands carefully selected staff at a time when they are not always easy to provide, and a generous spirit of cooperation and unselfishness about the varying roles of the ward team in fulfilling the child's deepest needs. Social workers are taught about themselves as part of casework training as well as about the interaction of emotional, psychological and physical development, and an opportunity to share these skills at inter-disciplinary meetings can be a useful preparation for the introduction of case assignment.

Student nurses should not be expected to take a full share in the ward system of case assignments, or to take on 'difficult' children, although they may take responsibility for a number of patients as the climax to their initial paediatric experience. Some ward sisters move student nurses from the care of one child to another because they feel that this makes for a better training experience. In practice, eight to ten weeks is not long enough to learn about the medical conditions of children, and it is probably better to use the time to give students an understanding of the children's emotional needs, always bearing in mind that children are in hospital because they are ill and that the first priority is to get them better and back home where their emotional needs are more normally met.

The organisation of a ward to include case assignment based on care plans for each child and continuity of care from one shift to the next, allows for the concept of the nurse as the person who shelters the child in the ward and who in so doing meets a very important emotional need. A parent normally acts as an intermediary between her child and the world and, in the absence of a parent and in the medical context, the nurse ought to take over this role. Student nurses are likely to be able to take a larger share in patient assignment if and when they become supernumerary on the ward, as recommended in the Briggs Report, as this presupposes that there will be more supporting staff to supervise and instruct the learners.

Support and counselling

Support for front-line staff is essential in both acute and long-stay children's wards. Regular staff meetings, involving all ward staff from consultant downwards, provide opportunities to discuss any problems and long-term childcare plans. An occupational health service including a supporting psychiatric service or a counselling service, where these exist, is valuable in view of the particular stresses involved in caring for children in hospital - stresses both in meeting the needs of acutely ill children and distressed parents and in meeting the mothering needs of abandoned children in long-term care. As emotional problems with others, whether these problems arise out of their work or personal situations the need for acceptable outlets should be understood and proper provision made. The Salmon nursing structure is also proving helpful because it supplies nursing officer support to the wards and creates a framework for regular unit meetings.

6 INTENSIVE AND SPECIAL CARE

The skills of the paediatric nurse are employed to the full in the care of the severely ill, acutely handicapped or dying child, but this is also a situation which brings out her finest qualities. The frustration which may be experienced by staff who are unable to alter the child's prognosis and the distress of parents who are about to lose a child through death, or the need for long-term hospital care, are emotions which have to be acknowledged and worked through by all involved. Where this happens, the wards containing children in need of intensive or special care will be truly happy places where life is lived to the fullest extent possible from day to day. The job of caring staff is to respond to their patients' needs sensitively and appropriately, remembering that the important thing is not only what happens to the child but also how they can help him, and all around him, to get through this experience creatively.

Crisis at birth

The birth of a severely handicapped child is a crisis situation and when there is established life viability, the first priority of the staff involved has to be to forge the close links between the child and his parents which will prevent him having to cope with rejection as well as his other handicaps. Where a child has to be sent to a specialist unit at once it is important that the mother should have a chance to hold, or at least take the hand of, her baby before it is taken away. Some units have found it helpful to take a polaroid snapshot of each baby for the mother to keep.

The integration of the NHS may make it possible for mothers to transfer with their babies to special neonatal care units and to receive there the obstetric care they need, rather than having to remain in the maternity unit. Once the mother has left hospital the links can be maintained in the usual way through unrestricted visiting, the opportunity to participate in the care of, or at least to hold the hand of, her baby, and through support from professional workers and voluntary bodies such as the Spina Bifida Association or the National Association for Mentally Handicapped Children, depending on the child's handicap. See Appendix A.

One aspect of the care of parents and child is the assessment of the support they need and, in particular, to decide if and when they are ready for referral to the appropriate voluntary society. Some parents shrink from this contact, perhaps because they are aware that they are not coping with their present situation, and do not want to know what may lie in store for them, but the societies can be most helpful, providing factual and optimistic information about a child's handicap which can be read and absorbed over a period of time and which can help parents to ask the right questions about their child's condition and prospects.

Terminal illness

The role of staff in the care of the acutely ill and dying older child moves from being one of forging relationships to being one of supporting the parent/child relationship until the break comes, if indeed it does. Staff will, of course, make every effort to make a child well but in some cases there comes a point at which they have to accept that it is good nursing care to let a child die in peace, and that their role is not only to save life but also to enable people to live well their allotted time span to its end. Some bereaved parents have felt that the hospital withdrew its support when the doctors and nurses could do no more for their child. Families must not be abandoned to face the death of a child alone.

Personalities vary greatly. Some doctors do find it very difficult to accept that they cannot make a child better. Where this occurs the ward sister must ensure that the feeling does not adversely affect the work of the nursing staff and their determination to offer alternatives to fulfill the necessary support roles for staff and parents. This support is particularly important for young and inexperienced staff and can be provided through staff groups led perhaps by the hospital chaplain or a psychiatrist, through discussions with the ward sister, tutor or medical social worker and by encouraging students to discuss their feelings among themselves. Staff have to reach an understanding of their own attitudes to death and be able to express their feelings of anger and helplessness if they are to help patients and parents. Students are helped if their first experience of death in a children's ward is properly prepared, if they know the prognosis of each child and are reassured that the children are not in pain.

The need for properly considered support for staff is greatest in wards where a majority of the children have terminal conditions, and will be very relevant in the proposed regional oncological centres. Staff may be helped by a temporary change to another type of work and by specialised training, case conferences and staff discussions at which their feelings and experiences can be ventilated and insights developed.

Talking about death

A child often accepts death more easily than an adult, and over the crisis of a long illness, often shared with others who have the same condition and receive the same treatment, is able to come to terms with the possibility of his own death. Parents and caring staff have to develop the sensitivity to know what a child needs at any particular time. They have to listen to the child, to ask questions to find out what he is thinking, to sow seeds for later thought and to share experiences of happy and sad times so as to give the child the words to express his own anxieties. Adults have to offer the child reassurance to fight and cope with his illness and the effect that drugs or other treatment may be having on him.

Children are almost always optimistic and a direct question about a child's own death is rare. Indeed, if adults wait for this they have probably waited too long. They have instead to tread a delicate path between picking up false leads and saying too much, and leaving it too late and saying too little. This can be done by getting to know about the child's own family background and by building on family beliefs and religious faith in so far as this can be done with sincerity. Many children have no religious background and staff who have a deep faith, cannot trespass beyond the limit of the parents' philosophy without the risk of creating barriers in the parent/child relationship.

For many children the real fears are about pain or of being abandoned at the point of death. A well-meaning nurse can create more fears and fantasies at this time by talking about leagues of angels than by promising to stay with the child, come what may. A child knows that things are different when he is approaching death and he wants a calm adult acceptance of this together with a reassurance that he is safe in shared love and that he will not be left alone. Death can be faced with someone holding his hand and until that time comes a child can enjoy living from day to day. Some will find their joy in their religious faith but staff can help others to find joy in the value of life, in hope for the future or in the simple belief that sun follows rain.

Children cope less well with this situation as they get older, and adolescents find the deaths of other patients very distressing. They may react by complete withdrawal - under the bedclothes in some cases - and ward staff may need to call in psychiatric help. An adult visitor from outside the family possibly the chaplain or a local priest or minister, can be very helpful if they have the time to help the young person to talk through his feelings.

Support for parents

Although children can usually come to terms with their condition, their parents naturally find this very difficult and need the maximum possible support from caring staff throughout and beyond this trying period. Parents need hope up to the very end. They can accept what is likely to happen if they feel that medical and nursing personnel are actively involved and that they are all part of the fighting team.

This feeling is most likely to develop in a ward where there are no rigid staff roles and where flexible support alternatives are available to the parents. For many, contact with other parents who are sharing the same experience is the most valuable outlet there can be. This may be purely informal, by the bedside or in the parents' room where one is provided; it may be initiated by the ward sister, informally as the need arises or through more formal parents' groups, or it may involve referral to a voluntary society.

Parents should be encouraged to look after their dying children at home where they feel able to do this and where the necessary community support and 24-hour hospital emergency service are available to them. This must, however, be part of a well planned and helpful programme of care and not an abandonment of child and parents when the hospital can do no more for him. Both parents and child will be aware if they are abandoned - if, for example, the regular visits to hospital for tests and treatment are stopped - and the removal of hope will be an additional burden for them all to bear in the child's last weeks.

The need for support continues after a child's death. Death has become a taboo subject, prolonged mourning is no longer respectable and parents find they are avoided after bereavement. The mother whose child dies after a long illness, in fact, faces a double loss - the loss of her child and the cessation of regular visits to the hospital with its supportive staff and services. The mother whose child dies suddenly has had no time to think about the possibility, no supportive contacts at the hospital and possibly, has additional feelings of guilt at the circumstances surrounding the death.

All bereaved parents therefore need support and a choice of alternatives to meet their individual needs. The possibilities include formal bereavement counselling offered by the hospital, with appointments which give support to the parent, contact with the GP and health visitor who knew the child and have a continuing interest in the family (and so need to know when their patients are in hospital) or contact with other bereaved parents through a voluntary group such as the Compassionate Friends, which specialised in linking bereaved parents.

Contact with other parents however is likely to prove the most useful outlet of all. What bereaved parents really need is a good listener, often for up to two years after their loss. A mother may need to tell and retell her experiences with her child in a way which bores or embarrasses her friends, but which is essential for her because the retelling with changing insights is part of the healing process. Professional staff at the hospital cannot undertake this time-consuming role unless their special skills are clearly needed, and parents recognise this. The ward sister's responsibility is to indicate the alternatives available and to reassure parents that their child will be remembered and that they will be welcomed back for occasional visits.

Deprived siblings

The needs of a very ill child's brothers and sisters also have to be taken into account. The truly deprived child is often the sibling of the handicapped or very ill. Those supporting the family must be able to recognise the possibility that brothers and sisters are being neglected in favour of the handicapped or dying child either because a large part of the family income is spent on a search for a miracle cure or because all the parents' available time is spent with the child in hospital.

Siblings should be welcomed in the ward, reassured that they are not caught up in the disease situation and introduced to children who are in for only a short time and are clearly getting better. They should be considered in any decision to send a child home for terminal care. Where parents cannot cope well with this, the position of the surviving children may be made more difficult and the effect of a death within the home can do lasting harm. Parents need to be reassured that their feelings towards their other children, perhaps a temporary rejection after their bereavement, are normal and that they can be helped through this stage.

7 LONG-TERM HOSPITAL CARE

A number of children have to spend long periods of time, or even the greater part of their lives, in hospital wards as a result of mental or physical handicaps. These children make rather different demands on the staff looking after them because the childcare element becomes the most important part of the nurse's work. Parents are not able to spend as much time in the wards as they would in the case of acute illness; they often live some distance from the hospital that treats their child's special condition and in some cases they cease to visit altogether. In these circumstances the hospital staff have a responsibility to meet children's emotional needs and to provide a good quality of life.

In practice this is often very difficult and demands a concerted and nationwide effort to improve upon traditional approaches and attitudes. The existence of large long-stay hospitals in rural areas has allowed parents, and society as a whole, to hide its damaged and mis-shapen members away out of sight and still hinders the development of new and better alternatives. The provision of such alternatives will cost money for staff, buildings, and equipment, but should be seen as a national priority when the care of children in long-stay hospitals lags so far behind childcare provision in other areas.

Lack of parental contact

The DHSS estimates that there are at least 2,000 children in long-stay hospitals who are infrequently or never visited. Infrequent visiting is to some extent understandable; it may involve a great expenditure of time and money by the family. Assistance with fares may be available from the hospital social worker, local social security offices in certain circumstances, or the parent's local authority, but the time needed for the journey may still make visiting difficult or impossible. Parents have an equal commitment to other members of the family, and whether they visit regularly or not, are likely to feel guilty at neglecting either their handicapped child or his siblings. Where the problems are mainly financial, help can be sought from a number of voluntary funds. See Appendix B.

Hospital staff have to understand the reasons why children are abandoned - perhaps feelings of guilt and acute distress at having produced a handicapped child, or at having to give him up to residential care, or bad advice at the time of the child's birth to put him into hospital and not to try and make a relationship, or just the needs of the rest of the family. Whatever the reasons, it is up to those currently caring for an abandoned child not to condemn but to help and encourage the renewal of contacts with his family and to offer the sort of alternatives which can make those contacts possible and prevent the desertion of other children. This can be attempted in two main ways - support and counselling for the parents, and practical part-time care arrangements.

Practical help for parents

Parents can be encouraged to renew contact with the hospital and their child through some social occasion, and then to join a group with other parents of similarly handicapped children where they can discuss their feelings and practical problems. Hospitals can try to involve local authority social workers to help the whole family. A family with a handicapped child is a handicapped family and needs long-term and comprehensive support which, because of pressure of casework, local authority social service departments are not always able to provide. In some cases, support is provided while a handicapped child is living at home but is then withdrawn when he is taken into hospital or long-term care, leaving the parents to cope with their distress or guilt alone or totally to forget the child.

Hospitals and local authorities should see that parents do not abdicate all responsibility for their child, by offering them suitable alternatives. These may be short periods of residential care to give parents a break, care throughout the school term, home help assistance, or regular 5-day or weekend care. These choices allow the mother to work or run the house during the week but have her child home at weekends, or leaves her free to concentrate on the rest of the family at weekends. Even where children are in permanent care, parents can be encouraged to provide clothes and birthday presents and to take their child out occasionally.

Care in the wards

Whatever the arrangements, there will always be children who present such management problems to those caring for them or whose parents have so many other problems themselves that they are unable to cope, and so have to be taken into long-term residential care. These children have a right to the best possible substitute arrangements which many are not receiving at the present time. They live in large groups in old hospitals. Often they are suffering from multiple handicaps and are so severely disabled that the small number of staff who care for them have no time to provide for more than their most basic physical needs, and potential staff members and voluntary workers are frightened away by the intense demands created.

DHSS memoranda and Hospital Advisory Service reports which spotlight deficiencies and alternatives in long-stay hospitals appear to ward staff to fall on deaf ears because those at policy-making levels are not childcare orientated. Where the skill in child care exists within the hospital field it cannot always be exercised because of poor organisational and administrative framework, the lack of suitable buildings and shortage of appropriately trained staff.

Alternative approaches to care

There is indeed no reason why handicapped children needing long-term care should be kept in hospitals, with a routine governed by nursing shifts, and cared for by a changing procession of staff whose training fits them for meeting physical rather than emotional or developmental needs. Their primary need is for a childcare orientated environment and many participants at the meetings felt that handicapped children should be cared for in small family groups, in small domestic-scale buildings, by care staff and under child life specialist/wardens rather than medical consultants. Such units are likely to encourage community involvement as well as offering a better environment to the children.

Even within the context of the present large hospitals, much can be done to break them down into smaller wards and to provide a family-type life for the children.

Changes in staffing patterns to ensure continuity of care, patient assignment so that the children know which is 'their' nurse and the involvement of carefully chosen volunteers as 'aunts and uncles' can all help those who have to stay in hospital for a long time to develop a normal circle of relationships. Volunteers are particularly important in long-stay hospitals because they can provide the children with horizons beyond the hospital ward, but just because the children have so few alternative outlets, the continuity and reliability is also very important. This and many other points are covered in HM (72)2.

Occupation or schooling in or outside the ward, a normal daily routine, a wide variety of leisure time activities and opportunities to observe or share in domestic tasks are the rights of all children, including those in hospital. The introduction of domestic type washing machines to a ward might, for example, make it possible for many of the children to wear their own clothes and also to observe the processes of washing and ironing that they would see if they lived in their own homes. Handicapped children, as much as any other group, respond to the quality of their environment and are likely to improve as their living conditions improve.

A charter for the handicapped

Handicapped children have rights which are not always being met within the present situation. They have a right to quality of life, as described above, a right to be accepted for themselves rather than for what they have or have not got, a right to treatment which is only in their interest and ultimately a right to die. These last two rights raise questions about the whole context of care for the handicapped which is at the moment often fragmented and spasmodic. Treatment has to be in the interest of the child and seen solely in the context of his total needs. It should not be designed solely to further medical knowledge or the interest of a specialist, or to encourage the parents and in so doing to raise false hopes and expectations.

Ideally each child should be the responsibility of a team, coordinated preferably by a consultant paediatrician who is used to looking at the total context. Such a team would collectively make all decisions on assessment, treatment, education, care and coordination with other services, and this arrangement should ensure the provision of both integrated care near to the patient's home and of consistent and realistic help and advice to his parents. Circular HM (71)22, in fact, recommends that 'facilities are provided in children's departments for the comprehensive assessment by a multi-disciplinary team of all children who are physically and/or mentally handicapped'.

8 ALLIES IN THE COMMUNITY

Although many children spend some time in hospital during their early years it is, for the majority, a brief and isolated experience. They are known, and their medical and social needs are met, by doctors, nurses and social workers working in their home areas. These community workers are essential allies for the hospital staff and vital if the hospital experience is to be kept in perspective.

General practitioners

In most cases, a child's admission to hospital is initiated by his general practitioner, and the GP is likely to want to keep in touch with his patient's progress. He needs access to the paediatric department to enable him to act as liaison between hospital, family and patient, contact with his medical colleagues, and speedy information on admissions and discharges so that he can arrange support at home and continued treatment.

Contacts between hospitals and general practitioners have improved over the last few years but there are still hospitals where a GP is not welcomed in the wards or where a consultant saves all his discharge letters up for a three-day session at the end of the month. General practitioners on the receiving end of this treatment cannot hope to provide a proper service to their patients. A GP can be put at a disadvantage when a child is taken into a specialist treatment unit. The parents' contact with this specialist care may lead them to suspect their GP's overall ability and to devalue his care for the rest of the family. If, however, he is seen as the fixed point in family care he can provide the necessary continuity and long-term overall care for a handicapped child.

Health visitors

In practice the bulk of day-to-day liaison between hospital and community is undertaken by nurses, and the health visitor is the sister's first line of communication with the community. Many hospitals have a liaison health visitor for the paediatric wards. This health visitor spends perhaps one day each week at the hospital, going into the out-patients department to handle waiting list preparation and follow-up, attending ward rounds to get information on admissions, discharges and treatment plans, and giving home reports and other information to the sisters.

The liaison health visitor is able to pass on the information gained in the wards and department to local health visitors so that they can support families with a child in hospital, encourage parents to visit, and help to alleviate feelings of guilt or inadequacy which may hinder acceptance or understanding of the situation. In return, she can collect and pass on home reports and other information known to local health visitors, and which can be of help to the ward staff. These contacts may be vital in cases such as 'failure to thrive' if the local health visitor is to understand the hospital feeding programme and support the mother after her baby's discharge.

Health visitors like to talk to nurses on an equal footing but some sisters still prefer to use a good ward clerk to maintain contact with local authority nurses. This may be because there is no way in which sisters can get to know health visitors personally, or because health visitors are not attached to some general practitioners and cannot easily be contacted. One method of contact is to invite health visitors to attend hospital study days.

The many administrative and organisational changes now taking place within the health service are likely to make hospital/community contacts easier. All hospital and health staff will be responsible to the same authority, and health visitors moving into health centres and group practice premises, to cover the patients of one or more general practitioners rather than all the families in a geographical area. This has advantages for the health visitor. In the absence of a liaison scheme she is more likely to receive information on admissions and discharges; she is in closer touch with general practitioners and with their treatment or other plans for the child and she can built up a relationship with parents at a time when doctors seem less approachable in the health centre context. It can also create problems. Under the geographical area system, the health visitor could approach any new mother and introduce herself as the area health visitor, but now she cannot be sure whether a mother is a part of her group practice or not, or has even registered with a doctor at all. In areas of high mobility this could lead to children being missed altogether until their first school medical examination.

Health education

The health visitor also has an important educational role in conjunction with the hospital. She can help to meet the emotional needs of children in hospital, beginning with preparation for parenthood classes given to pregnant women and secondary school children. She is also much concerned with the prevention of home accidents, such as accidental poisonings and burns which are an important cause of hospital admissions among children. Health visitors can make a very great contribution to the campaign to reduce them. In some hospitals, the accident and emergency department informs the medical officer of health of children seen following accidents, and this information is passed on to the appropriate health visitor, to enable her to make a follow-up visit. This visit is not intended as an additional accusation or punishment, but as an opportunity for the parents to discuss any feelings of anxiety or guilt they may have and to ensure that anything similar cannot happen again.

Social workers

Hospitals which have no liaison health visitor arrangement may use their medical social worker as their prime contact with the community service.

This is often the only possible approach for a hospital with a large catchment area which cannot be visited by liaison health visitors from every local authority area. The MSW may, in turn, have close contacts with local health visitors, or may prefer to contact local authority social workers. The latter might appear to be the correct professional action but it is not always appropraite in a paediatric context. The new generic area social work teams are likely to be in contact with most of the 'problem families', but the local health visitor should know all the families in her practice or area. She is the more likely person to have an existing relationship with the family of a child in hospital and to be in a position to support and help them during and after that admission. There is always a danger that problem families will receive help and support from every side, while those families which appear to cope well are ignored, although they may need help badly at the time of a child's acute illness or in the long-term care of a chronically ill or handicapped child.

In some cases families will already be receiving, or will be in need of, skilled social work help, and the community social worker will be an essential ally for the hospital team. A social worker can be a great help to families with a handicapped or rejected child and may have to work with them for many years to ease them through the problems involved.

The reorganisation of the Social Services Departments along the lines recommended in the Seebohm report has created difficulties both for those working in the service and for hospital staff who have to cooperate with them. New gaps in provision have appeared as old ones are filled, and continuity of support and communication with hospital and other services have not been all that they might be, but these problems are slowly being resolved as the departments move towards new and more efficient ways of working. Hospital staff need to be able to call on social workers with specialist skills; they need to be sure that children and their families will not be forgotten by the local social workers once they have been taken into long-term hospital care and they need to be taken into the confidence of social workers in the handling of difficult cases, such as baby battering.

Liaison for the handicapped

Hospital/community contacts are likely to be particularly important in the case of children with a long-term disability or handicap who may have to go in and out of hospital on many occasions. These contacts need to be developed as soon as the child is born or as soon as the handicap develops, in order to avoid the likelihood of rejection or loss of parental contact. Liaison health visitors with a special interest may be valuable in this respect. They can, in addition to their other work, give parents specialised advice about the management and prospects of handicaps such as spina bifida, maintain contact with the home area health visitor while the child is in hospital receiving treatment and put parents in contact with voluntary associations concerned with their child's handicap. Parents facing the shock of having produced a handicapped child, of having to live daily life with that child and of supporting him through a succession of operations or other treatments are in great need of long-term help and support, which cannot be provided by community workers any more than by hospital staff unless they see themselves as part of the same team - as allies in their concern for the child and the family unit.

School teachers

Another ally in the community, and one who is often neglected, is the school teacher. In spite of busy professional lives teachers are often able to contribute to keeping a child in touch with the community during his stay in hospital or to attend multi-disciplinary case conferences seeking best care approach for an individual child. Many disabled children remain in hospital schools or local authority schools for the physically handicapped when they could be attending ordinary schools, because teachers have not successfully been made to feel part of the team caring for these children. It is obviously not desirable for handicapped children to be allowed to become exhibits in normal schools, but the establishment of special schools in this country may have served to slow down the absorption of the handicapped into normal schools in Britain as compared to other countries. Education authorities have only recently been required to build schools which can accommodate children in wheelchairs. Thus many head teachers are able to claim that they cannot manage handicapped children in their schools.

A refusal by a head teacher is often based on a misplaced anxiety about damage to the child, and the hospital should point out that the emotional damage which could result from prolonged hospitalisation may be greater than any physical damage which could happen in the school, and to offer realistic medical help should the need arise during school hours. Where it is felt that a child should leave hospital and return to, or start at, a normal school, a professional worker from the hospital or community services should approach the head teacher to ally his fears and to offer practical advice and continuing support including a telephone number. Close liaison between the hospital and the local school health service may be all that is needed to get a handicapped child into the 'right' school.

Problems are sometimes seen where none exist, but parents also have to be prepared to send their child to the most suitable school in an area as some schools may have genuine size or accommodation problems. Some handicapped children have learning difficulties and schools also need to know what they can expect of a child, or whether a special school would in fact be more suitable. The academic standard at special schools have improved greatly and the advantages they can offer in terms of very small classes have to be weighed against the quite different advantages to be gained from attending an ordinary school. The latter choice offers advantages, both to the handicapped child who is then part of the 'normal' environment of his area, and to the normal children who grow up to accept people with handicaps of all kinds. Despite the anxieties of head teachers, most children are very considerate towards the individual handicapped child and ready to help him join in all their activities.

9 SPECIAL GROUPS

Battered Babies

A great deal is now known about the battered baby syndrome. This is something which is attracting increasing public attention and causing great concern to staff in paediatric wards and community services. It may show itself as physical injury to, or as a failure to thrive in, babies and small children. Research workers have identified the groups of children most at risk, and the type of parents most likely to batter their children. Problems generally arise with parents who have difficulty in establishing a normal parent/child relationship due to emotional deprivation during their own childhood, to stressful living conditions or to lack of early contact with the child.

Hospital staff and particularly those in accident and emergency departments, have to be on the alert for this syndrome and should be suspicious of all injuries in children under three. It is vital to discover whether the damage is compatible with the parent's explanation for it, and whether there has been unnecessary delay in seeking medical help. Where battering seems likely, the first priority has to be to get the child into hospital as a place of safety and the second to coordinate information from a wide variety of sources over a large area to build up a full picture of the case. There may be a register at county or city level containing much of this information on children thought to be at risk. Once a case has been established through medical and social investigations, a case conference can be arranged to decide on the best course of action.

The case conference is likely to involve not only the hospital medical and nursing staff who have recognised the syndrome but also the general practitioner and health visitor, where the family have links of this sort, the social services department which has a statutory obligation for child life protection and can offer long-term support the child's school teacher and the NSPCC which is entirely child-centred and can offer shorter-term intensive and residential casework.

The case conference provides an opportunity to make a long-term plan to ensure both that there is no unnecessary duplication of help and support to the family, and that the family does not continue to fall through the net altogether.

As a result of the reorganisation following the Seebohm report there have unfortunately been cases of families being passed on to social services departments and then being dropped for a variety of organisational reasons which often only come to light when a further battering incident occurs.

Prevention is the first priority in tackling this syndrome. This involves both the prevention of initial cases by the recognition of children and parents at risk, and the offer of support or a life line - perhaps someone to talk to, a telephone number to ring, or a brief separation of the child to give the mother a break and the prevention of rebattering by the offer of intensive and long-term support, or by taking the child into care. The police are particularly concerned that, by the time they are involved in a case, it has often become one of child murder.

A decision to call in the police is always difficult but health care and social workers have a duty to be suspicious and to inform the police when they feel a child may have been subjected to violence. The police have skills in investigation and back-up resources, such as the crime intelligence unit and the experience of police surgeons and forensic pathologists, which may help to establish a case. They do not have to prosecute automatically and their involvement may save a child's life. It is usual now for the police to be called after a decision to do this has been made at a case conference attended by the health care and social workers involved. However, where immediate action is necessary, it is important that all the caring team should be informed as soon as possible, so that they can initiate appropraté help.

The information that could protect a child is usually available to someone but unless area registers or some other arrangement are in operation, it is not shared until a child is in a serious condition and in hospital, or until such emotional damage has been done that the child is unable to cope with school or some other aspect of life. More awareness of the problem at an earlier stage could prevent much of this damage.

Immigrant children

Whilst the whole question of children in hospital requires special attention and understanding, there are additional difficulties for staff in coping properly with immigrant children who speak little or no English and whose family or ethnic customs are alien to those of the majority of their fellow patients. Work is being done in this field. The National Association for the Welfare of Children in Hospital (NAWCH) and other organisations produce a number of leaflets in immigrant languages some of which are listed in the bibliography. Courses for workers attempting to help immigrant families are organised by community liaison officers in areas with particular problems. Some training schools include courses for nurses on the pattern of child care as it varies from culture to culture, but language difficulties are often not overcome for short-stay patients unless the staff includes members from the same country. All hospitals should keep a stock of basic information in the most common immigrant languages, and particularly information for mothers on the care of their babies and small children.

Hospitals have to cope not only with immigrant children who are likely to learn English anyway once they get to school, but also with children from those under-developed countries which lack specialist medical and surgical facilities. These children are likely to be very frightened and lonely when they find themselves far from home in a British hospital. The community relations councils or the appropriate High Commission may be able to help by providing an interpreter, though this latter approach is unlikely to be available to immigrants who no longer have any national bond with their country of birth.

Another distressing problem can arise when children have to interpret for their parents when they are admitted to hospital; for example, a young boy may have to explain his mother's gynaecological complaint. Attempts are being made to offer home tutor language schemes to immigrant women but many Asians still prefer to register with an Asian GP and do not learn English as quickly as they might.

Language however is not the only cause of misunderstanding. Cultural background and social behaviour also differ and a failure to allow for this can cause distress. Problems that have arisen include Pakistani girls whose eyes were carefully made up by the parents and the make-up later washed off by nurses. Asian children may expect to be able to stay up late, particularly if the mother is encouraged to live in the hospital. Some immigrant fathers on the other hand do not seem to take much interest in their hospitalised children possibly because they see child-rearing as woman's work.

There also may be difficulties with meals due to religious dietary rules, inability to accept mass cooking and a normally unbalanced diet. A Hindu diet, for example, often contains little or no animal protein. It is not possible to alter eating habits overnight and the sudden change to hospital food is difficult for the immigrant to manage, especially at a time when other things are strange and frightening.

Many nurses find that children from the Middle Eastern countries form the most difficult group of all. Many of these children who come in as private patients have never been away from home before. Embassies and legations can supply visitors for them but these people are often officials who see their function as disciplinary and concentrate on warning the child to be good. Some nurses have felt that attitudes towards affection in Arab countries can be rather different from those of the West and physical proximity to parents is not considered so important. Financial problems have occurred in some instances and it was felt that hospital authorities should ensure that parents of private patients should know what is involved and be able to pay for all the treatment that may be needed, before the child is admitted. Despite all these problems, however, hospitals have an obligation to offer immigrant children as well as visitors, and indeed, all child patients, emotional care reflecting the same high standards as the medical and surgical care that they come to Britain to obtain.

Adolescents

Adolescents form a quite distinct social group and it is absolutely essential that they should be nursed separately as a group. When put into children's wards they are likely to present problems and be very bored with life. It is equally unsuitable to move them into adult wards from the age of 10 or 12 years, as is the custom in some hospitals. Adult wards today usually contain a large number of elderly patients some of whom are confused and this means that young people may overhear inappropriate conversations, such as lurid and misguided details about operations and other experiences in hospital.

Young people are happier and easier to look after in a general hospital if they are treated together in one ward rather than spread throughout the hospital. They can then receive schooling during the day and can take part in pop concerts, films and other entertainments suitable to their age during evenings and weekends. Volunteers, including teenagers, are usually most willing to help to organise suitable entertainment.

The care of adolescents in a long-term hospital setting raises different problems. They are likely to be suitably accommodated in either small mixed age family groups or in special adolescent wards or units, but more effort has to be made by the staff to provide contact with the community than is necessary for short-stay patients. Much depends on the reason for hospitalisation. Some children can leave the hospital daily to go to school or training centre in the community while others have to depend on people coming into the hospital for their essential contacts with others of their own age.

Appendix A VOLUNTARY SOCIETIES CONCERNED WITH ILL OR HANDICAPPED CHILDREN

Association for Spina Bifida and Hydrocephalus. 30 Devonshire Street, London W1N 2EB
British Epilepsy Association. 3-6 Alfred Place, London WC1E 7ED
British Red Cross Society. 9 Grosvenor Crescent, London SW1 7EJ
Cystic Fibrosis Research Trust. 5 Blyth Road, Bromley, Kent BR1 3RS
Invalid Children's Aid Association. 126 Buckingham Palace Road, London SW1W 9SB
Lady Hoare's Thalidomide Trust. 78 Hamilton Terrace, London NW8
Leukemia Society. 24 Cavendish Road, Woking, Surrey
Malcolm Sargent Fund for Children With Cancer. 56 Redcliffe Square, London SW10
Multiple Sclerosis Society. 4 Tachbrook Street, London SW1V 1SJ
Muscular Dystrophy Group of Great Britain. 26 Brough High Street, London SE1 9Q6
National Society for Autistic Children. 1a Golders Green Road, London NW11
National Association for the Welfare of Children in Hospital. Exton House,
7 Exton Street, London SE1 8YE
National Deaf Children's Society. 31 Gloucester Place, London W1H 4EA
National Society for Cancer Relief. Michael Sobell House, 30 Dorset Square,
London NW1 6QL
National Society for Mentally Handicapped Children. Pembridge Hall,
17 Pembridge Square, London W2 4EH
National Society for the Prevention of Cruelty to Children. 1 Riding House Street,
London W1P 8AA
Royal National Institute for the Blind. 224 Great Portland Street, London W1N 6AA
Salvation Army Tankerton Children's Emergency Home. Anna Wilson House,
47 Marine Parade, Tankerton, Kent
Save the Children Fund. 29 Queen Anne's Gate, London SW1H 9DH
Schizophrenia Association of Great Britain. Llanfair Hall, Caernarvon, North Wales
Scottish Spina Bifida Association. 7 S E Circus Place, Edinbrugh EH3 6TJ
Society of Compassionate Friends. 27a St Columba's Close, Coventry, Warwicks
Spastics Society. 12 Park Crescent, London W1N AEQ

This is by no means a complete or comprehensive list. Further information can be sought from medical social workers who are likely to keep a full and up-to-date list of charities and to be able to advise on the most appropriate help for patients and their families. Most of these societies and many other voluntary organisations are listed in 'A Handbook of Organisations relating to the health and social services' published by the Health and Social Service Journal. (Price 20p, from King Edward's Hospital Fund for London).

APPENDIX B

Sources of financial assistance for patients and their families (particularly help with the cost of visiting patients in both long-stay and short-stay hospitals).

Government Departments

Department of Health and Social Security

1 Local social security offices are empowered to give help with fares to parents who are already receiving supplementary benefit or family income supplement, at the discretion of the local manager. This should be available for short or long-stay child patients.

2 Local authority social services departments are empowered, under Section 1 of the Children and Young Persons Act 1963, to provide "assistance in kind, or, in exceptional circumstances, in cash" to promote the welfare of children by diminishing the need to receive them into care. This provision has been used by some local authorities to give help with fares for visiting children in long-stay hospitals, to prevent them being abandoned by their parents and thus 'coming into care'.

Department of Education and Science

Local authority education departments are empowered under Section 56 of the Education Act 1944 to pay the travelling expenses of parents of 'handicapped children boarded away from home, to enable them to receive special educational treatment'.

Voluntary organisations

The Association for Spina Bifida and Hydrocephalus

The Spastics Society

The British Epilepsy Association

(see p53 for addresses of the above)

The Soldiers', Sailors' and Airmens' families Association (SAAFA)
35 Catherine Place, London SW1

Trade Union benevolent funds (related to parents' trade or profession)

Other sources

The family Fund for families of handicapped children

Families with a very severely handicapped child normally living at home may be eligible even though the child has to spend periods in hospital or it at school during term time. Familes with a child living permanently in a residential home or hospital might be assisted with the extra expenses involved in visiting the child. Applications should be made to the Medical Social Worker or the Secretary. The Family Fund, Joseph Rowntree Memorial Trust, Beverley House, Shipton Road, Yorks YO3 6RB.

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All above are available on hire from Concord Films Council Limited, Nacton, Ipswich, Suffolk, IP10 0JZ.

Gary and Susan. Set of colour slides with commentary available from National Association for the Welfare of Children in Hospital, Exton House, 7 Exton Street, London, SE1 8VE.