KING'S FUND CENTRE
KFC 79/308

(9 Oct 1979)

King Edward's Hospital Fund for London
King's Fund Centre

CARING FOR CHILDREN IN RENAL FAILURE

Summary of the conference held at the King's Fund Centre
on Tuesday 9 October 1979

Reported by Ruth Lupton

November 1979

The King's Fund Centre
126 Albert Street
LONDON NW1 7NF

HRUF (Lup)

KING'S FUND LIBRARY

126 Albert Street, London, NW1 7NF

Class Mark HRUF	Extensions Lup
Date of Receipt OCT 1979	Price donation

King Edward's Hospital Fund for London

King's Fund Centre
126 Albert Street London NW1 7NF

CARING FOR CHILDREN IN RENAL FAILURE

A conference to be held on Tuesday 9 October 1979

Chairman: Mrs M White SRN RCNT RNT, Nurse Adviser, Royal College of Nursing

PROGRAMME

10.00 a.m.	Registration and coffee
10.30	Welcome to the Centre Miss Hazel O Allen, Assistant Director
10.35	Introduction by the Chairman
10.40	Treating Children in Renal Failure Dr Cyril Chantler, Consultant Paediatrician, Guy's Hospital
11.00	Questions
11.10	The effect of renal illness and treatment on the family Dr Rosemary Baillod, Consultant Nephrologist, Royal Free Hospital
11.30	Questions
11.35	Co-ordinating the Caring Team Miss Elizabeth Winder, Nursing Officer, Renal Unit, Guy's Hospital
11.55	Questions
12.00 p.m.	How the Social Worker can help Miss Christina Toliani, Medical Social Worker, The Royal Free Hospital
12.20	Questions and Discussion
12.45	Lunch
13.45	The Panel Speaks Miss L Michael, Dietician, Alder Hey Hospital Mrs Marcelle de Sousa, Ward Sister, Guy's Hospital Mrs Maureen Davidson - Parent Mrs Elizabeth Lanham - Parent Miss Carol Young - Former Patient
15.00	General Discussion, Questions and Recommendations
15.40	Summing Up by the Chairman
15.45	Tea
	Conference Ends

CARING FOR CHILDREN IN RENAL FAILURE

Inspired by the success of the conference in 1977 (Renal Society News Letter 22) and related to the International Year of the Child, a second conference was arranged by the King's Fund Centre in consultation with the Renal Society and Royal College of Nursing Haemodialysis and Transplant Nursing Forum. It brought together medical professionals, patients and their relatives, as well as others in the caring team, such as dieticians, social workers, teachers and occupational therapists.

The main speakers were, Dr Cyril Chantler, Consultant Paediatric Nephrologist, Guy's Hospital, Dr Rosemary Baillod, Consultant Nephrologist, Royal Free Hospital, Miss Liz Winder, Nursing Officer, Renal Unit, Guy's Hospital, Miss Christina Tolaini, Social Worker, Royal Free Hospital, and a panel, consisting of a dietician from Alder Hey Hospital, two parents of children with renal failure, a dialysis patient and a sister from the Paediatric Dialysis Unit at Guy's Hospital.

Dr Chantler emphasised the need for children to be treated in special units where facilities were geared to their needs and special expertise was available. Following criticism over the years in the United Kingdom, in 1978, for the first time, our provision was comparable with many European countries, although about half the children still die untreated. Special units, however, are few and far between and this involved families in travelling great distances, with consequent expense of time and money.

Survival rates after five years' treatment are now 90% for dialysis patients, 80% for those having both dialysis and transplant, 70% for live donor transplants and 50% for cadaver transplants. With an expected survival rate for all patients of 70% for ten years, the balance is now in favour of treatment for most children. Very young children and those with multiple handicaps may not benefit from treatment and it can be too stressful for children without the committed support of their parents.

There are two main areas where we must endeavour to improve matters. First is the quality of life of our child patients. Some children are well and have few problems. For many, their life is totally unsatisfactory with frequent visits to hospital, many operations, much distress and constant anxiety. The second is the stress on the family living with a chronic illness with problems that will not go away. We could and should provide more help and support, both in the kidney unit and in the community. Having achieved some success medically and technically, we must now demand more resources for social and financial support for the patients we keep alive and for their families.

Dr Baillod spoke further on the effect of Renal Failure and treatment on the family. She, as a Consultant, felt in a privileged position in being allowed into the home and lives of her patients in depth and, for a long time, as are GPs. Once doctors have identified the problems, the familieswill find the answers. They needed early warning of the difficulties they may have to face and plenty of reassurance from medical staff.

There are three likely ways in which children will reach the renal unit. Firstly, the disease may be diagnosed in infancy and parents have come to expect the worst. Secondly, a long illness and wide searching for help may leave the parents embittered when they eventually reach the treatment centre.

Thirdly, and most commonly, children may be well today and very ill tomorrow. In each case, parents endure deep emotions, shock, anger, fear of the future and constant nagging anxiety. If we, as doctors, don't get our patients well, we lose credibility with the family, there is poor mental and physical rehabilitation and a lowering of standards leading to difficulty of acceptance in the family and in the community or school.

The first thing that hits you as a doctor is the overwhelming sense of guilt of parents. Mothers can express this more easily and by taking the role of dialyser, can be helped to overcome their feelings of failing the family. Fathers should also find their part in the treatment to relieve their feelings of frustration.

Home dialysis has proved to be the most acceptable form of long term treatment because it is personalised to the child. We want our children to have a normal family life and schooling, so we have to adapt dialysis to home circumstances and back it up with good equipment and good organisation. The accumulation of small annoyances and changes of dialysis schedules due to machine failure cause upsets to the whole family, throwing blame on the child and its parents. The biggest area of failure is in blood access. Fistulas, Dr Baillod has found unacceptable for children and shunt management, though it has improved, still causes much difficulty.

Nearly all younger siblings have extra problems arising from the illness of their brother or sister. They may be hyperkinetic, get into trouble, fall back in their school work and, almost always, are attention-seeking. This can put extra demands and strain on already burdened parents, who, generally, have the sympathy and co-operation of older children.

Survival for children is now very high. They have great tenacity, better than adults but, they survive at the expense of the family. But, while there may be moments of regret at starting the treatment, these are short and most parents are accepting and adapting to the demands made upon them.

Miss Elizabeth Winder said her role was that of a caretaker and protector. We know of the stresses within the family. There are parallel stresses for nurses who have to carry out aspects of treatment that are unpopular and distasteful for their patients. If as staff of the unit we learn to handle our own problems, then we can help and share the parents' problems. Certainly, we want all our patients, both children and adult, to receive successful transplants but, for some, this will never happen. Her job was to care for the dialysers so that they can care for the dialysed.

Miss Toliani said the social worker is there as an enabler who can try to ameliorate the social, emotional and psychological factors that may interfere with, inhibit or impede the successful treatment plan and, allow the family to adjust in the best way, to the situation they are faced with. Her work with the families of children with life threatening conditions of all sorts had taught her the kind of help that was needed - patient listening, gentle reassurance and practical advice. She could advise about possible benefits and grants but, financial difficulties will continue. After-care in the community needed developing as many fresh problems relating to school, careers and sibling troubles arise.

In general discussion, the following points arose:

Diet

Dialysis is now so good that a normal balanced diet suitable for the whole family is the most appropriate. Financial cuts in some areas have affected the provision of special extras but, generally, children's hospitals were more relaxed and better provided for. There is a diet allowance for patients on Supplementary Benefit of £6.40.

Special Children's Units

It was several times stressed that children should be treated in special units rather than in adult units. Even when long distances were involved, once on home dialysis, contact by telephone and good management reduced the number of hospital visits. For adolescents, minimum care units would be ideal.

Schooling and Employment

The provision of teaching in special units for children could overcome the problems of missed school. We had saved the lives of these children, we must now give them the best opportunities for learning and taking their places as adults within the community. We should not expect children who grow up with limitations to achieve normality and compete in the open market but there is ignorance and prejudice among employers who need educating and making aware of the potential of disabled youngsters. Often, a good record of school or college attendance can be an advantage at interview and careers advice was generally better in further education colleges than at ordinary schools. All congenitally handicapped school leavers were having a pretty difficult time and job opportunities are very poor indeed. Perhaps a project on job-sharing should be instituted.

Marriage and Sex

The marriage prospects and sexual awareness of patients were considered lower than average. SPOD (Sexual Problems of the Disabled) is an organisation that offers counselling and support to disabled people in a realistic way.

Growth Problems

Children transplanted before or at puberty grow better than children on dialysis whose growth was very poor. Many drugs have been and are being tried but, results are discouraging. Children make up for their small stature by developing their character and personalities and display great realism in their choice of future career - jockey, zoo-keeper with small animals, nursery nurse, for instance.

Holidays

Many units have holiday homes and portable machines make continental holidays possible. Ideally, children should be able to visit other units, thus relieving parents of the tedium of dialysis but, we must maintain extreme vigilance, in regard to hospital risks and urge European units to raise their standards to those of the United Kingdom.

Kidney Patients' Associations

Associations for Kidney patients, their parents and friends can help in muy ways by raising funds for holidays, amenities, research and general support for their units, also by joining in national efforts to increase resources to provide better support and help for children and their families.

About 14 Patients or parents, 17 nurses and 8 hospital team members attended the conference on 9 October 1979, with representatives from patients' associations and doctors. Nearly everyone took part in the discussion which was a really useful interchange of views and experiences.

King's Fund
54001000225915

0000 048572 02000