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CARING FOR CHILDREN IN RENAL FAILURE

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

Report by Ruth Lupton

November 1979

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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

The conference, arranged by the King's Fund Centre, in conjunction with the Renal Society and the Royal College of Nursing Renal and Transplant Forum, was intended to bring together, for discussion and interchange of views and experiences, both the medical professionals and patients and their relatives, as well as others in the caring team, such as dieticians, social workers, teachers and occupational therapists. It turned out to be an extremely good mix and the contributions from the floor were as valuable as the material from the listed speakers.

Opening the conference, the Chairman, Mrs White, Nurse Adviser, Royal College of Nursing, quoted G. B. Shaw who said "All professionals are a conspiracy against the laity". Perhaps this sort of meeting could overcome some of the artificial divisions and emphasise the necessity for sharing of problems between members of the medical team, parents and others.

In this International Year of the Child, the slogan chosen by the World Health Organisation was, "A healthy child: a sure future" and the message of the year was that no effort should be spared to promote self-reliance of the family in regard to the health of its members particularly in child-rearing. This is especially relevant for families with a child with renal failure.

Treating Children in Renal Failure

Dr Cyril Chantler, Consultant Paediatrician, Guy's Hospital

1.5 children per million of population, or 5 children under 15 per million children, could be expected to have renal failure· that means in the United Kingdom, about ninety children per year, many of whom would be suitable for treatment either by dialysis or transplant. New patients in Europe accepted for treatment numbered 280 in 1978. In the same year, with the improvement in the provision of facilities in the United Kingdom, following criticism over the years, 48 new patients were accepted for treatment and, for the first time, our provision was compatible with other countries in Europe. Of children who started treatment ten years ago, 50% were still alive. Those with live donor transplants had the best opportunities· others might alternate between dialysis, transplant and return to dialysis· others again might remain on dialysis and be unsuitable for transplant. The quality of life of children with renal failure was crudely measured by the European Dialysis and Transplant Association (EDTA), according to their record of school attendance. 85% of transplanted children enjoy complete rehabilitation compared with 70% of those on dialysis and just under 50% of those in hospital. As adults, 90% of transplants have full time employment, 70% on home dialysis and 50% of hospital patients.

One of the major problems for children with renal failure is growth retardation. Much research is being done on this. Small stature is a major disadvantage but studies show that on the whole, boys grow to an acceptable size. As recommended by the British Association of Paediatric Nephrologists, because there are only 12 centres treating children in the United Kingdom, many families have to travel large distances with the consequent expense and time spent.

The small numbers of centres is a consequence of the small numbers needing treatment and the need for fully developed teams at those centres. Survival rates after five years' of treatment are 90% for dialysis patients, 80% for those having both dialysis and transplants, 70% for live donor transplants and 50% for cadaver transplants. Summarising, an up to date reckoning is 70% survival for 10 years, most will grow adequately, though some not at all acceptably. With successful transplantation, which is a better form of treatment than long term dialysis, children can enjoy a relatively normal life, going to school and joining in sporting activities.

There are two main areas in which we must endeavour to improve matters. The first is the quality of the life of our child patients. Some children are well and there are few problems. For many, their life is totally unsatisfactory, with frequent visits to hospital, many operations, much stress and constant anxiety. We could do more to alleviate anxiety by giving more help from Kidney Unit personnel and by providing extra support in the family and home. Many units have their own patients' support groups to provide extras to help to make life tolerable. The British Kidney Patients' Association has also provided funds for holidays etc. The second, is the stress on the family It is disastrous to be told that a child has renal failure. In some ways, it is worse now than it was 15 or 20 years ago when the child died, the family grieved but they did not have to go on living with the problem. How we can treat these children. There is no guarantee of success but there is an offer of life which parents have little option but to accept. Dr Chantler admitted that he believed that treatment was not right for some children - those who are very young with multiple handicaps. They must have the support of the family. If that is not there, the stress for the child is too much. Death is then an acceptable alternative to a miserable life. If we ask what percentage of success is acceptable, the balance is in favour, having regard to the quality of life and the survival rate.

The aim of childhood is to lead to an independent adult life. To do this, we must improve the quality of life for the patient and alleviate stress on the parents and siblings. The medical team have not enquired too closely into what the stresses are because we knew we could not do anything about them because we have not the resources. Those who provide the funds should recognise these problems and provide for them.

The effect of renal illness and treatment on the family

Dr Rosemary Baillod, Consultant Nephrologist, Royal Free Hospital

Dr Baillod spoke further on the effect of renal failure and treatment on the family. She, as a doctor of patients on home dialysis, felt in a privileged position being allowed into the homes and lives of her patients both in depth and for long periods, as are GPs. Once doctors have identified the problems the families will find the answers but they need early warning of the difficulties they may have to face and plenty of reassurance from medical staff that they can cope.

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 and, in fact, may feel deprived if treatment is offered. Secondly, a long illness not diagnosed and wide searching for help may leave parents embittered when they eventually reach the treatment centre. Thirdly, children may be well today and very ill tomorrow.

In each case, parents endure deep emotions, guilt-shock, fear of the future and constant nagging anxiety that they could have done more.

If we, as doctors don't get our patients well, they 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 verbally express this more easily and by taking the role of dialyser can be helped to overcome their feelings of failing the family. Fathers are often unable to do this especially if their work is of a professional type and is demanding. Those fathers who can find their part in the treatment are able to relieve their feelings of frustration. Those that cannot help often relieve their feelings by getting angry with doctors and nurses.

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 is improved, still causes much difficulty.

Nearly all younger siblings have extra problems arising from the illness of their brother or sister. Two siblings of patients were hyperkinetic. Others 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, although older children feel the injustice of always having to give way to the sick children.

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

After their talks, Dr Chantler and Dr Baillod were asked questions.

Mrs Ward, President of the British Kidney Patients' Association, asked why a number of children were not being treated. Their parents were told that treatment would not be of benefit and that there was a lack of money forkidney machines. If this was not so, then Paediatricians should be honest and tell parents the real reasons why treatment was not offered.

Dr Baillod said there was no lack of money but there was a lack of trained staff in kidney units. Sometimes her unit was so busy that they simply could not cope with new demands and extra problems. If there was a lack of support from parents, then it was better not to start treatment of a child. Dr Chantler said it was true that possibly half the children who could be treated were dying. The difficulty was to find such patients. They were not turned down by Paediatric Nephrologists but they were not being referred by General Paediatricians who may think that treatment either may not be desirable or that it is not available. However, with positive publicity, parents are now asking for machines and more children are getting treated. Some areas of the country have few facilities but, the south east is well served and Dr Chantler knew of no case in this area that had been turned away. There are reasons for not treating certain children but consultants have to acquiesce with parents' views if they insist, this sometimes with unexpected success.

A nursing sister from Liverpool remarked that support groups raising funds for kidney machines should be told that there is more to treatment than simply providing machines.

Dr Chantler agreed and said that if there were not properly staffed units then children with renal failure would not be referred but as soon as a unit was provided then the children would come. Plenty of people will work in renal units, it is a highly rewarding job though it may be very stressful too. Dr Baillod said that it was not at all easy to get staff in London because of the high cost of living but, she agreed with Dr Chantler that there was a lack of expertise for training willing staff and funds were not being provided to allow for such training.

Mrs Joan Wright, the parent of a boy on dialysis from Leicester, asked the consultants if they agreed that children should travel to special paediatric units rather than be treated in a normal adult unit.

Dr Baillod said there was a great advantage for children to be in special units, with special expertise related to their problems. The drawback of travelling for long distances were lessened as soon as home dialysis was possible. If home dialysis was not possible, then it would be better for the child to be treated in the nearest unit to its home. Once started in a unit it was unwise and very difficult to transfer to another unit.

Co-ordinating the Caring Team

Miss Elizabeth Winder, Nursing Officer, Renal Unit, Guy's Hospital

Miss Winder said she pictured herself first as a cheerleader urging her team on to greater things, then, as a grey clad figure with a lamp in her hand, walking the corridors and touching the hands of her patients. But, her real role was that of caretaker, the person left in charge of the house, or, a protector. Who was she protecting and why? We know the family problems of stress and anxiety, intense physical and emotional involvement, fear of future troubles. Nurses too have a very close relationship with their patients and they are expected to give support and guidance in a positive way. Renal units are known to be high stress areas for nurses, they are said to be 'so depressing' and many nurses have a fear of machines, though many in the audience know the technical matters are not hard to master. There are real frustrations and conflicts for nurses who know the benefits of certain aspects of the treatment that are unpopular and distasteful for the patients and their families.

Questions from parents may be repeated to several members of staff who may give inconsistent answers leading to antagonism and feelings of being let down by colleagues. These are the sorts of stresses we, as staff of the unit, must learn to handle, then we can help and share the parents' problems. We hear much of the miseries of dialysis and the wonders of transplantation. Certainly we would wish all our patients, both children and adults, to receive a successful transplant but, for some, this will never happen and dialysis is here to stay.

Miss Winder said that it was her job to take care of the dialysers so that they can care for the dialysed.

Mr Ferguson a parent from Glasgow, said that where there was a successful team unit, the patient had such confidence in them that they were reluctant to leave for home dialysis.

Miss Winder emphasised that more support was needed to help patients settle back home and home dialysis Sisters were now being appointed, whose job was to visit homes and give that support in the community. Guy's Hospital had one sister for 80 patients and this clearly was not enough but, it was a start.

Dr Baillod said all children wanted to get home: the reluctance came from parents.

Dr Chantler said, most patients were glad to get home though the first few weeks (interjection of "or years") might be hell in adjusting to the new way of life for the family.

Dr Baillod said that her unit sends a nurse home with the family who stays until she feels the family can cope by themselves but who is ready to return when necessary.

Miss Sangster, a ward sister from Alder Hey Children's Hospital, Liverpool, said she could sympathise with the parents· she had been on holiday with a group of children on her own. She was immensely relieved when things went right and felt she had the same experiences as a patient going home for the first time.

A Liverpool nurse asked if there was a place for self-care or minimum care units for children. These were units set up in conjunction with the parent unit with, say, one nurse looking after six beds for patients who carried out 'home' dialysis in the centre. Two such units had been opened in Liverpool and a third was planned.

Dr Chantler said, his reaction was that this was unsuitable for children whose place was definitely in the home. Long term hospitalisation or outside treatment was very bad, psychologically, but, for emergencies such units could be useful and for adolescents preparing to leave home, it was a reasonable step.

Dr Baillod agreed that such units would be superb for young people at College or University but, parents would resent time spent in travelling to such units and would dislike sharing equipment if they were used to having their own particular dialysis set-up.

Two parents said their children preferred to stay at home though they were now grown up. It suited them best but, as parents, they needed boosting from time to time. Another parent said her son had a transplant but was hoping to choose a College near his unit as a safety line. She felt she should try to cut the parental strings and urge him to launch further afield. If he had to return to dialysis, a minimal care unit would be ideal.

Finally, Dr Chantler related the results of a study of stress on parents and patients. At the start of treatment, it was found that half the patients had signs of stress. A year later few had but 50% of parents were found to be in trouble. However, some families coped very well and for all the talk of anxiety and stresses, half of the studied group were managing successfully.

How the Social Worker can help

Miss Christina Toliani, Medical Social Worker, The Royal Free Hospital

Miss Toliani was working not only with families from the renal unit but also met families with children who had life threatening conditions of all sorts. She said she had learnt from them what sort of help they need. Any member of the family may come and see her and for each of them it was a first time experience to which she could apply the knowledge she had gained from other families in similar situations, recognising that for them, it was an intensely personal and individual matter. There was a need to go back over the hows and whys of their children's illness and to get their feelings of guilt out of the way by repetition and recital of what they thought they had done wrong. She had to find out how a family had coped with life up to the time of the illness of their child and bring their strengths to bear on the new situation.

If there is an acute illness most people can cope with a crisis but chronic illness is different and there is a continuing need to help the family to adjust to the new demands made on them and to advise on how and where to seek further help if, for instance, there is financial stringency or difficulty about jobs. During the initial stage of shock, grief and depression she must pick up cues from the family as to when they are ready to accept new ideas and advice. During training and treatment she relies heavily upon the unit staff for feedback about things that may be going wrong and new areas where help is needed. Staff may not realise the impact of the appearance of and behaviour within the unit: for some parents it may appear like a sort of Space Station and they may react with a combination of contradictory emotions - relief that their child is receiving treatment, horror at the equipment, bewilderment at the routines, anger that it is <u>their</u> child who is afflicted but, most of all, a fear of failure. Parents need more time spent with someone who can share these struggles and help them to overcome them. Near the end of training, when the family is getting ready to go home, there are pressures on the dialysing parent to do right by the child and if things go wrong, the child may get impatient and angry if mistakes are made. Parents evolve self-help groups but some get left out and need special help.

Once patients go home, there is a continuing link through hospital visits and by phone. It is then that after-care is most needed, with the appearance of many fresh problems relating to school, siblings and financial pressures. The Social Worker can advise about possible benefits and grants available and patients can fight to get things by right but, money problems will continue.

There is then the question of transplantation and the build-up of hope that this will solve all the family's problems. The technology of organ transplantation has far outstripped any attempts to work out the moral, ethical and social implications, let alone the psychological business of accepting a foreign body as part of oneself. There may be tremendous relief at the time of the transplant but there is bound to be a constant fear that it may fail with the traumatic experience of a return to dialysis, with the dependence and intrusions into the family life that it involves.

The social worker is there as an enabler who can try to ameliorate the social, emotional and psychological factors that may interfere with or inhibit or impede the successful treatment plan and allow the family to adjust in the best way to the situation they are faced with.

Dr Baillod interjected that some obvious stresses could easily be removed by the provision of money by the DHSS for travelling to and from the hospital. There was pressure to keep patients in hospital because there was no statutory provision for the payment of transport costs during training. Fares had been provided by social workers approaching charities but this was a contrary way of going on.

Mrs Ward, British Kidney Patients' Association, said that renal medical social workers could apply to the Association for grants for travel expenses by sending a financial statement with the letter asking for help for patients.

Mr Moreton Livingstone, Chairman of the Humberside Patients' Association, said that they had a benevolent fund to assist patients in need. Some areas, Trent and Oxford among them, pay all fares from NHS funds for hospital visits for training.

Dr Chantler said it was wrong to set up Regional Centres which may involve patients travelling very long distances without providing the means to get to those Centres. People should write to their MPs protesting at this and seeking for improvements in the provision for travel expenses.

The Chairman, Mrs White, set the tone for the afternoon session by telling the story of the young man who approached the father of his intended bride, asking for his approval of their marriage. The father answered "I doubt very much whether you could afford to support my daughter in the style to which she is accustomed". The young man, not daunted, said "If you can hardly manage it yourself, perhaps if we pooled our resources we could do it". She was sure that caring for the child in renal failure was a case where pooling of resources was needed.

A panel of speakers gave brief talks followed by general discussion.

Miss Leslie Michael, a Dietician attached to the renal unit at Alder Hey Children's Hospital, Liverpool, told us of the ideal arrangement for regular meetings of all staff in the unit, consultant, nurses, dietician and social worker, for the interchange of information, tutorial sessions for revision of the physiology of the condition, or talks by, for instance, laboratory staff. These meetings were a real example of team work where not only patients' problems could be examined but where niggles, jealousies and doubts among staff could be openly untangled. In addition, they had started occasional Saturday morning meetings with children and families together with the unit staff which are very useful for sorting out problems and making contacts in a relaxed atmosphere away from the wards.

Adequate nourishment is an essential part of treatment - you are what you eat. It is very difficult to make a regular and accurate assessment of the intake of children and it takes considerable skill in sifting the truth from what the patient tells you. Dialysis technique is now so good that a normal adequate diet suitable for the whole family is best and expensive special food and protein are an indulgence only needed when children are having difficulty in enjoying any food.

It is sometimes hard to make children eat. Due to stress they may be anorexic, and the apathy and depression that often goes with renal disease reduces the chances of successful treatment. The important thing is to get a good balance of protein and calories. To achieve this is sometimes frustrating but it is no good being neurotic about it. Dialysis patients get the pick of menu and if anything special is asked for the kitchen will do its best to provide it. Some units find that the current cuts have stopped children being provided with little extras or treats; others may have cut catering costs but the needs of renal patients have been realised and their food is not affected.

A nurse from Exeter said, that while in-patients are not affected, visiting dialysis patients were not counted for food which meant they went for many hours without a meal.

Variation between Regions arose because of the way the health service is funded but, on the whole, children's hospitals are more relaxed and better provided for, which underlines the need for special children's units. There is a diet allowance for patients on Supplementary Benefit of £6.40.

Parents' experiences

Mrs Maureen Davidson is the mother of a 12 year old boy. She gave a brief history of her experiences. She had been against dialysis thinking that transplant was the easy way out of her son's problems. His first transplant was from herself and lasted for three years. When it failed, he was on dialysis and nearly ready to go home when he had another transplant which kep him in hospital for a year. After the second transplant failed, he went back on dialysis which she now feels is no worse than a bad transplant. Things she had read gave her a distorted view of dialysis but after the first month of learning to cope at home, though there were extra burdens, she was happy enough. Her husband, who was very upset at first, now had his set part in the dialysis treatment and her family now has no problems, having adapted to the needs of their son, though she would want another transplant for their son eventually.

Mrs Elizabeth Lanham told us about her son, who became ill suddenly and she thought he would be in hospital for the rest of his life. She hated the thought of home dialysis but they learnt and went home. After two years, when they had really forgotten about transplants, suddenly there was a phone call, asking them to go to the hospital. At first, there were rejection symtoms and it was six months before he had enough energy for sports. The transplant is now two years old and her son is doing tremendously well, swimming, playing football and using more energy than the rest of the family.

When he was on dialysis she had a great struggle to make him eat properly; after the transplant, his appetite was enormous and she had to switch from urging him to eat to preventing him from overeating. Apart from regular medication and the monthly hospital visit, he is now a normal healthy boy.

Patient's experience

Miss Carol Young is a patient on dialysis. From the age of five she was in and out of hospital and her kidneys finally failed when she was ten. She has been on a dialysis machine now for eight years. She said she felt her parents had had a lot to put up with. They had expected she would be constantly ill and in hospital but she was very much better with the machine. She said it did not affect her life-style that much, she had a full-time job, went out a lot and enjoyed life. She had decided that it would be better to finish her schooling before she opted for a transplant.

Special Children's Units

We heard from Mrs Marcelle de Sousa, Sister of the Children's Dialysis Unit at Guy's Hospital which the three previous speakers attended. Up till this year, children had been treated with adults. Now there is a purpose built four-bedded unit which is geared to the children's needs. She wanted specially to mention the teacher at the unit whose job was vital. We must be preparing the children we treat for life by giving them the best opportunities for learning and achieving all they can. The dietician and the social worker were also very important members of the team. Often parents want to come and talk about all sorts of things apart from dialysis and the nurses too rely on the social workers to help them with their difficulties. She said she felt very strongly that it was essential to treat children in their own units. She loves her job and would not go back to any other unit. She gets to know the children and their parents long before they are admitted to the unit and the long and close relationship is part of the pleasure of the job.

Marcelle was asked about the transfer from the special children's unit to the adult unit. She said that it was impossible to fix any particular criteria for making the transfer but, generally, it was when schooling was over and the patient was starting their working life. It was a matter of individual judgement of the right moment.

Carol Young said she had recently transferred to the adult unit. She was told to grow up at home, she was working and she felt adult but, she missed the children she had known for so long.

Employment and Schooling

Mr Frankham, the father of an 18 year old girl with kidney failure, said she had had difficulty in finding a suitable job. She was small and could not be expected to compete with normal people of her age.

Carol agreed that starting work was a problem for many children. She herself had completed a course at college in spite of a good deal of discouragement and now did a full days' work with the Community Service Organisation. She had found and chosen her job by herself without her parents' help.

Another parent said that her son had found a good job after University and a transplant but it had needed a recommendation from the surgeon.

Mr Livingstone mentioned that 1981 was to be the International Year of Disabled Persons. Though many kidney patients were reluctant to carry the disabled label, there could be an advantage in registering as disabled since larger firms were obliged to employ 3% of disabled people on their staff.

Miss Toliani said it was wrong to expect all children who grow up with limitations to achieve normality and compete on the open market. There was much ignorance among employers, careers advisors and teachers. They needed educating and making aware of the potential of disabled youngsters. The disability employment scheme was fraught with pitfalls and she was pessimistic about it ever being enforced. The question should be posed : We have saved these children's lives, now what are we offering them?

A teacher from Glasgow emphasised that it was only recently that children had been taught in hospital. Many children miss some schooling and can never catch up. In many areas all young adults had difficulty in finding jobs quite unrelated to renal function. One parent said she had a great struggle but insisted on her son going to a normal school. Another's son was already at a school that knew him, they had been very understanding and her son had been able to keep up in every way. One girl who started dialysis when she was four had missed only one term of schooling so had managed to stay with her age group.

The Chairman asked if parents felt they were getting the right guidance and advice and if so, where did they turn for it? Mrs Wright, Leicester, said her son had been forced into a special school and had to do 'O' levels at night school. He had had three jobs each of which he had lost when he mentioned his dialysis machine. So, the only job he kept was one where he did not mention it and had a medical and a urine test and passed A.1. This caused much laughter.

Someone from Leicester remarked that patients are encouraged to get into further education for a couple of years. This may simply put off the evil day but a good record of attendance can be extremely useful at interviews. Careers advice at further education colleges seems to be better than in ordinary school.

Miss Diana Irish, a member of the 'Long Term Care' team at the King's Fund Centre, said she was involved in a project looking at the opportunities for handicapped school leavers. There is a fairly comprehensive system for careers officers to refer these children to Disablement Resettlement Officers for training and assessment. All congenitally handicapped school leavers are having a pretty rotten time and many of the jobs open to them are very poor indeed.

Mr Livingstone said that there was a vicious circle : we go out saying that life on a kidney machine is hell, to try to pursuade people to carry kidney donor cards but, on the other hand we are saying we are fit and capable of working.

Marriage and Sex

Dr Evans, transplant surgeon, from Liverpool, remarked "Why don't we suggest two jobs for the price of one i.e. job-sharing, especially for women. Perhaps a project could be instituted." She then introduced the subject of marriage and asked what 17 and 18 year-olds thought of their prospects. Carol answered that she did not want to marry early. She wanted to keep her job, make what she could of it and perhaps marry and settle down later on. A father remarked that his girl was neither so sexually aware nor so physically attractive as other teenagers. He felt her prospects were less than average.

The Chairman informed the meeting of the organisation called SPOD - Sexual Problems of Disabled People - which gave support and counselling to disabled people of any age. Their counsellors were realistic and practical. Society expected disabled people to be sexually unaware but we all need to come to terms with our sexuality whether or not we are disabled. SPOD should be more used and more widely known about.

Growth Problems

Dr Evans also asked what studies were known of relating to retardation of growth in children. Was this worse amongst dialysis than transplant patients? Marcelle de Sousa referred to research results published by the EDTA which showed that children transplanted before or at puberty tended to grow better than children on dialysis. The growth was not comparable with normal children but growth on dialysis was very poor and though many drugs have been and are being tried, the results are not encouraging and there had not been much success.

Holidays

Many units have holiday homes or caravans for dialysis. If children can be taken on holiday without their parents it gives them a feeling of independence and the parents can have a real holiday - a second honeymoon? Portable dialysis machines could be taken away on holiday (British Airways carry them free of charge if they are insured) but the best answer would be to dialyse in another unit. The risk of hepatitis was a very real one particularly on the continent. We should urge European units to raise their standards to U.K. levels.

Dr Evans said surgeons operate on all sorts of patients and never know whether they will contract hepatitis. It is an occupational hazard but the risks should be minimised. Nurses' attitudes were to discourage continental holidays, to encourage the use of portable machines and short holidays, returning home for dialysis.

Kidney Patients' Associations

These were able to provide very great help with holidays. Humberside had three caravans for 65 patients who could be helped from the benevolent funds if they were unable to afford holidays. St Thomas' Hospital had, through their patients' association, arranged an interchange of patients with a Finnish hospital. The Royal Free Hospital had two dialysis children's holiday homes and a fund to provide trips such as their weekend in Guernsey.

A patient from Oxford said that their association was very active and had raised money to help with the building of their transplant unit, to send doctors and nurses and technicians to conferences. They had social activities which were enjoyed by both staff and patients. Any group of patients without an association would find that if they started something they would find it snowballed and became an essential part of the unit and a real support for patients.

A touching and true story was told. A twelve year old boy was asked what he hoped to do when he grew up. He is very fond of animals and he said he'd work for nothing as a zoo-keeper - he'd look after small animals such as monkeys and make himself indispensible. (Another mother interjected that her son actually was a zoo-keeper). What this boy lacks in stature he makes up for in character and realism.

Rounding up the conference, the Chairman said that every problem needs an individual solution. Opportunities to speak together mean we can teach and learn from one another. To talk is to reduce the size of the problem.

Thanks were offered to the King's Fund Centre and particularly to Mrs Hazel Edwards, the organiser of the conference, to the Renal Nurses Forum and to the Renal Society whose ideas had sparked off the organiser.

The Renal Society

Treasurer : Miss Grace Blick, 64 South Hill Park, London NW3
Secretary : Mr D Allen, 9 Pinewood, Kingswood, Bristol

Royal College of Nursing Renal and Transplant Forum

Chairman : Miss Liz Winder, Nursing Officer, Renal Unit, Guy's Hospital, London SE1

European Dialysis and Transplant Association c/o St Thomas' Hospital, London SE1 7EH

Chairman : Dr A J Wing (EDTA Registration Committee)

National Federation of Kidney Patients' Associations

Chairman : Mr Brian Pearmain, Swan House, Wickham Skeith, EYE, Suffolk
Secretary : Mrs Ruth Lupton, Orchard Close, Winterbrook, Wallingford, Oxon

The British Kidney Patient Association, Bordon, Hants

President : Mrs Elizabeth Ward

SPOD - now : Committee on the sexual and personal relationships of the disabled.

c/o RADAR, 25 Mortimer Street, London W1N

King's Fund
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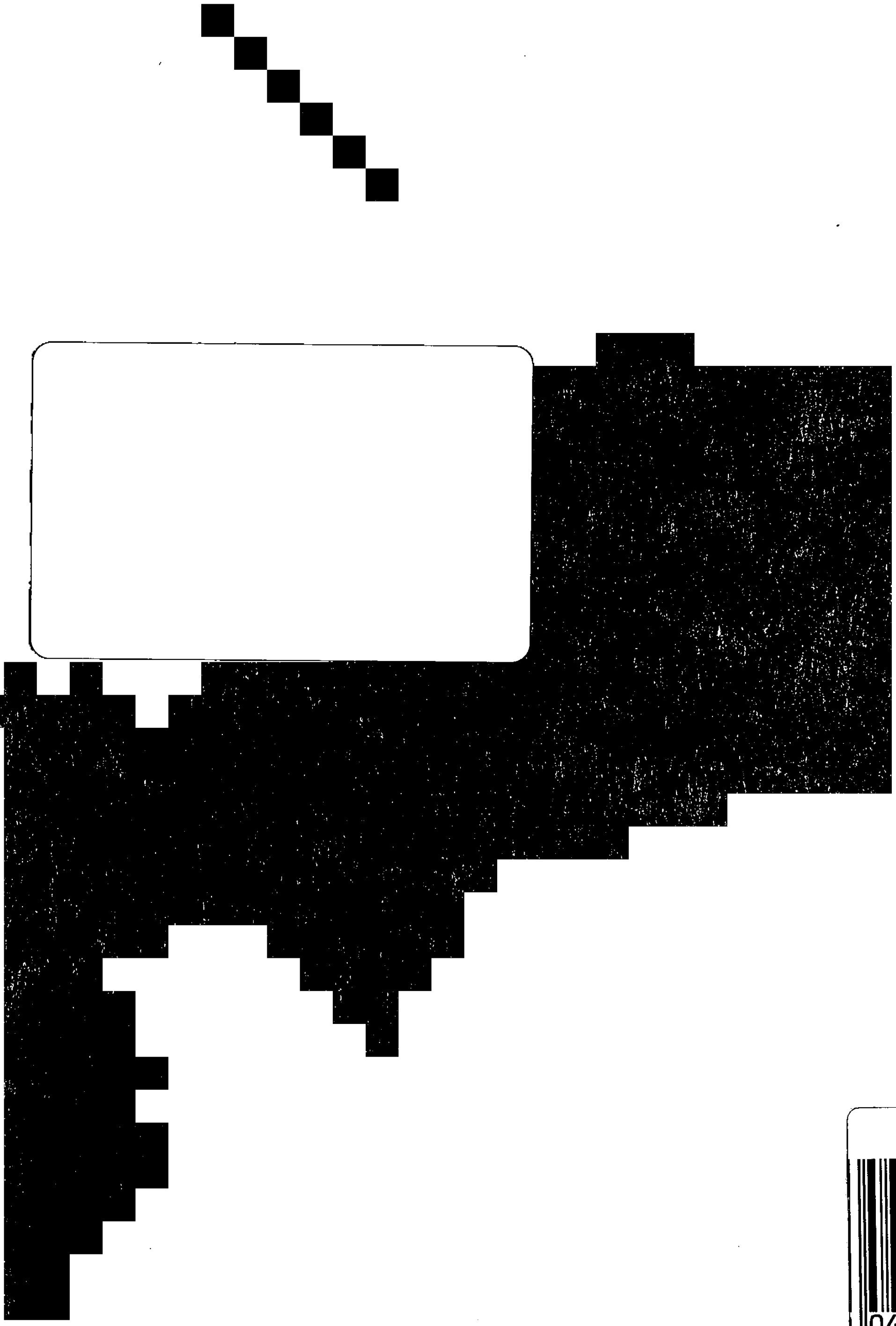

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