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CARING FOR ADOLESCENTS IN RENAL FAILURE

A seminar held at the King's Fund Centre

Tuesday 11 May 1982

Report by

THE RENAL SOCIETY

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King Edward's Hospital Fund for London is an independent charity founded in 1897 and incorporated by Act of Parliament. It seeks to encourage good practice and innovation in health care through research, experiment, education and direct grants.

The King's Fund Centre was established in 1963 to provide an information service and a forum for discussion of hospital problems and for the advancement of inquiry, experiment and the formation of new ideas. The Centre now has a broader interest in problems of health and related social care and its permanent accommodation in Camden Town has excellent facilities for conferences and meetings. Allied to the Centre's work is the Fund's Project Committee which sponsors work of an experimental nature.

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A seminar held at the King's Fund Centre on Tuesday 11 May, 1982.

This seminar was the third arranged by the King's Fund Centre with the Renal Society, and was a follow-up to the one held in 1979 (the International Year of the Child), on 'Caring for Children in Renal Failure'. Miss Hazel Allen, Assistant Director, King's Fund Centre, welcomed Mrs Moureen White, Nurse Adviser, Royal College of Nursing, who was once again acting as Chairman. She in turn welcomed the speakers and audience and remarked how, having enjoyed the last conference, she hoped this would be as useful a day with as many people as possible adding to the discussion later.

Patients talking with the Chairman

The morning opened with a general conversation between three young people and the Chairman. Liz Noble is 19 and started on dialysis when she was 16. Liz became ill quite suddenly, too ill to understand the implications of what was going on. Vincent Watters was found to have faulty kidneys in 1968. He was put on a diet that maintained his health until 1975, since when, he has been on dialysis and has had three transplants. Possibly the young person who has been on dialysis longest in Europe, Diana Northover, who is now 22 years old, started in 1969 when she was 9. She described life with the machine as 'great' but admitted that it had interferred with her life style as she would have liked to go to university or college away from home. However, she is now training to be a chiropodist and really enjoying that, knowing how much chiropodists are needed and appreciated, particularly by elderly people. Liz did not agree that life with a machine was so great, though after a couple of years of resentment and feeling she was missing out on many things, she has grown out of those paranoid feelings. Vincent was really hoping for a successful transplant to free him from the machine and the restrictions on travel, going out with friends to the pub and other normal things. Diana described how she had got over the problem of being so small - she tells the barman that she is driving so that her age is not questioned. When she was younger, she did have some difficulties with her taller sister, but she had sorted that out herself. She had talked to a psychiatrist but had not found it very helpful; nor had Liz who knew she needed help with emotional problems but resented being sent to the 'shrink'. She felt she got the best advice on all aspects of life from a Social Worker, who was neutral, non-family, non-patient, non-medical. Having older brothers and sisters, Vincent had been able to share his problems with them, and when away from home had been able to visit them for weekends or evenings to 'chat it out'. He felt that his illness had possibly had something to do with the break-up of his sister's marriage because her husband had disagreed with her giving Vincent one of her kidneys. However, the guilt he had felt about that was lessened when she married again and was so happy with her second husband.

Mrs White asked the three about their jobs. After two years working in a geriatric hospital, Diana had switched to her present training. There were some initial doubts over whether she could cope with her job but they were soon allayed. Vincent had lost his first job-opportunity because of the machine but he was well-placed now, so long as he did not let the machine interfere with his work. Liz, because she dialyses in hospital, had found it impossible to find a part-time job that paid well enough to be worth taking. She had boosted her self-respect and confidence by getting three O-levels taken in hospital. Recently, she had started a college jewellery course - an interest that came from her grandfather - and that is going well. She still hopes for a working transplant, unlike Diana who has taken her name off the transplant list now that she is on her course, because of the unknown quantities of success, timing, hospitalisation etc. She has been on dialysis for 13 years and prefers the greater certainty of that way of life.

Asked whether their illness had had any untoward or serious effects on their parent's marriages, Vincent reckoned his parents had always been and still are very close, though if things had been different his father might have gone to Canada. Liz's parents were divorced when she was very small and she had spent much of her life with her grandparents. When she became ill her mother had felt guilty about it and went through a panicky stage, though she accepts it now. Liz left her grandmother to live with her father and that had given both her mother and her grandmother a chance to sort out their lives, so good came out of evil.

Vincent and Diana agreed that dialysis training with adults had helped them to grow up and get on with the job. Liz does not dialyse at home because her mother could not cope, whereas Diana's mother and Vincent's father give them a lot of help so that their lives can be as normal as possible.

The achievement of independence by the adolescent

Dr McKendrick, Consultant Paediatrician, Alder Hey Children's Hospital, contrasted the three previous speakers with others who find it much less easy to grow up and adjust to adulthood. Withdrawal and denial both by youngsters and their parents is quite common - they try to pretend there is nothing the matter, no need for diet, non-acceptance of the machine regime. Often children came to dialysis with other handicaps which accentuated the failure in physical growth and development leading to less confidence and greater difficulty in maturing. We are treating mentally handicapped children whose expectations are limited. Dialysis is an arduous business whether at home or hospital. The possible complications when starting dialysis may continue to upset young people emotionally. The fluid intake and limitations are often seen as very restrictive. The personality of the patient makes a great difference to the achievement of independence. There may be the lucky ones with ambition and drive; others are overwhelmed by the thought that they are stuck with dialysis for life unless they can have a good transplant. To someone on the threshold of independence, that can be a very sobering thought. As time passes they get used to and accept the pattern of life they must follow. Sometimes a job or a new interest can transform a sickly depressed person into a lively creative adult. Body image is important and many youngsters do feel unhappy at being short; others with transplants have the side effects of steroids such as puffiness in the face. They feel they are unattractive to the opposite sex and at a great physical disadvantage.

Parents and hospital staff can do a lot to help the children to grow up, and it is a natural reaction for parents to wish to protect and help their children but this can be carried too far and becomes 'smothering'. Dr McKendrick said he had the feeling that there were a number of adolescents who, if challenged more, and expected to do more at home, might mature faster than they do. Hospital staff can help here too by encouraging people to look after themselves and take on more responsibilities for their own treatment.

When it comes to finding jobs for adolescents, both parents and employers can have too high an expectation. There may have to be a certain amount of absence and certain physical limitations needing greater tolerance than normal. Sexual immaturity is often a part of the 'End Stage Renal Failure' syndrome. Most girls are not held back and menstruate regularly, but many boys seem to remain distinctly infantile and may find difficulty in adjusting to normal life.

To summarise, some of our teenagers find great difficulty in getting independence, for physical reasons, or their basic personality and, perhaps, sometimes from the support they get from their parents and from the extended family including their medical attendants.

Job Prospects

Mrs Paula Ashley, Social Worker, Alder Hey Hospital, said this was not a good time to talk about job prospects even for those without the handicap of having to dialyse either at home or in hospital. In hospital you got to know children and their parents very well: however bright and clever the child, if they don't have parental support, it wont help the child. Many well-meaning parents over-protect their children and sometimes regard schooling as a 'bit of a bind'. The more qualifications the better is the chance of getting a job.

We try to have a very close relationship with teachers, and we invite them to visit their pupils on dialysis so that they can see them looking well and able to work while in hospital.

At about 14-15 years, there is a specialist careers officer dealing with the disabled: they have more time and really know what opportunities and schemes there are for handicapped people. There is, for instance, a 13-week training scheme whereby teenagers can go to college, not to do a particular course, but to assess what sort of course would best suit them. There is also the Short Term Employment Programme (STEP) recently renamed the Community Enterprise Programme, by which firms will be paid to take on a young person for about 6 months. There are bursaries available from a special fund started by Lord Snowden but these are

'Topping up' awards once a basic grant has been allowed by the local authority. The BKPA has also funded patients on a variety of courses, and could help more people in this way.

The biggest step is actually starting the job once it has been found, and convincing the employer that the youngster can do the work required. We find that there is a lack of sympathy among employers which demands a concerted effort by everyone concerned to make people aware that dialysis can mean just a 'hiccup' in life; renal failure patients can do just as good a job, given the chance and given time to adjust, as anyone else. So that they know what they are dealing with, we invite Careers Officers into the unit to meet dialysis patients - then they become living breathing people and not just another statistical number. Once a patient is settled in a job, it is very important to report back to the specialist officers and to thank them for their help.

The advantages and disadvantages of treating adolescents in a children's unit

Dr M H Winterborn, Paediatric Nephrologist, East Birmingham Hospital, said it was only recently, over the last five or six years, with the development of specialised children's units, that there was the choice between the latter and an adult unit; adolescents, being the size of small adults can be treated perfectly adequately using adult equipment and methods. Indeed, since children's units are small in number (8) this may be preferable, purely on the basis of saving travelling to a distant specialised unit. However, it is not merely the size of the patient that should decide where he or she is treated, there is more to a children's unit than simply the expertise of adjusting the techniques of dialysis.

The medical staff in a paediatric unit are used to dealing with the needs and delays in emotional development and growth that adolescents encounter as they start dialysing. Nurses are trained and expect to cope with children easily, and also to handle anxious parents with tact.

Whereas in an adult unit, the nurse takes on more the role of an assistant, as each patient must be responsible for their own treatment, in a paediatric unit nurses have to be more authoritarian.

Then there are the ancillary staff: the Psychiatrist, the Social Worker, the Dietician, and the Teacher. Though the Psychiatrist may appear to be a somewhat alien figure because of the role as a 'head-shrinker', he/she can especially help the staff with their problems but also, can recognise emotional disturbances.

At East Birmingham, our Psychiatrist devised a scoring system for upsets after transplantation, which arose, partly at least, from being nursed in an adult ward, and compared unfavourably with transplanted children being cared for at Guy's in a children unit with the necessary children's staff. The Dietician who, in our case, is a paediatric dietician for the whole hospital, has more knowledge of the likes and dislikes of children and adolescents. One of the factors which leads to poor growth is undoubtedly poor nutrition, so the dietician is extremely important in the treatment of adolescents on dialysis.

If we look at ways of measuring the success of our treatment, we can take firstly survival. Another measurement is the time spent at school, for which children dialysing at home and those with transplants can score better than those dialysing in hospital. We must prepare our children for the adult world, and for this they must achieve as much as they can of their educational potential. So, the teacher is an exceptionally vital member of the unit's staff.

The attitude to parents is more relaxed than in an adult unit: for instance in our unit we welcome them, recognising that they can help with their adolescent's development, given the support and advice of our team.

The characteristic phases of adolescence fall into three stages, corresponding roughly to ages 12-13, 14-16 and 17-18, these correlating with pubertal and phsychological development. The earliest phase typically involves rebellion, moodiness and rejection of parental discipline. Sympathetic handling by the parent is extremely important as mistakes can lead to difficulties in development and a breakdown in relationships. In the middle stage, adolescents seek to find their relationships and friendships outside and different from the family, with a peer group. Often parents are dismayed by the habits and behaviour of this group and seek to prevent such association by their children. Children's Units provide opportunities for mixing with other youngsters, by arranging outings and holidays for groups.

If all has gone well up to now, the final stage of adolescence should be a more adult independent attitude of the child, who should be able to communicate with and confide in his parents more as an equal. Dialysis should not delay this normal development, even though at the start of treatment children may be a year or two behind in their emotional development.

Dr Winterborn summarised his talk by saying that sometimes children's units can be over-protective to adolescents because they are in among much younger children. For some, it is only when they are transferred to the adult unit that they begin to take responsibility for their own treatment. On the whole the training of the staff in a children's unit is more likely to help adolescents to achieve normal development than most adult units.

Educational aspects

Mrs Susan Cowley, Unit Teacher, East Birmingham Hospital, enlarged on some aspects of the special educational needs of young renal patients. She first looked at the normal adolescent who, by the time he or she enters secondary school has already developed social skills and self-discipline. He is reaching the stage when he can theorise and hypothesise, and he plays his part in the network of intertwining relationsips , all of which is necessary to become a useful member of adult society. The essential link between personal, or social, and academic development is considered so important that some schools have set up special departments of personal development. Adolescents with renal failure should achieve these same patterns essentially. The average adolescent at school has interactions between his classmates, both friendly and unfriendly; he usually has a special friend of the same and opposite sex; he has relationships with the adult population and a strong relationship with his family. How does this differ from the interactions both academic and social of the adolescent with chronic renal failure? Due to long absences from school, because of illness, he has little association with his classmates; he tends to be on the outside and to develop no special friends; he has reduced interactions with the teaching staff and, therefore, misses out on academic work; often there tends to be an over-anxious and unnatural relationship with his family and, of course, there are the hospital visits.

Mrs Cowley told us how they tackle these problems at East Birmingham Hospital. On the academic side there are two distinct areas: Remedial work, giving a good basis for further learning, to enable pupils to catch up on things they may have missed through absence with illness; and secondly, normal continuous school work, which can only be achieved by very close liaison with the school, both by the hospital teacher and the Sister of the children's ward so that the school staff know what they should expect from their pupils undergoing dialysis, and thus avoid the children being able to 'play off' hospital, school and home.

The personal or social education of the adolescent is more difficult because under normal circumstances this knowledge is gained unconsciously by interaction with others and not by instruction. If an adolescent is dialysing three out of five school days, the hospital unit must somehow reproduce 60% of these social interactions. There will be relationships with adults, ranging from the ultimate authority, i.e. the Consultant, to parents of the other patients, nurses (near-contemporaries) and other staff. Interaction with other adolescents and younger children is more complicated. We tried at first to create relationships whilst children were dialysing, but that was useless. So we formed all our patients, adolescents and younger children, into a group and created situations, such as outings, parties, holidays and weekends, etc. which would stimulate social interactions and the formation of relationships. This has proved successful and the unit children now work as a group, with leaders emerging, friends and enemies occurring and the older ones looking after the younger. And there is more interaction whilst they are on dialysis.

It is difficult to measure our success and to compare our patients with their peers but a questionnaire revealed that both had a similar approach to school, though our adolescents seemed to have a more mature and realistic attitude to their future with good expectations of themselves. Some are more timid and isolated and still need a lot of encouragement to face up to new situations and relationships.

If the adolescent is to take his place in our adult society, and by treating him the medical staff have given him that chance, then it is up to all of us to ensure that he receives an education that will enable him to live his life to the full, both for himself and for others.

Peer relationships - Psychological Aspects

Dr A V Murphy, Consultant Paediatrician, and Dr J D Sharp, Principal Psychologist, from The Royal Hospital for Sick Children, Glasgow, showed a video-tape which had been made in Glasgow of conversations with two young patients.

The first interview was with Colin, an 18 year old university student on dialysis who talked about relationships in his life, with his friends and also with friends of the opposite sex: relationships with parents and the difficulties of being on dialysis were discussed and his view of the future.

Dr Sharp analysed some of the issues Colin seemed to be facing: first, coming to grips with treatment as a way of life. Colin seems to have accepted that his very survival depends on the machine - a fact that his friends have not fully realised and have not even had to contemplate. He has carefully considered the question of going on the transplant list but has turned it down while he is at university because of the disruption it could cause to his academic progress. Colin has also had to come to terms with his size affecting his self-image. He has no doubt about his own manliness and is mature enough not to have to prove it by drinking his friends under the table. He does not seem too sure of himself with relationships with girls but accepts that tall girls are not for him. He has obviously considered his marriage prospects but this is connected with the idea of someone to provide a home and help with dialysis, something at present provided by his mother. He realises that his work prospects may be limited by the necessities of dialysis and remaining near his hospital unit.

The second interview was with Noreen, also 18 years old but with a two year old transplant which she could compare with her time on dialysis, the main difference being the freedom from restrictions on her time through hospital visits and being on the machine. She is very concerned about her looks and prettiness and conscious of the change in her face since her transplant. She is looking forward to starting training as a nurse but is apprehensive that her small size and juvenile looks may attract comment as they do when she is out with her friends. She said, "Because of your looks you are questioned about your age if you go to the pub with friends, so the social pressure is for you not to join them in case you spoil their evening".

Noreen is reticent about boy friends and marriage - she says she wants to see more of the world before settling down and anyway, other girls are bound to be more attractive to boys than she is.

Dr Sharp drew conclusions about the issues discussed with Colin and Noreen.

Personality: There are no stereotypes but the art of helping a young adult is to tune in to the issues of concern in each individual.

Age: Adolescents gradually advance from being concerned mainly with day to day hassles to a wider view of their place in the world in the future.

Sex: Smallness of height is a drawback for both boys and girls and affects their self-image a lot.

Independence: A very big issue at 18½ years. You are a young adult and yet you have a degree of sustained dependence, which you would like to do without. If you spend all your energy fighting that, it will take up a lot of your stamina. Somehow you have to be able to accept that, and then forget it, and capitalise on all the other aspects of your young adulthood.

Future Anxiety: You have to think about it and think it through. Both of these young folk had to give considerable thought and planning to their future management, self-image and social acceptability. If you feel good you feel you warrant being accepted socially and if you are socially accepted, it makes you feel good.

Questions from the audience

In answer to questions from the audience, Dr Sharp said, all patients at some time have to face up to the choice between the devil they know (dialysis) and the one they don't or which might be a saviour, (transplant). Some idealise and see that as a solution, others are more level headed and see it as a different sort of life style but with, perhaps, different kinds of problems.

Colin likes to plan, and for him the predictability and feeling of being in control of his haemodialysis are very important elements in his life. Dr Murphy said that rather than discussing transplantation in a one to one situation, they have groups coming together of patients, staff and parents, which helps in the preparations for the decision on possible alternatives of treatment. This can apply to the choice between haemodialysis and CAPD when patients can visit the unit and meet patients of all sorts to help to make up their minds. Rather than having specific appointments, psychologists are around in the unit with time to sit down and chat over a cup of coffee.

A further question from the audience sought answers to the possibility of emotional blackmail from overstrained parents to urge a transplant for their child. Dr Murphy said that they need to be aware of the stresses on parents to avoid such a situation arising. Dr Sharp added that because parents were not allowed to feel angry, when they were, they had guilty feelings and this led to the demand for an escape through seeking transplantation. Dr Winterborn said they had avoided this sort of pressure by placing all children starting dialysis on the transplant list.

A practical answer to the problem of size and proving your age was suggested, by obtaining a year's passport. It has no possible stigma of mentioning kidney treatment but simply shows the date of birth.

Mr Cadranel, Principal Psychologist, St James's University Hospital, Leeds, raised the question of the limitation of experiences and social contact through the necessities of hospital dialysis. Liz Noble answered that the hours on the machine were not the handicap: it was the side-effects of anaemia, tiredness and lack of energy that had reduced her opportunities of joining in with friends for evening outings, country walks etc. Mrs Cowley said that the sort of outings and trips made by their Birmingham patients gave them similar experiences to normal adolescents. It was felt that the more varied activities of this sort, the better it was for their patients.

Dr Sharp raised the question of getting the balance right, comparing the optimum provision of socialising opportunities for adolescents with the optimum level of stimulation for babies in hospital. Sometimes organised outings are just the ones that an 18 year old least desires, so there should be a wide option provided by renal units. Family groups should be included sometimes so that parents do not feel excluded; but equally, opportunities could be made for parents to escape from their responsibilities. The BKPA holiday dialysis centre set in the middle of an ordinary self-catering village, combines a family holiday with relief from the responsibilities of dialysing for parents.

From the general participation of all the panel and the sort of questions raised by the audience, Mrs White, the Chairman, concluded that the discussion could continue far longer. She ended the seminar by thanking all the participants and expressing the hope that further opportunities would arise for parents, patients and others from the renal teams to get together regularly.