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Memoir

A career in paediatric oncology

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It is not often that one is invited to remember one's professional experience and if one does so in the course of conversation, a glazed look soon afflicts the recipient of such reminiscences. When I started medicine, methotrexate had just been shown to induce temporary remission in childhood leukaemia. Surgery and radiotherapy for Wilms' tumour had resulted in a few long-term survivors and these children acted as a beacon of hope. Admittedly, some adult patients had relief of symptoms of Hodgkin's disease from the use of nitrogen mustard, but the sequential use of alkylating agents and vinblastine was not curative.

I had qualified and had a junior consultant post when Professor Gordon Hamilton Fairley asked me to look after children with cancer at St Bartholomew's Hospital. It was now the early 1970s and the efficacy of chemotherapy had much improved. Vincristine and prednisolone were producing remissions in acute lymphoblastic leukaemia and Donald Pinkel and John Aur were pioneering cranial prophylaxis for meningeal leukaemia and developing Total Therapy at St Jude Children's Research Hospital [1]. Already adjuvant chemotherapy as advocated by Farber and developed by Dan D'Angio, led to a remarkable improvement in the survival of children with Wilms' tumour [2].

I was very fortunate to be able to visit St Jude Children's Research Hospital, in Memphis at the time that cranial irradiation was first proving successful in preventing meningeal leukaemia. At the same time, patients with rhabdomyosarcoma and Ewing's tumour, were showing improved disease-free-survival and possible cure as the result of adjuvant 'combination' chemotherapy added to surgery and radiotherapy. It was very exciting to witness these changes. To quote Donald Pinkel, "This consolidated my addiction to the treatment of children's cancer."

Essential to the management of children is the physical and mental care of the child and conscientious care and support of their parents, in surroundings which are suitable for a multidisciplinary team. It is vitally important for everyone that care is given in the right environment. In the early years, paediatric oncology wards were very inadequate for their purposes and, as treatment became more intensive and included high-dose chemotherapy and bone marrow transplantation, these deficiencies became more glaring. While many of the isolation measures that were advocated were, in retrospect, excessive, ward configuration was often the culprit in the spread of infection. This was nowhere more evident than in the Royal and Ancient Hospital of St Bartholomew where the children were nursed in a building dating from the time of the French Revolution. After a particularly depressing inspection of these premises in the company of the Hospital Manager, pointing out the general dilapidation, it was agreed that it was not right to treat children in such conditions. No money was forthcoming from the National Health Service (NHS) and so we had to raise it on appeal. We were fortunate to engage the services of the architect Mr Peter Barefoot, now retired, to carry out the £4 million project. It was a delight to work with him and we both learnt lessons. A few months seeing what had been done elsewhere was time well spent. Peter visited similar units in Europe and due to the kindness of colleagues in America I was able to visit most of the major centres in the USA. We both came back with a portfolio of photographs and drawings and were able to decide on the most appropriate design. Clinicians and nurses tend to be excluded from design working parties, but we are the only people who really know what is needed. We may be difficult, have expensive ideas, and sometimes cannot make up our minds, but at least we do not design doorways which would not allow a hospital bed to go through them or a lift which is too narrow and cannot take equipment. Always insist on being present at a planning meeting and never miss one or you may find that what you agreed has been rescinded!

This is not the place to describe in detail what you need from a design team, but some of the following may be overlooked. An interview room is needed and needs to be as homely as possible with easy chairs, a nice table and a little of John Betjeman's "chintzy,

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chintzy cheerfulness''. Comfortable overnight accommodation for parents who need to be close to a very sick child should be near the ward and should have a small kitchen for tea and coffee nearby. A school room and a play room are obvious necessities in an area where children can be supervised but out of earshot of the ward.

Sick adolescents have been one of the most deprived groups in nearly all hospitals. One of the consequences of the increasing success of paediatric cancer therapy has been the inevitable occasional late relapse, second tumour or one of the other late sequelae of therapy, rendering it necessary to admit these young people to hospital. Their need for privacy, needs to be considered including protection from toddlers and a place where the increased decibels, so often associated with this age group, will not cause disturbance. At a more mundane level, do try and provide the nursing staff with enough storage space for equipment and make sure the dirty and clean linen do not meet on the way in and out.

Once a nihilistic attitude had been dispelled and protocols for treatment had been introduced, it gave everybody, both parents and nursing staff, increased confidence. Although treatments were increasingly successful, they were stressful for the children. I never failed to be impressed by the steadfast courage of the children in facing the side-effects of therapy. I am sure it helps them, given that their parents approve, to be told as fully as possible about the diagnosis and the plan for their treatment. Two of the greatest advances were the introduction of the Hickman catheter avoiding the need for venepuncture and the introduction of effective antiemetic regimens with the introduction of the 5HT3 antagonists.

Intensification of therapy produced problems for parents. To see your child go through an unpleasant treatment whose efficacy could not be guaranteed is an awful experience. The concern as to whether the symptoms you observe in your child are the side-effects of treatment is progression of the tumour are difficult to imagine. One can only counter anxiety by a careful, kindly and intelligible explanation of what was proposed, not once but twice and repeated at times when a new phase of treatment starts. I admit I sometimes failed, especially early on. I suspect I made it too difficult and I know that my senior nursing staff had sometimes to explain afterwards ''. . .what the doctor meant''. I got better and I found a most useful phrase was ''What do you understand about your child's condition and treatment?'' If only I had used this with one family where the father was in a phase of complete denial, I would probably have been able to anticipate the assault that occurred when the son died and the father became distraught. It taught me that, whenever possible, both parents should be interviewed together. The burden must be shared. Life-threatening illness may bring a family closer together, but this is not always so. If one parent is singled out, the other feels excluded and a family break-up can follow. Added to this is the irrational, but often expressed, guilt that parents feel when their child is diagnosed as having cancer. Reassurance that in no way is it their fault is of great help.

While on the subject of parental involvement, it is important to remember that a ward for children is a very close-knit community. Parents interact in a variety of ways and, while this may frequently be supportive, and if handled in the right way, may often lighten the individual parent's burden, sometimes parents under stress can damage the confidence of the other parents. I always felt it important that parents should realise that each child's case was different and that the only secure source of information about their child's illness was the medical and nursing staff.

As the work of the children's unit increased, it soon became evident that children were being referred long distances. This was especially so in the case of retinoblastoma which became the national UK centre for referal and is now run jointly by John Hungerford, Judith Kingston and Nick Plowman. It is easy to forget, living as most professional people do close to their work in an urban setting, that many parents live in country villages and relatively few have spent any length of time in major cities. It is very hard for some parents to find suitable accommodation, look after the other children in the family and have to manage in what they often feel is a threatening environment. The need for a 'home from home', especially where children may be referred over long distances was first appreciated by Dr Audrey Evans at the Philadelphia Children's Hospital. The Ronald MacDonald houses were the solution in the USA. In Britain, the Sick Children's Trust, founded by Jon Pritchard, myself and colleagues, provided care for the parents and siblings of children being treated for cancer at The Hospital for Sick Children, Great Ormond Street, and St Bartholomew's Hospital in a house on the Gray's Inn Road. Later, we were fortunate to have the Sick Children's Trust open a similar facility in a house on the 'Bart's' site. I think it is important to have designated accommodation, not actually on the ward, but close by. Comfortable, homely surroundings give a chance for the parent to relax and relieve tension by talking together, helping prepare meals and even doing a little shopping.

Keeping the family together must always be a prime aim. Enabling parents to stay near their children, providing adequate financial support where necessary and dealing with their increased travel costs and food bills are of great importance. On the subject of the family cohesion, I was surprised, although I suppose I should not have been, at the intense amount of sibling jealousy. This is provoked by the increased attention and inevitable spoiling of the affected sibling, but it is often enough to make the other children cross. In this context, the expertise of a trained, experienced social worker is vital.

At the end of treatment, in order to re-integrate the children, holidays were offered particularly when there had been problems with other children in the family. A variety of holidays were arranged. I never assessed whether these were successful, but the children had a lot of fun.

One of the most impressive features of the care of children with leukaemia and solid tumours in Britain has been the degree of co-operation between paediatric oncologists. The Medical Research Council (MRC) acute leukaemia trials were an early example. In solid tumours, my own experience started with the Children's Solid Tumour Group (CST) between the Royal Marsden Hospital, St Bartholomew's Hospital and The Hospital for Sick Children, Great Ormond Street. The Group developed and run cooperative studies on rhabdomyosarcoma, Ewing's sarcoma, Hodgkin's disease and non-Hodgkin's lymphoma. A most important development was the formation in January 1977 of the United Kingdom Children's Cancer Study Group (UKCCSG), which eventually grew so that every region in the UK had a centre specialising in the care of children with cancer. Another outstanding contribution has been that of the Childhood Cancer Research Group at Oxford University. This independent organisation has been at the forefront of epidemiological studies in childhood cancer and has had a profound effect on planning strategies for cancer care. Where are we going next? In their review of the treatment of children with Hodgkin's disease, published in this issue, Thompson and Wallace [3] give us a number of insights into what the first half of the 21st century may bring. An increasing number of cancers will show cure rates similar to the ones now being experienced in Hodgkin's disease. As these authors point out, this has been accompanied by a small, but significant, number of long-term side-effects of which second tumours are amongst the most devastating.

Large controlled trials of therapy have led the way, not only in identifying the best modalities of treatment, but, in long-term follow-up, secondary effects have been identified and quantified. As long as the cure rate is not prejudiced, it may be that greater individualisation of therapy will be seen, for example in therapy avoiding alkylating agents in boys or breast radiation in girls [3]. This will undoubtedly make it more complicated to explain to parents the reasons for the treatment programme for their child and it is important that voluntary codes of practice continue to be developed. Every encouragement must be given to those who have to address the increasingly complicated ethical and other issues that are likely to be met. Treatment for most children's tumours is still at the stage where trials are necessary and every encouragement must be given to entering children on to these protocols. When discussing this with parents, I always found it helpful to quote the finding that children 'on the protocol' did better than those who were not [4].

I am sure paediatric oncologists can look forward to the future with every confidence. The principles of multidrug therapy were worked out in childhood leukaemia and adjuvant therapy in childhood solid tumours. They were able to ensure, years before 'adult' cancer specialties, that 85–90% of their patients saw the appropriate cancer specialist. Years before anyone else, they organised specialist centres with satellites and developed the idea of 'shared care'. Their collection of epidemiological data is superior to anywhere else in the NHS. With such a track record, hopes should be high for the next half century.

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