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Parent Perspective

A journey through cancer—parental views, then and now

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"At the beginning of 1980, our son Hamish was outwardly a healthy and fun loving boy of 5. By his sixth birthday in February of that year, although he still seemed well, he had occasionally complained of an abdominal pain. We all know that often crops up with young children. I was not unduly concerned, although I discreetly checked for worries at school and took more frequent interest in his stools. During the following weeks, the tummy aches were mentioned more often and his normally voracious appetite slackened off. Inside me alarm bells started ringing. Early in May, I began what was to prove a long and agonising series of visits to our local Health Centre.

Our own doctor was away on sabbatical leave. As a family, we had not attended our Health Centre much until then. He was certainly the only member of the practice who really *knew* Hamish. Only he could have seen for himself that, in comparison with Hamish's usual appearance, he was indeed not well. The colour was fading from his face, the robust body becoming thinner and more lethargic. He sometimes complained of pain in his thigh, sometimes in his chest or his abdomen. Occasionally, he would scream with pain when I hugged him. My son's sparkle was disappearing. Friends and teachers commented on the changes.

During the course of 13 weeks, we consulted five different general practitioners (GPs) (none of them our familiar doctor who was still away), and a sixth GP on the phone when Hamish ran a particularly high fever in the middle of one night. None of them, while listening mostly sympathetically, could provide a firm diagnosis. I was repeatedly told that it was probably a 'virus' and it should eventually go away. I requested a haemoglobin count. While revealing slight anaemia, it was not considered significant.

At the beginning of July, I could stand it no longer. Something inside me knew my son was very seriously ill. With no forthcoming referral from any GP, I made a private appointment with a local paediatrician. The night before we saw him I wrote down every detail of my child's case history to that time. Hamish was examined at great length. The paediatrician told me he could find no problem. The choking fear I felt at that point was almost stifling. I took a deep breath and insisted on two specific tests. One, a broader spectrum blood screen (in desperation I suggested testing for glandular fever), and two, a simple chest X-ray. The latter could surely not offend this paediatrician who was, quite reasonably, keen not to inflict invasive procedures on a child for no apparent symptom—and, incidentally, it informed me for the first time that Hamish had dextrocardia! Within 24 hours, we received a phone call at home. Hamish's blood erythrocyte sedimentation rate (ESR) was very high. We were advised to admit him immediately to the hospital for investigation.

I *know* they had a list. It went, I guessed, from common cold to cancer. As each day passed and each intravenous pylogram (IVP), electrocardiogram (ECG), ultrasound (US) scan, and blood sample was taken I found myself preparing my mind to cope with what I knew would come. On 16 July 1980, I was told that my son had a stage IV neuroblastoma and, without treatment, was likely to survive no more than 3–4 months. It may be hard to understand, but my tears were of relief—at last someone had recognised our plight!"

I wrote that many years ago and have since been closely involved with the Neuroblastoma Society, which this year marks its 20th Anniversary. Hamish died on 1 December 1981 and this year I set out to discover what changes there might have been in the experiences of parents then and now. It's one thing to be aware of the progress that may have been made in the world of medical research which is working towards better *treatment* and eventual cure for this aggressive childhood tumour. I wanted to find out how attitudes now may differ as regards possible improvements in *diagnosis and care*. Is the average GP any more aware these days of the existence of neuroblastoma? Does that front line medic take the views of the parent more seriously now? I know that the presentation of something as rare as a neuroblastoma may not occur even once in the vocational life of a family doctor. That, however, should

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ensure that the modern GP is more inclined to refer the patient—it is simply a case of listening to the parent. In the course of my research, I was invited to attend a paediatric oncology clinic. It was deeply disturbing to learn that there are often still long delays between initial presentation at the local Health Centre and the eventual assessment and diagnosis in hospital. This is not to suggest that those delays might affect the prognosis, but to highlight the fact that the stresses involved for those families and the untreated suffering incurred are largely avoidable when more acute awareness is applied.

Hamish was diagnosed at a regional hospital which, despite being an academic centre of medical excellence, had at that time no paediatric oncology unit. He was referred to a specialist London hospital where he started the offered treatment. Within a very short time, he was clocking up many cannula insertions daily. He got to the outrageous figure of 100 needles before the advent in the United Kingdom (UK) of the Hickman catheter made chemotherapy and blood sampling an infinitely less gruesome trial. Hamish used to mark out of 10 those that used the needles, as if to make their jobs even more testing!

Staff at the specialist hospital began to cope with my hunger for knowledge. It must have been very daunting to be faced, not only with a set of very frightened parents, but a mother who insisted on having every cytotoxic drug's chemical formula and history explained. I needed to be an integral part of the medical team to the extent that I was keen to administer the ketamine that was used to dissociate my child from the bone marrow trephine to be taken. I am assured by a local paediatric oncologist that procedure today is covered by a more conventional general anaesthetic.

Continuing 'normal' life was then very important to our family and a good example of this was the intention to allow Hamish as much access to school as possible. Although there was a Paediatric Oncology Community Nurse attached to the regional hospital, that role was a rarity compared with the numbers of today's Outreach Nurses. So, in order for Hamish's chums to understand the condition of their friend including an explanation of certain precautions that he may need, I was the one to stand in front of his class and tell them about his disease and show them the Hickman catheter just so they would not find the whole situation frightening, but also so that they would understand that Hamish should not be involved in rough play. I am sure that the more open communication and media coverage about the whole world of medicine, and cancer in particular, has informed greater sections of the public to a fuller understanding of the issues surrounding a cancer sufferer. In 2003, we have easy access to so many sources of advice and guidance, especially via the Internet, that it does not take long to discover the protocols of care that might surround a friend or relation.

Patient comfort was then not easy to achieve. The specialist hospital had eternal laundry and linen problems. Often there were not even enough sheets, blankets or pillows (let alone pillow cases) to go around. Finding this unacceptable when my child was, in any case, being subjected to the sort of treatment that many humans would not put their pets through, we marched on to the ward for our second visit clutching a duvet from home. This, in due course, generated the most enormous row within the hospital administration. Needless to say all members of the medical staff were only too glad to allow such an invasion of home comfort. The Department of Health and Social Security, however, represented by a fierce Scottish female who appeared one day at the bottom of Hamish's bed, claimed we were violating safety precautions. Apparently this "downie" (to use the messenger's term), was a fire hazard! Were the children likely to smoke in bed, we wondered? An outspoken Irish surgeon at that time was reported to snort indignantly that the very idea was ridiculous as he had "Never heard of a duck on fire!" Today, most of the children on paediatric oncology wards are cosily covered by duvets if wanted and, in any case, items from home would not be viewed as an insult to the hospital environment.

The existence of a parents' common room and the facilities for producing light refreshments 'on the ward' was another rarity. I believe the ability to escape for a supportive chat with another inmate is now well catered for and one should not underestimate the value of such facilities. A few minutes away from the child patient and the sharing of fears and hopes with like-minded people can be very therapeutic. The solidarity gained by the natural revelations within the confines of such an area is almost always beneficial to those most in need. I spent a lot of my time in those circumstances encouraging others to talk; but I was aware that, for me, that was a good way to put some of my own concerns into perspective. To discover that Parent A was a mother on the breadline with a husband working abroad and four other children in the family or that Parent B was a single father whose boss had reacted unsympathetically to the time he needed off work made me immensely grateful that my husband's family business meant that he and I could be together whenever we needed and that our bewildered, 5 year old daughter was being well cared for by a raft of loving relations and friends.

The world's first children's hospice, a place of 'respice' for families like ours, was still to be built almost a year after Hamish's death. The vision of Sister (then Mother) Frances Dominica of Oxford for such a 'home from home', called Helen House, was to change so many approaches to caring for children with life-threatening or life-limiting conditions. Since that world first in 1982, there are now more than 27 similar places, just in the UK, with more being developed as I write. In 3 months time, there will be another 'first' in Oxford—a building called Douglas House for young people aged between 18 and 40 years. Progress in medicine has succeeded in extending the lives of some of those who 20 or more years ago were not expected to survive childhood.

Pain control, thankfully, has advanced most of all since those hyper-cautious days in the early 1980s. Many health professionals, especially those away from the specialist centres, had the spectre of the 'Dr. Arthur case'[1] sitting on their shoulders. Some of them argued for the possibility of addiction to opiates. Here we were, witnessing a child in unimaginable pain who was almost certainly going to die of his cancer and a medical person dared to suggest that the reason for not providing (in my pitiful parental view) enough pain control was a concern for diamorphine dependency! Again I refer to the treatment of animals. A self-respecting veterinary surgeon would no sooner inflict on or allow pain in an animal than cut off their own arm. Today, we have patient-administered syringe drivers to keep abreast of pain levels. There are also transdermal patches releasing Fentanyl. The whole ethos of palliative care is part of modern medicine. My own experience of postoperative medication assures me of a very different emphasis on the suppression of pain nowadays.

These are my hopes for the future.

I wish all medical personnel to regard any parent of any sick child as a valuable member of the total caring team. Even those parents who give an impression of not wholly grasping the concept of a treatment, protocol, medication or medical procedure, need the empathy of the doctors, nurses, social workers and any attendant care-givers. This is the greatest gift in the practice of medicine. The ability to stand alongside, even when all therapy is failing, to be honest in the face of the inevitable or even the likely, is lovingly-given care at its most complete.

I wish that no parent should ever feel the need to become assertive in order to be heard. Too often we still learn that parents feel they are regarded as 'neurotic' when attempting to bring a concern to the notice of someone with the power to comprehend.

I wish that all those well-intentioned instructive leaflets or booklets, so meticulously produced by organisations for the information of frightened and suffering parents, should *not be hiding in some cupboard never to see the light of day!* **Hand them out**.

I wish that those who would most benefit from hearing the frustrations of some parents should be shut in the same room and forced to listen. Those who *really* care do not need converting. There are many of us who are available and willing to help health professionals better to understand the needs of the families involved with life-threatening conditions. Please use us as sounding boards, speakers, broadcasters, and writers. The barrier I most fear is the resounding clang of the division that separates some health professionals from patients and families. You can see the 'curtain come down' across the eyes of the medical person. The explanation might be that they feel the need for a wholly objective approach to protect the efficiency of their medical judgements, let alone their own emotions. But that is not an excuse, and greater progress will be made in their chosen vocation if the professional communication is fully two-way with the sufferers. Over the 21 years since the death of my son Hamish, I have witnessed the best forms of support, care, guidance and healing given by those willing to expose their humanity and 'share' the experience.

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[1] Dr. Arthur, a highly respected paediatrician, was accused, and acquitted, of blatant active euthanasia. In 1980. a Downs syndrome baby in his care was rejected by the mother soon after birth. Dr. Arthur prescribed a sedative designed to stop the baby seeking sustenance. The child was given only water and died within 3 days.