The patient's journey: palliative care—a parent's view

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BMJ 2006;332:1494–5

My initial contact with palliative care was through the illness and death of one of my children. This account is, by necessity, highly personal and is oncology based because my son had cancer. Parents of children with other conditions will have different problems and different experiences. Even parents of patients with terminal cancer to whom I have talked faced a variety of issues that I did not encounter, arising from their child's specific needs and the provisions in the area in which they lived. However, the conclusions about palliative care that arose from our experiences are fairly general, I think. This is what happened to us.

Starting the journey

My son Andrew died of cancer five years ago, at the age of 17. He became ill in March 1999 and received a diagnosis of ganglioneuroblastoma shortly afterwards. Two operations to remove tumours followed, as did chemotherapy, radiotherapy, and a stem cell transplant, but the cancer progressed, and we were told at the beginning of December 2000 that he had only a short time, between four and 12 weeks, to live.

Although the progress of the illness—the months of anxiety, hospital admissions, treatments, improvements, relapses—does, to a certain extent, prepare you for such news, it is difficult to describe the effect of it. I think crushing, stunning defeat after a prolonged, painful struggle sums it up. And of course it is the end of all hopes for recovery, when treatment stops and palliative care takes over.

Travel companions

For me as a parent this was a time of many urgent and sometimes conflicting demands: the need to prepare my other children, Andrew's sisters, his grandmother and aunt, his many friends and teachers; the practical considerations demanded by his condition, which centred around the prompt supply of pain relief; and the huge and overwhelming desire, within the confines of his weakened condition, to make his last weeks as happy as possible.

How to prepare for death?

And just how does one prepare a 17 year old for death? I didn't know then, and I still don't know the right way—if there is one. What I did impress on Andrew, on his sisters, and on myself was acceptance. Don't fight it. Everything that could be done medically had been done. We fought for life as hard as we could, now we will accept what comes next. I think this worked to a limited extent—certainly Andrew faced his last weeks

Lifeforces

Lifeforce was established with funding for three years from the Big Lotto (formerly known as the New Opportunities Fund). The team's primary aim is to ensure optimal support and home care for children with life threatening or life limiting illnesses. The Lifeforce team consists of a specialist nurse, respite nursery nurse, a youth worker specialising in play therapy, and also has a paediatric palliative care consultant and clinical psychologist, both of whom work part time.

The team covers the primary care trusts in the London boroughs of Camden, Islington, and Haringey. All three trusts agreed to continue funding after the initial three year period.

Around 18 children across the three boroughs currently make up the team's caseload; they receive care from the palliative specialist nurse and paediatric palliative care consultant, and also respite, play therapy sessions, and psychological support.

The team works closely with families with children needing palliative care, helping them to make the most of the time they have together. It supports them at the end stages to keep their child at home, hospital, or hospice, depending on the family preference.

Respite care is offered to families, allowing them time off and an opportunity to do shopping, meet friends, or if needed just to rest. Play therapy provides a forum through which anxieties can be identified and children can discuss their illness and, with the support of the clinical psychologist, mechanisms can be developed to tackle issues raised. The play specialist also works closely with siblings, developing a friendship that can help in bereavement work after the death of a child. The specialist nurse is a key worker for the family, working closely, when appropriate, with the community children's nursing teams in the three primary care trusts. The specialist nurse also works closely with the palliative care consultant to ensure problems in managing symptoms are dealt with.

Stephanie Darnill is a parent representative on the steering group of the Lifeforce paediatric palliative community care team. This is her experience of caring for her dying child at home before the development of the Lifeforce team.

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with serenity, dignity, and forbearance which also typified his behaviour throughout his illness.

At the same time as dealing with the psychological aspects of this final phase of Andrew's illness, there were practical issues to consider as well. This proved to be something of a minefield. The doctors were not entirely sure what course Andrew's symptoms would follow, but

it was clear that pain relief would be a major concern. There was no need for him to be in hospital, and he himself wanted to be at home. We were issued with a pharmacy of painkillers, pump syringes, swabs, and needles, and Andrew was discharged from hospital.

Finding help

This was when we discovered two things: one was that we live in a "black hole" as far as community nursing was concerned—no community nursing covered our area. The second was that unbearable pain usually strikes in the middle of the night, with arrogant disregard for office hours.

Our local hospital did its best to overcome the nursing problem, and we were given many offers of practical help. Unfortunately, the need for help usually manifested itself at night, when all we had was the telephone number of a nurse at the local hospice. As she could not leave her post to administer the morphine Andrew needed, all she could advise was to give two paracetamol tablets in addition to the existing pain medication. This actually helped, but eventually Andrew ended up in hospital because we could find no reliable method of administering the pain relief at home out of hours.

Other issues made it difficult to look after Andrew at home. As his mobility decreased we could have done with some advice on how to adapt our house to his needs. We were also rather confused at times as to who was actually medically in charge of Andrew's case. Because he was treated at two different hospitals we were never 100% sure where we should turn to when we had problems, or how updated his medical records were with the various agencies which we were told we could call on. For example, we could have used our general practitioner more than we did in our efforts to keep Andrew at home. Andrew had not seen our general practitioner since the original diagnosis, and I did not really want to involve someone who knew nothing about his case. I did not realise that our doctor was kept updated by the hospitals treating Andrew, and his name was in fact on some kind of out of hours priority list. I had experienced insufficient information being passed between the various medical bodies throughout his illness, shared-care books not updated or consulted, and discharge letters being filed, but not read, and sometimes illegible. In all this uncertainty there was one thing I did know. In an emergency, when the pain became too great, we could take Andrew to hospital, which is what we ended up doing.

Dealing with pain

During the night of 16 January 2001 Andrew developed severe pain. He had had a good day, saw some friends for lunch and went to the cinema with them, but the pain increased in the evening and could not be controlled with oral medication. We took him to our local hospital in the early hours of the morning and the pain was brought under control. A few days later he was transferred to the Teenage Cancer Trust Unit at the Middlesex Hospital, where he had had most of his treatment. The pain control team there worked hard to make him comfortable, but there was nothing else that they could do for him. At this point there was some talk of sending Andrew home, but the pain issue seemed insurmountable to the medical team, and Andrew himself now felt safer in hospital. He was in

one of the three isolation cubicles at the trust, where he had spent some of his previous admissions.

Journey's end

As the days passed, the various side effects of the medication and the general weakening of his condition became more and more apparent. His friends and teachers visited him, and he continued to receive the counselling which had been set up in the early days of his illness. The unit was full, and when a patient came in who needed isolation, Andrew was moved to the main ward. This was less comfortable, but Andrew did not seem to mind. I stopped going home altogether as both my husband and younger daughter were unwell, and I did not want to bring infection to the ward. I slept on a camp bed next to Andrew, and early on the morning of 30 January I realised that his breathing was laboured. The doctors told me that Andrew was dying. The patient who was least ill in the isolation cubicles was hurriedly moved out into the unit's day room, and Andrew was moved in. He died four hours later.

Conclusion

So what did the experience of Andrew's last weeks show me?

- That it would have been good to have someone in overall charge of palliative care
- That it would have been useful to discuss all the possible options and contingencies from a palliative point of view with someone who knew Andrew's case
- That the philosophy of acceptance is not enough for siblings. My attempts to prepare Andrew's sisters were totally insufficient. It should have started earlier and with professional help. The prospect of my own loss was so great I could not sufficiently appreciate my daughters' loss
- The fourth conclusion I came to was that despite all the excellent medical care and loving nursing offered by the Teenage Cancer Trust unit to its patients, dying in such a unit is not the best choice, if one has a choice. It is a place of hope and optimism, and over the months of treatment, the patients become friends and the staff allies in the fight against illness. We were there when a patient died about a year before Andrew, and we knew the devastating effect this had on both patients and staff. In addition, with the constant pressure for the admission of patients who can be treated successfully it is not a good use of resources to use a bed in such a unit for palliative care only. Andrew was very aware and felt the pressures of both these constraints, but as he grew weaker and could see no alternatives he was forced to accept the only option that seemed to be on offer, and he was shown tremendous kindness and compassion by the staff and patients at the unit in his final hours
- Finally, what the experience of Andrew's death showed is that palliative care in the community offers an extra option for the last weeks of a child's life. This is especially beneficial to families with terminally ill children, enabling the child to remain at home in familiar surroundings and with the people who love them most.

Competing interests: None declared.

(Accepted 28 April 2006)