The death of a disabled child
THE DEATH OF A DISABLED CHILD

We never expect our son or daughter to die before us: it is against the natural order. The death comes as a terrible shock, and the grief that ensues causes us to experience many powerful emotions, such as denial, anxiety, fear, guilt and anger – all of them bewildering. We find it a struggle to cope with our daily lives, and at first we can see no end to our sorrow. There is no pattern or time-scale to the stages of grief, and each person grieves in his or her own way. We are left with a void in our lives, and many years may have to pass before we can grow accustomed to it.

Those of us whose children were disabled, since birth or after an accident or illness, have already endured a grieving process, which followed the time when we were first made aware of the extent of their problems. The dreams that we all have for our children’s future were shattered as we realised the implications of the disability. We have often asked ourselves the question, “Why my child?” as we watched them suffer, and felt the unfairness of it all. We have had to come to terms with the effect that the disability had on them and the rest of the family, and accept that we all needed to develop appropriate attitudes, responsibilities and skills in our new roles as carers. However, in no way were we ever prepared for their dying, even if they had a life-limiting condition. We clung on to the hope of some improvement in their health through advanced medical research and new treatment.

Depending on the degree of disability, we have had to spend more time than usual caring for our children’s everyday needs, often to a later age. After their death, there are all these hours to fill when we were once so busy. We have come to know health and social workers as friends through our regular visits to hospitals and clinics, and we find ourselves now without their support in our grief. Many of us are facing our bereavement at the end of years of worry, and we are already drained.

Sadly, we live in a world where disabled children and adults are not so readily valued in the community as their able-bodied peers, and are considered to make less of a contribution to society. The modern practice of pre-birth screening identifies many problems, and parents have the choice of whether or not to proceed with the pregnancy. In a country such as ours, there is an expectation
that every child born should be “perfect”. Families with disabled children are viewed with a mixture of pity and admiration for the way in which they manage their lives. Some people find it hard to believe that we love our child as much as any parent does. This is reflected in the attitudes we encounter when we pass on the news of our bereavement. We hear comments such as, “It must be a relief to you now that your burden has gone,” “You’ll have plenty of time now to get on with your own life,” and “It’s all for the best – a blessing that s/he has died.” We share none of these sentiments, and soon realise that often we are thought not to be deserving of the sympathy that is offered to those who have lost a “normal” child. This may make us very angry.

If we have other children, we have always had to reassure them that we did not love them less because we had to spend so much time caring for their disabled brother or sister. Now the whole family has to make many adjustments to our loss. In the past, social activities may have been limited by the disabled child’s problems. Our surviving children can sometimes feel guilty when they experience a feeling of relief that such constraints have gone, even though they loved their brother or sister dearly and, in many cases, helped to look after them. We must tell them that it is perfectly normal to have these mixed feelings after a bereavement, and they need not blame themselves. We must try to focus on the happy memories we have of their dead sibling’s life, and their abilities rather than their disabilities.

We are no different from all other bereaved parents. We have lost a much-loved child. The whole structure of life has changed for us, and we must find a new normality in the future. In spite of what others may have thought, our children were able to lead full lives and achieve their potential, within the limitations of their physical or mental disabilities. We did not necessarily expect academic success or highly-paid jobs for them – unless, of course, these were realistic aims. We had different criteria. Their health and happiness were our prime concern, and we worked hard towards gaining some degree of independent living for them. We were glad to see any progress that they made, however long it may have taken for them to acquire new skills.

Our disabled children have taught us much. Their legacy is that, through their example, we now understand more about love, joy, patience, perseverance, courage and acceptance. We are proud to have been their parents, and we will carry them in our hearts for ever.
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