

It could be conjectured that the existing familiarity at an emotional level with other family members generated a climate of openness in which fathers could reveal their true feelings.

Is it the child that remains in each of us that causes us to turn to our own parents in times of despair? Certainly, the unquestioning support of members of our extended family helped greatly with establishing the valued place of our disabled child in our family. Their capacity for support is endless. Is it duty? Is it love? Whatever the reason, the emotional dialogue we have with our extended family has at times been our salvation.

### **The calm after the storm**

When the family returned from the hospital, the fathers reported that no help was offered specifically to them by the professionals. All help was focused on the wife and baby. The fathers' needs were not addressed or, perhaps, even noticed, all being seen as 'The supporter' and adopting the role society expects - that of being competent in a crisis (Tolston 1977).

Having been on hand at the hospital to receive all of the necessary information first hand, my frustration began to mount at having to receive all information via my wife, as I had returned to work. The telephone would ring and the professional would ask to speak to my wife; all appointments were made for my wife to attend (although the offer was occasionally made that I should attend, it was often impractical to do so). I accepted much of this, but just once in a while it would have been wonderful if one of the many professionals we were dealing with had offered to call one evening so that I could have actively engaged in the dialogue of care for our child. What gradually happened was that I, as the father, became in some ways 'disabled' also in the supportive role I was expected to fulfil. Although my wife recalled conversations with professionals as accurately as possible, there was inevitably something that she had omitted to ask, or that they had not explained fully enough. But it is hard with a struggling baby on your lap to totally concentrate, and articulate your thoughts. My frustration grew at never being part of the interaction with professionals who were playing such a major part in my child's life, and to some degree influencing the direction and shape of our family life.

### **Searching for normality**

All seven talked of returning to work and of trying to keep a 'sense of reality in our lives'.

I returned to work, but in a fog. The feelings of disorientation were enormous and even simple tasks took considerable effort to complete. This only served to disempower me even further.

### **Planning for the future**

Although this may be seen as a need for 'normality', it can be viewed as an escape from the situation at home. Perhaps if more effort was directed towards the fathers in these early days, it would enable them to explore and formulate strategies to cope with future crises. They were aware of their need to talk to someone and perhaps for a third party to help out with their wives, but no one fulfilled, or fulfils, this role.

At the end of the day only you, as the parents, can make the ultimate decisions. But in those early days, this was a mammoth task. With levels of concern about our child so high, combined with tiredness and the routines of caring for other family members, the quality of decision-making was far from what it ought to have been. In spite of the care of family and friends, the support of various professionals, the experience of having a disabled child can, in the early days, be very isolating. All either partner wants is the other. This child was

created out of your love for each other, a product of your union. That same love must now help to reformulate what you had anticipated for your family whilst absorbing the pain and the grief. What the family unit needs most during its phase of readjustment is to feel safe and secure; that there are people around - friends, family, professionals, holding you together, enabling you to exist. And at times it is existence not living.

### **Professional access**

One reason for this issue may be that the majority of support services work only during the day when many fathers are at work, and after the first few days all such contacts took place during the day and, therefore, all information reached them second-hand with the changes inherent in the retelling and giving the mothers' construction of events.