

# I became a changed person

NIEMANN-PICK TYPE C DISEASE IS A DEVASTATING CONDITION FOR THOSE AFFECTED AND FOR THEIR CARERS. DAVID WRAY RECOUNTS HIS EXPERIENCE OF CARING FOR HIS SON, ANDREW, AND THE IMPACT THIS HAD ON HIM AND HIS FAMILY.



## Sally

My wife, Sally, was asked by the social services department of our community to keep a diary of a typical day with Andrew, as evidence for our request for additional help. The first entry was at 04.05 in the morning: “**Attend to Andrew who is in distress**”. 43 items later, the final entry for the day was at 00.40 the next morning: “**Finally in bed to sleep**”. There were 22 medication episodes during the course of the day, whilst she was also looking after Andrew’s five year old sister, Louise. My observation at the end of the diary in bold type was...

☞☞ This is not an exceptional day of unusual, extra-ordinary demands. It is an ordinary day of the usual exceptional demands ☞☞

## The immediate impact on the carers

Parents who care for a terminally ill child experience lack of sleep, loss of privacy and personal space, fewer opportunities to be creative and reflective, an absence of freedom of choice in personal and family matters, loss of leisure activities, including holidays and social isolation.

All the above has an immediate impact on the carers. I became a changed person; tense, anxious, pre-occupied, very serious and totally focussed on our son and his needs. Decision-making became increasingly difficult as I had no previous experience of a similar situation.

Owing to disrupted sleep patterns, I felt constantly tired and this certainly affected my day-to-day functioning, especially my emotional state and ability to quickly assess situations and arrive at appropriate solutions.

Particularly difficult was the feeling that there was no escape from the 24 hour, 7 days a week treadmill of demanding and endlessly repeating care tasks

## The impact on family dynamics

My wife and I had to face what no parent wants to face – the eventual death of their child. I had to fight hard against feelings of desperation and hopelessness. I could also see changes in the family dynamics as my wife and I became work colleagues on different duty shifts. The normal elements of a supportive, loving and caring relationship became increasingly attenuated, to be replaced by the priorities of personal survival.

By being good carers to Andrew we were in danger of becoming poor parents to Louise

In the midst of all the turmoil, we had to try and maintain a “normal” lifestyle for Louise, which included daily attendance at school, ballet lessons,

gymnastics, staying with friends, birthday parties and short holidays with relatives. In addition, we knew we had to emotionally support Louise while Andrew was very ill and help her cope with the eventual death of her older brother.

## The longer term impact on the carers

Looking back, I realise that the experience has changed everyone within the family. I now have a very different view of the world and react differently to given circumstances. I am aware of the transience of many aspects of life, the fragility of life itself and the need to use time carefully. I know now that I suffered some degree of post traumatic stress disorder, with flashbacks and periods of anxiety. I have noticed, from a variety of parent-carer forums that the loss of a child seems to have an extra dimension for the mother; she has carried the child through pregnancy and will feel that she has lost part of herself.

I also feel that my wife and I are far more tolerant of each other than perhaps we might otherwise have been; we had developed strategies for containing or side-stepping disagreement in order to not be distracted from our primary role as front-line carers.

We came to realise that what seemed to be a major problem of today was not necessarily a major problem of tomorrow

## Andrew's gift

I have found that writing about my experiences has been therapeutic. It has also been helpful to try to view our son's illness in a positive light and recognise that some long term good has come out of a very sad and extremely difficult period. On reflection, I have realised that the whole family has developed interests, which have their origins in that period.

It is almost as if Andrew has left a gift for each member of the family to carry with them for the rest of their lives