

A Life Worth Living

John Steven Kerr: 20th May 1988 – 23rd Oct 2007

By Fiona

Those of you who were at the conference last year will possibly remember that the Kerr family gave a presentation on life with John, including some photographs of him taken over the years. At that time the newsletter editor suggested that in a year's time we could perhaps submit an article for the newsletter to let folks know how we are getting on, and surviving life without John. It's hard to believe that more than a year has passed since then and I find myself sitting at the keyboard trying to work out what to say.



John's 1st birthday

SOFT has been part of our life for the last 20 years. We were fortunate to have been involved with Jenny and Chris from the very beginning. Over the years we have looked forward to receiving the newsletter and have drawn great encouragement from many of the articles although it is many years since we made a contribution. In fact I think the last one would have been in 1993 when John started school. Since then my excuse has been that we were too busy living life to be writing about it, always full of good intentions but just never got round to it. We are all still busy living our lives now but it is a different kind of life now without John. Our first major hurdle was our first Christmas without John in 2007. We didn't send cards

that year because I couldn't get my head around being a family of four instead of five. Signing our names in a particular order is a very hard habit to break; I do sometimes still write cards from *Duncan, Fiona, John, Stef and Rachel*. We didn't take many photographs that year either because they just didn't look right without John in them. Our family is a different shape now and it takes time to get used to. Traditionally we would all gather in John's bedroom on Christmas morning to open our presents, this is just one of many family activities that we have had to find a different way of doing.



John's 18th birthday

Birthdays can be very difficult too. This year John would have been 21 and to celebrate we spent the day in Edinburgh, a city that John was very familiar with as he attended school there for 14 years. We did the tourist thing and visited the castle then had dinner and went to a show in the evening. It helped us to feel close to John by being in a place where he had spent a lot of time but not necessarily with us. Sometimes it is being in situations that would never have involved John that remind us so much of his absence. For example holidays. John was quite often in respite if we had a holiday abroad; it was so

strange last year not phoning home to see how he was. Similarly on return from holiday we would rush to pick him up. It surprised me how sad I was on the plane home from Cyprus last year when it occurred to me that we wouldn't be picking him up.



Canoeing at school

Most of all we miss John's company. Each one of us had our own special relationship with John. Duncan summed it up when he said I just miss "wasting time" with him. John was a good listener as you could tell him anything and know that your secret was safe with him. My favourite time was Sunday afternoon listening to the radio with John in his bedroom, enjoying a snooze after lunch and then taking the dog for a walk around the village. John enjoyed meeting the various two legged and four legged friends we met on our travels.



Summer 2007

We know that John's death has left a huge gap in the lives of many others too. We were overwhelmed by the number of friends who attended his funeral. One way in which we

managed to capture the essence of those relationships was by asking people to write in a memory book. We circulated a notebook at the funeral and asked people to recall funny stories and happy memories of John. We cried many tears of sadness and laughter as we read some of the things he had been up to and the mischief he had caused. It was particularly interesting for us to hear stories that we had no prior knowledge of and confirmed to us the nature of the independent life that John had managed to lead just like many 19 year old young men (without the handicap of his mum and dad). Even our Lawyer had a funny story to tell about the circumstances surrounding setting up "Power of Attorney" to manage John's affairs.

Another source of great comfort for us is a memory box which had been presented to John on leaving school (just four months before he died). It is packed full of photographs video diaries and various arts and crafts and memorabilia from his years at the Royal Blind School. We are so grateful to the staff there for maintaining this living history. Next month we are proud to be opening a new sensory room at John's former school, where some of the equipment has been funded from the donations that were given in lieu of flowers at his funeral. As we approach the second anniversary of John's death it's hard to believe that it is so long since we heard him giggle, or ran our fingers through his spiky red hair. Sometimes it feels like only yesterday and other times it feels like an eternity. Sometimes it is a particular smell or a song that transports us back in time and triggers one of the many thousands of memories that we all have. It's these memories that enable John to live in our hearts for ever and it was such a privilege to be part of his life. John taught us many things;

he taught us how to laugh, how to be brave and how to love unconditionally.

We are so grateful to everyone at Soft for travelling with us on this journey. When John was born I was so motivated to find someone who had a child with Trisomy 13. I just wanted a glimpse of what we could expect along the way. I now know from my various experiences

of talking and listening to other parents that nothing prepares you for the birth of a child with Trisomy. I now also know from experience that nothing prepares you for the death of a child with Trisomy. What I am so grateful for is the 19 and a half years of life that we lived with John in between.



Left to right - Duncan, Fiona, Rachel and Stef Kerr, standing behind John