

### **How others see us...**

There have been several occasions recently that caused me to reflect how, as bereaved parents, others see us.

In early January, I gave a lift to a neighbour who comes to the art class I run in our village. It was the first morning after the Christmas break and we exchanged the usual enquiries as to how each of us had enjoyed Christmas. I made the mistake of saying that we had found it difficult this year, because the calendar dates were the same as the weekdays and it had been almost impossible not to relive the six weeks Will was in hospital. I should have known better. She turned to me and said, "Gill, I think I know you well enough to say this to you." Oh dear, I thought, here we go." And I was right. "From what I knew of Will," she continued, "He would not want you to feel like this. He would want you to enjoy your life."

"Well", I replied, "I like to think Will is proud of what I have done. I have written two books and try to be a support to other bereaved parents. I started the drop in centre, although I have had to suspend it for a while." But that was not enough.

"Yes, of course, and I am sure he is proud of you," she responded, "But it's all about the same thing"

The ironic part of this is that this very nice woman has a friend who lost a young daughter some years ago. The child suffered from a distressing hereditary condition throughout her short life. She often talks about her friend, saying how wonderful she is and how much money she has raised for charity. "Tell me," I asked, "which cause does your friend raise the money for?"

When she replied that it was for a children's hospice, I had to say, "But is that so very different from what I am doing? Except that I am trying to raise funds for a charity that supports the parents of children who have died." She didn't say any more after that.

Not long after this, some married friends came for supper. To protect their identity I will call them by different names – John and Joan. This couple kindly invited us to stay with them when we first returned home after Will died – our house was in the middle of being extended and in our raw emotional state, we could not cope with the chaos. I thought that they both understood our grief, especially so since Joan helped me to present the talk I gave to our church, two years after Will's death, on the subject of parental grief, . During the conversation at supper, I said how precious being a member of TCF was and how writing about grief was my way of going on with my life, knowing that there was nothing I could do to change what had happened and bring Will back. John's reaction shocked me, "I am really pleased to hear you say that", he said.

I am surprised I did not swallow my tongue in my effort not to respond sarcastically. He was inferring was that he was pleased I had at last "come to terms" with our loss and accepted that Will had died. I felt angry. Did he – did both of them – really think for six years I had been in denial? Surely they knew us better than that. But sadly, I know that despite having had a fairly close relationship with them, they still do not understand our pain. Many times Joan has said that they cannot really understand because they themselves have not lost a child. Don't people always say that to us? Surely, if they have children of their own, it is not impossible to imagine how life would be without them?

One of the members of our previous church lost a baby of eighteen months over twenty years ago. I have lost count of the number of times Joan has said to me that this mother did not "Handle it very well"

How do you handle something like that? We don't have any lessons on the subject. And why does an elderly woman from the same church, whose husband died after they had been married for nearly sixty years, get more support and understanding than my husband and I did when Will died.

But that is the problem. Charities which work with ill children and their families, receive more understanding and support than a charity like Compassionate Friends. We are expected to "Move on", "Get on with our lives," and not continue to stay in touch with parents in a similar situation.

This fact was highlighted when a friend kindly collected our dog from boarding kennels so that he would be at home when we returned from our first National Gathering. Phoning to thank her for collecting him, I also asked her where his lead and food bowl were – they had been left at the kennels. She said she didn't know, adding that I seemed more concerned about them than I was about the dog. Naturally, I was upset at this and she then said, "Well, if you will go to these things, what do you expect?" The implication being that I was overreacting because I had been mixing with other bereaved parents and many see that as unhealthy. Indeed, I was warned by another friend not to join TCF when Will died, as it would mean I would only have to listen to other people's sad stories and make myself feel even worse.

Herein lies the problem and much as I have tried to explain that joining TCF has been a very positive step and has probably saved my life, there are few who want to understand.

As we all know only too well, the loss of a beloved child it is like no other loss – another fact that is difficult for others to appreciate. And the curious thing is that, as bereaved parents, we seem to come in for more criticism than other bereaved people. The reason of course is that we are part of a great and much feared taboo.

We are the unfortunate survivors of every parent's worst nightmare. We have lost a child. It is unthinkable and beyond the desire of many to try and understand. They would prefer not to think about it and are more comfortable with those who have lost a parent or a partner than they are with us.

It is now just over six years since Will died. In March we moved from our previous church to a new one and our new vicar is unbelievably different. He truly understands our grief – he lost an infant son and a young teenage niece. But I think, even without his sad experience, he is the kind of minister I have been searching for. He has already been to see me on three occasions – our previous minister visited us only six times in the six years since Will's death.

During his last visit I described how displaced I feel – that, as Will was our only child, we are no longer a family and no longer a couple the way we were before Will was born. And I am tired. Tired of having to make such an effort to appear normal when in truth I don't know what normal is any more.

One of the aspects of our new church I value the most is that every week the service includes a prayer for the departed. It seems more modern and evangelical a church becomes, the more praying for - or even acknowledging the dead - becomes undesirable.

Furthermore this church provides beautiful candles that can be lit in memory of loved ones. And since this church is never locked, I can go at any time and light a candle for Will or the children of TCF friends. I find this a huge comfort.

Another reason for my tiredness is the effort involved in keeping up appearances to keep others happy. The other evening I asked my husband, Edwin, how he feels, six years on. Did he feel that his grief for Will has changed, adding that, if anything, I feel my grief deepens with time, the longer I am without Will, the more I yearn to see him. "Yes", he said, "It has changed but only because I have become more practiced." He has always referred to his work place as a "Will free zone," because no one ever mentions Will and he has now become practiced at concealing his grief and giving the impression that we are indeed, "Over it now." Incredibly, someone asked him that very question when he tried returning to work only three weeks after Will died!

And isn't that how it is for the majority of us? We do— because we have to — learn to cope with our drastically changed lives. But, deep down, the pain is as raw and our grief as strong as ever it was. Yes, it softens a little with time but it never goes away. One mother I know whose eighteen year old elder son drowned, gives a great impression to others that she has "got over it". And I am sure that I am often compared to her. But although it is more than twenty years since her son died, I know she has not got over it. **I know** because she has said things to me that she could not say to others. I know there are still situations she cannot cope with. I know she will go out of her way to avoid walking past the homes of any of her son's friends in case she sees them with their children. And I know that, upstairs, under one of the beds, are various belongings of her son's that to this day she has not had the courage to look at.

There are times when I wish it was not like this — when I wish we could be honest and open about our feelings. I wish we could talk about our children, join in the conversations others are having about their children without feeling uncomfortable because we are talking about a child who is no longer alive. But, sadly, it is not acceptable in a society that does not bring grief into the open. Odd, when the one certainty we all have is that we will die one day.

We do not want pity — none of us want that. And we don't want to be defined by our loss. What we do want is to be acknowledged for who we are, for others to accept that what has happened to us is very, very, sad and not something we will ever "get over". We want others to offer us the understanding and compassion that would help us to face the new and changed lives we as bereaved parents have to contend with. And to allow — indeed encourage us — to talk about our children and share memories of them. To be able to say our child's name means so much to us, we don't want to feel that if we do talk about them we are — as the member of my art class implied— we are not getting on with our lives. To honour our children we do try to go on living. But we are not the people we were before our children died and never will be again. And life would be more bearable if others accepted us for what we are now — not criticise us because they believe we have not "moved on" enough.

Edwin and I were pressurised lately by well-meaning neighbours trying to persuade us to attend the street party being organised for the Royal Jubilee. We have said politely that it is not for us. But we could well imagine what the neighbours are thinking - that it would do us good; we need to get out and socialise more. I don't want to have make excuses or try to explain why it would not help us. But it does make me all the more thankful for TCF.