

A Level in Understanding

I recently had a chance encounter with a lovely man who used to come to the watercolour group I run in our village and whom I had not seen for several years. Catching up with each other's news, I told him about Will, my twenty-two year old son who died in January 2006, from a mystery illness. His reaction surprised me. He then told me that he too had lost a child, his ten-year old son, thirty years before. Why I mention this encounter was because of the tangible relief on this man's face, not because of Will, obviously, but because he was with someone who understood. His pain is just as deep as it was thirty years ago and he said the very words I have heard over and over again from many bereaved parents, "No one understands, do they?"

Sadly, this is true. No one, unless they too have experienced the death of a beloved child or, as in some desperate cases, all of their children, can really understand. When Will died, my husband and I became part of a huge body of largely unrecognised sufferers, set apart from society by the very nature of our loss. Our families found it difficult to cope and we see little of them. Old friends failed to keep in touch. Our circle of friends is now quite different.

Our new friends now include many bereaved parents, the majority of whom we have met through The Compassionate Friends (TCF) a charity run by and for bereaved parents and their families. TCF have provided a true lifeline for us and for thousands of bereaved parents. Founded in Coventry in 1969, TCF is now worldwide and this year celebrates its fortieth anniversary, with a National Gathering at Bosworth Hall, in Warwickshire.

One of the advantages of meeting with friends from TCF is that we speak the same language. We don't have to explain to each other why holidays are

so difficult, or why we are having a “bad day”. And, as far as TCF are concerned, Edwin and I, in our fourth year without Will, are still in the early days of our grief, whereas most people think we should be “getting over it” by now.

I realise that people can only measure grief by their own experience. Hence the words, “I know how you feel”. The truth is, none of us know how the other person feels, whether the bereaved person is mourning the loss of a parent, a cousin or a much loved family pet. But that said, to lose a child is a different kind of loss. For a start, it is the wrong order of things – we are not supposed to bury our children. The Jewish people say that there is a word for widowers, there is a word for widows, there is a word for orphans. But for a parent who has lost a child, there are no words.

Ask any parent what their worst fear is and they are almost certain to reply that it is a fear of losing one of their children. I think this is perhaps why bereaved parents feel so isolated in their grief. It is almost as if we have a contagious disease and if others get too close to us, it might happen to them too. I also think that because it is so unimaginable, people don’t want to think about it and, if they do, they like to imagine that it couldn’t be that bad; they would find a way to cope. This is where the awful clichés come in. At any meeting of bereaved parents, you will hear endless examples of the things people say. There is always laughter at such ineptitude. But beneath the laughter is pain.

Ever since Will’s death, I have felt burdened by a sense of having to put on a brave face for everyone. I soon found that it did not help to be too honest and that it was much simpler to say “I’m fine, thank you.” The worst

aspect of this is that I became so afraid of appearing weak that I became my own worst critic. I had to be strong and it was almost as if I felt the need to apologise for grieving. In this country we have a very strange attitude to grief. It is deemed admirable to display the very British stiff upper lip and people love to tell you how well you are doing. If they only knew...

Although an active member of our local church before Will's death, I do not attend now. Indeed, Will was planning a career in the church and was in the second stage of his application to become an Anglican Minister, when he became unwell. Although I would not want to single out churchgoers, there seems to be an unspoken expectation that, because of our faith, we should somehow cope in a different way. This of course is not the case. Being told that our loved ones are in a better place is no consolation to grieving parents or, for that matter, to anyone else who is grieving for a loved one.

During the weeks our son was in hospital, we could not have coped without the support of our families and our church family. It was only after his funeral that everything changed and we began to feel isolated and misunderstood. A dear friend, also a bereaved mother, made the comment, "The trouble is, when the thunderbolt falls, it's sudden isolation."

The brutal truth is that others have their own lives to lead and only have a limited time to spare for you. They want you to say you are "feeling better" because it gives them permission to go on with their lives without worrying about you. They can stretch out the time between phone calls and visits without feeling guilty. It is hard for people to realise that to come alongside those suffering such catastrophic loss, it does require a deeper level of understanding, an understanding that this is a wound that time will not heal.

What many do not understand is the “on-goingness” of grief for bereaved parents. It is far reaching and never ending. In fact, now in our fourth year without Will, the pain is deeper, the sense of loss more final. Now I am beginning to realise that this is how it is going to be from now on, this is for real and Will is never coming back. For much longer than realised, we are cushioned by shock and disbelief. It is only when the façade begins to crumble and misery creeps in through the cracks, that the awful reality bites. Will was our only child and this brings aspects to our grief that those with surviving children do not share. With the loss of Will we have lost our past, present and future. We will never be grandparents. Conversely, parents with surviving children often have to bury their own grief in order to support the child’s siblings. And the balance of the family structure is irrevocably changed. Often the siblings of deceased children carry the scars of the loss of their brother or sister for life.

. When my sister failed to acknowledge the anniversary of Will’s death and I expressed my disappointment, she replied that people don’t acknowledge such anniversaries. It seems she was right. With the exception of a cousin and our vicar, it is only other bereaved parents who remember and send us cards every year. To have someone remember and acknowledge our child’s anniversary means so much to us. Birthdays matter, too. Whatever ages our children were when they died; they are always just that – our children. Their birthdays will always be poignant. And it isn’t just the obvious anniversaries that are painful. There will always be something to lock into the parents’ pain – Christmas, Easter, family weddings, christenings, holidays, seeing someone who resembles your child – the list is endless.

I also grieve for what I feel Will is missing out on. He was a very charismatic young man, bright, clever and with a wonderful sense of humour. He had so many plans, there was so much he wanted to do.

I was mentally and physically disabled by grief when Will died. After my husband had returned to work, I would get up, dress, go downstairs and just sit, staring into space, longing for the doorbell or the phone to ring. The need to talk about Will and what had happened was overwhelming. I would talk to anyone who was prepared to listen. By day I often phoned a helpline, such as The Compassionate Friends or the Child Death Helpline and often phoned Samaritans in the middle of the night. I think I believed that if enough people agreed how wrong Will's death was, particularly in view of his intention to enter the church, God would admit he had made a mistake and send him back. When you are in such deep shock, the impossible seems possible.

Not all parents experience the isolation we had to endure and are fortunate enough to have supportive family and friends, who are prepared to stay the course with them. But many have not. I often read of people turning up with the proverbial casserole but that never happened to us. I couldn't face going into the kitchen when Will died and if my husband had not taken over all the cooking, I would happily have starved. I do understand that people simply do not know what to say or do. But a hug and listening ear are what is most needed. I have learned so much from my experience that never again will I say to someone grieving, "You know where I am", or "Let me know if I can do anything" Expecting the grieving person to make the first move, is asking too much.

Parents are often accused of turning their deceased child's room into some kind of shrine. Whilst this may be true in a minority of cases, it is not true of the majority of parents. But, that said, what could be more heart rending for a parent than to be faced with all their child's possessions and not know what to do with them? I use my son's room all the time as an office, I sit at his computer and write but all my work is still filed under the icon "Mum's". I am surrounded by all his belongings. We still have his Lego, his train set and other childhood possessions. I cannot find the strength to clear anything away. It would feel like betrayal. And it would be admitting the finality of his death.

I fear, like so many in my situation, that my son is being forgotten. I need to keep his memory alive. So few people ever mention his name and although I try to bring him into a conversation, it is not always easy. I know if I do it will only cause an awkward silence and a change of subject. I cannot pretend Will never existed and have heard so many parents say the same of their children. Our children were, and still are, a precious part of our lives and we should have the right to talk freely about them, not feel that we must keep quiet in order to make others feel more comfortable. When someone mentions Will's name, it is music to my ears. By mentioning our children's names, you are not reminding us of something we want to forget – how can we forget? And why would we want to?

Sometimes it feels as if we are failing in some way when we want to talk about our dead child. It is as if we should have moved on, found something else to think about and occupy ourselves with. I have been told to "put it behind" me and that, "life goes on". And there is a sense in which we are

deemed to be selfish and self indulgent when we find it difficult to relate to other's problems – problems which involve the living, not the dead. In fact, those of us who have lived through such devastating loss are frequently amongst the most compassionate and caring people you could wish to meet.

One might imagine members of TCF to be a rather negative group of people but that is far from the truth. Through them we have met some wonderful and inspiring people. There is a need amongst those who have suffered such catastrophic loss to make something of what is left of their lives, to do something positive in their lost child's name. Some take administrative roles within TCF, volunteer to assist on the helpline or run a support group in their local area. Others set up some kind of trust fund in their child's memory, raise funds for a particular charity or go into the caring profession. Some go on to higher education. We somehow find a way to go on. Love for our deceased children keeps us on our feet. We have to find a way to honour our children.

A friend wanted to buy me a tee shirt emblazoned with the words, *"I am up and dressed. What more do you want?"* I turned her kind offer down but I was tempted. I often don't want to get up in the morning and face yet another day without my son. Life will never be the same again. But I am still here and that if nothing else, is an achievement.

Points to ponder:

People are often afraid to visit bereaved parents in case they make things worse. As a friend said, "You can't make it any worse. The worst has already happened".

Taking round something to eat is always welcome. I couldn't even make a cup of tea.

You don't have to say anything. It is better to be honest and admit you don't know what to say. A hug and a listening ear are preferable to uttering clichés.

Don't be afraid to mention the child's name, whether in the early days or not - parents want to hear it – again and again and again.

Don't say, "I know how you feel." You don't.

Don't try to jolly the grieving person along or try to persuade them to do something they are reluctant to do. The best advice I was given was, "Don't let anyone tell you how you should be."

Be patient. You may well have to hear the same account of what happened over and over again. It is vital for the grieving parent to do this. Please let them.

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“My True Son” by Gill Hartley. An anthology of a Journey through Loss.

Available by order from Christian bookshops or from the publisher,

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Free phone service for anyone affected by the death of a child.

The Child Bereavement Charity

The Child Bereavement Charity (CBC) provides specialised support, information and training for those affected when a baby or child dies, or when a child is bereaved. **Tel: 01494446648**