Losing your child: becoming a hero to zero parent

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Toni Bewley describes how she coped after her 23-year-old daughter Toni's death. Toni jnr had many complex health needs requiring 24-hour care at home. In this article her mother describes the profound impact on her as a parent following her daughters' sudden death and the ensuing void from her being seen by others as a 'hero parent' to one who became a 'zero parent'.

It is often difficult to portray one's feelings to others and this is especially so when the topic is one that is sensitive. Death and dying in UK society are themes that, in my personal experience, are often veered away from in conversation and this is especially poignant if, as I have found, the process of dying involves a young person.

This is because in the 21st century children are not supposed to depart this world before their parents. In my experience the thought of this ever happening renders conversations to an abrupt halt and creates uncomfortable silences. Indeed, I think that unless you have experienced losing a child, it is impossible to understand what it feels like. For me, the words of a song from Amy Sky, Olivia Newton-John and Beth Nielson Chapman in their LivOn album (2016) sum this up perfectly:

> *'There is no language for this loss, grief is a bridge that can't be crossed until you've felt someone you love slipping away, you don't know what to say.'*

Unfortunately, I do understand what it feels like, having lost my youngest daughter Toni in 2013 at the age of 23. Toni went through many challenges in her life, including more than 60 operations and many years in hospital, with the last few years of her life spent being nursed at home. Despite this she was living life to the full; however, to sustain her thirst for living and normality she required 24-hour nursing care and was dependent on technology, including a ventilator, for breathing. This meant that our home was different to what most people consider a home to be. Yes, it was a sanctuary and *our* sanctuary, but to maintain this we had to have carers in the week during the daytime. At night, I slept next to her bed and then went to work in the morning. Life was busy: it involved hospitals stays in London, not nearby to our home in North Wales. Unsurprisingly I ran my home with military precision to ensure that medical supplies were ordered weekly, carers' rotas actioned, sick leave covered, and medical emergencies dealt with. But I loved, lived and thrived on every moment, and lack of sleep was never an issue to me. Over time friends and family became used to Toni's prolonged hospital stays, so inevitably their contact with us slowly decreased. At the time this rarely resonated with me yet, reflecting on this now, I suspect that busying myself and advocating for Toni meant there was little time to miss normal friendships and family interaction.

In those last few years of Toni being nursed at home life continued at a frenetic pace and included all things social such as cake making (which Toni loved even though she could not eat), lessons on a computer for a European driving license, card making, cinema and concert attendance, and the usual weekend shopping sprees conversant to any young lady. The fine balance between life and death was normal to us, something that we as a family faced minute by minute and had done so since Toni was born.

So how does one cope when this all caring and 24-hour vigilance abruptly stops? This is the position that I found myself in following what was meant to be a routine three-day hospital admission at the end of November 2013. Within 24 hours of the hospital admission Toni became acutely unwell and passed away suddenly on 1 December 2013. The aftermath of this very sudden loss was inevitably hard and was not something that I had anticipated, even though Toni had always had a tenuous hold on life. Her death, and in such unexpected circumstances, was a situation for which I was not prepared.

Hero to zero

During Toni's lifetime, both my husband and I had been hailed as 'hero parents'. Stemming initially from us fostering our daughter when she was a baby, friends and colleagues felt that what we had done was remarkable as she was profoundly disabled. Over time her medical conditions worsened and as the complexity of her needs grew, we were labelled by others as being 'chosen', 'special' and 'heroic'.

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The reality was that Toni gave so much more to us and others than we could have ever given to her. Perhaps she was the hero, our hero.

As readers of this journal will probably know, after a bereavement life for others continues but for those bereaved it stands still. Bereavement counsellors note that family, friends and colleagues of those bereaved generally actively support them for just eight weeks, as I was told at my first bereavement counselling session. After this prescribed grieving time, the popular expectation is that one should 'move on'. I can relate to this because when the forecasted time came, true to the prediction, the care and empathy shown by others disappeared. I was no longer a hero parent, but rather a zero parent

My husband and I were expected to be OK because, as was commented often, 'we knew' that Toni had a life-limiting illness and through fostering her we had *chosen* to take her into our lives. I suppose that this belief in others' minds made it seem that we were alright and her death 'timely', as it was going to happen anyway. Because of this I felt I could not talk about Toni to anyone, and no one asked about her.

This silence, denial even, made my anguish harder to bear. It was interesting to hear people's audible sigh of relief when they enquired if I had other children. The reality of me still having two surviving children seemed to lessen the death of one of my children for others. This reaction almost always made me want to respond with a rhetorical question of 'which of your children do you not want?'.

My refuge

On the other hand, I guess work became and continues to be my refuge as, although people didn't ask me how I felt or was feeling, it became 'on with the day job'. Although I seized every moment (and still do) to talk about Toni and not to hide away either her life or death, I realised that this may have made many of my colleagues feel uncomfortable. But she had so much to give us all and still does and her attitude to her illness and to disability was exemplary, so at work when I talk about relevant issues in Toni's life to my students I cope well, but as a teacher and not Toni's mother. Indeed, it is interesting to reflect on how my workplace has provided an opportunity for me to express my feelings as a bereaved mother.

I have never thought of myself as being creative and it is extraordinary the way that things do somehow work out. A moment of inspiration occurred after Toni died when the President of the Student Union at Edge Hill University approached me and asked if I could contribute to the Disability History Awareness Month, where the focus was art. My imagination began to run wild; this was my chance to produce something meaningful with a purpose. Here there was an opportunity to bring my experiences as a bereaved mother into the workplace through shared creativity and a previously unexplored medium for expressing feelings. It was the chance to utilise both my professional identity and personal experience as a mother, now bereaved.

As I began to plan my artwork, I reflected on Robinson's (2006) four features of creativity: Imagination, purpose, being original and having value. All four features resonated with me and my experience with Toni, which is unsurprising given that creativity and critical thinking are often thought of in tandem, with the former enabling us to make sense of what is happening and the latter encouraging us to formulate creative solutions (Padget, 2012). As I decided what my 'creative solutions' would be I was further reminded of Ramsey and Sweet's (2009) assertion that photography and the use of photographs can become a process of self-expression that can facilitate an important means of self-reflection.

In telling my story of a 'hero to zero parent' I thus decided to use photography, music and text to see if I could make people take notice. Possibly this was me being rational and distancing myself from my inner torment to produce valuable, professional, meaningful outcomes. My imagination worked overtime as I thought of ways of producing artful and creative outcomes that could incorporate Robinson's (2006) features of originality and value.

Initially my thoughts were focused on the production of a poster titled '*Hero parent to zero'*. It aimed to capture the profound effect of loss for parents of children with

The poster Toni created.

Poignant images of Toni's room before and after her death.

disabilities. Responding to my original sketches for the poster the university reprographics department designed my poster, and while I was pleased with it, I felt there was something missing. It lacked movement and was a stark black. So while it was a meaningful poster it did not speak to me and lacked explanation. Accordingly I thought it would not resonate with the audience either.

Recognising that creativity is an evaluative process that shapes the outcomes and their relevance (NACCE, 1999), the next stage in this process was for me to produce a video to accompany the poster. Combining photographs and text, the video's purpose was to depict what life after a bereavement for parents looks like, the void that the loss of their child creates. At the start of the video there were pictures of Toni's bedroom packed with ventilators, suction machines and oxygen, as well as images of her two wardrobes stacked top to bottom with medical equipment. Her bedside table, complete with night time ventilator, suction, medication and oxygen, was also shown. Following on from these images of her busy bedroom were the poignant images after Toni had died, of empty wardrobes, bedside tables and even her bare bed, without its air mattress.

This imagery was striking yet I continued to try to visualise what else would help develop my project, in a way which could convey what my grief for Toni felt like. The missing link seemed to be something to listen to so that the poster and video would also speak to the audience. My next mission therefore was to find appropriate music.

Rifling through a plethora of recordings and listened-to music from a variety of sources my purpose at this point was to find some music with relevant lyrics that would enhance the poster and the video. After a great deal of searching, I came up with a perfect song by Amy Sky, Olivia Newton-John and Beth Neilson from their 2016 album *Liv On*. The lyrics of the song, some of which I included at the beginning of this account, could have been written by me; I felt that they were reading words spoken from my heart and were just perfect. At last, the project promised to convey what I had been feeling as a bereaved mother of a child who was 'expected' to die prematurely.

Poignantly, when I researched the background to this music, I learnt that these three musicians had each also experienced a bereavement, and this was their reason for creating an album that depicted their journey through loss. Their purpose in doing so was for those listening to understand and appreciate some of the emotions experienced by bereaved people.

Once I had completed all the component parts of my project, I piloted it by showing it to several colleagues. Colleagues' reactions were instantly evident, their facial expressions and teary eyes indicated that I had achieved my desired outcome. I had wanted people to realise just how much life changes when you have been used to 24 hours caring and being labelled a 'hero' parent. I needed them to experience what this loss felt like, reflect on its meaning and listen to the poignant lyrics of the song. I needed to be heard and recognised.

Presenting my work

Over the next month, the video was played in the main Student Hub in Edge Hill University, and in the Faculty of Health.

A comments sheet was left on the table in front of the video with a simple explanation on it, which said:

> *'This video depicts a little-discussed issue of how life changes for parents of a disabled young lady when she is no longer here. Their 24-hour care role stops, as does their role in life as they move from hero parents to zero parents.'*

The video and poster on display at Edge Hill University Disability History Awareness Month.

Below are some of the comments that I received:

- It is so sad when parents go from hero to zero. More support should be available and more awareness of the role that hero parents play.
- I think that parents deserve more support when losing a child and should gain all the help they need because after all they are still heros.
- A thoughtful and sad video that makes you want to help and allows people to show support for those who need it.
- The support of the carers after the death of a child needs to be considered and respected. It is important to ensure that they never feel socially excluded.

After reading the comments, it was obvious that the message portrayed in the video and poster had both achieved the desired purpose and had been of value to the audience. Maybe this way of presenting my story was also cathartic to me as it enabled me to open up to others in a safe way. I was exposing myself but not forcing others to listen, and in doing so I guess I was protecting myself from further hurt of people not wanting to listen to me and acknowledge the loss I had experienced. I am still saddened and indeed angry by the lack of caring by many professionals who had been involved in many aspects of Toni's life and were conspicuous by their absence once she died. Likewise, I am shocked by the lack of care shown by the many charitable organisations that we were involved with in Toni's lifetime and their absence when she died. Maybe this is because of the very clear remit that charities have, lack of funding perhaps, who knows? But I know very little support and recognition was available to me.

To try to reconcile the silence around Toni's death and my grief I sought and accepted bereavement counselling from the Alder Centre in Liverpool. This has been, and still is, my lifeline. Accordingly, I was heartened when the Alder Centre asked me if they could use my presentation in staff training sessions, as after all, this zero parent has and is trying to make a difference. I remember a comment made by my counsellor, who stated that many bereaved parents set up charitable organisations as a means of keeping their children's memory alive. In the same way through this creative process and artful presentations I have been able to draw on and share my feelings and experience as a hero to zero parent, in the hope that should the counsellors at the Alder Centre ever see someone in my position in clinical practice they will show them that they recognise their loss and that they care. After Toni died I was assumed to be OK because her death was inevitable yet, as my presentation showed, the gulf she left behind was enormous. Having not been able to be open about this initially, I am pleased that through this creative experience I have been able to engage with others and give insight into what bereavement for a child with a life-limiting condition can look like. By educating others maybe I am no longer a zero parent and, I hope, Toni's short life and her unexpected death can help others. ■

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