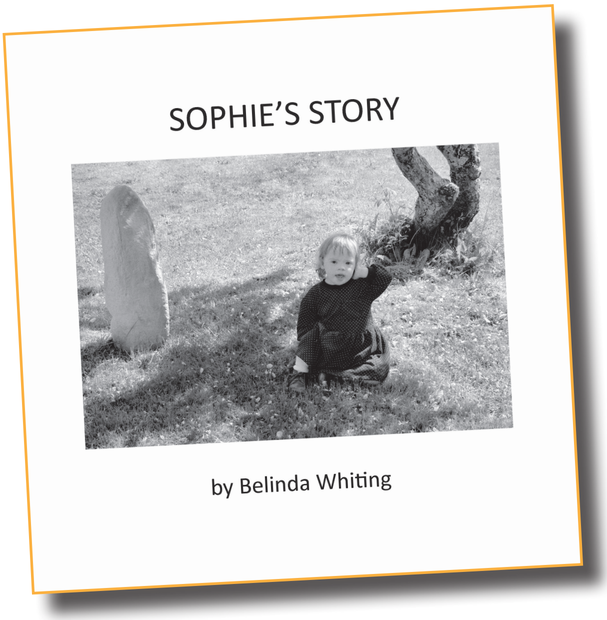
Sophie's story: Confronting loss and celebrating life

Belinda Whiting
belindawhiting@tiscali.co.uk

The picture book 'Sophie's Story' by Belinda Whiting gives an account of her daughter's life and early death, aged three. Written to assist the mourning process and confronting loss and grief it is nevertheless a celebratory reflection on a young life. Using simple words and alternating with photographs from the family album, it was written to enhance understanding (particularly for a younger audience), of the reality of a short life that was both ordinary and exceptional.

Pregnant at 37 with my first child, I felt that my life had been blessed and the life growing inside me was a thing of wonder. From the first moment of knowing this new state and throughout the pregnancy, I trusted with complete certainty that my baby was strong and healthy; that we had chosen each other and all would be well.

Cautious from a previous experience of radical and unnecessary medical intervention for a benign tumour I decided against having any tests or scans, despite my age. I very much wanted the baby I was carrying, intended to avoid any medical intervention as far as I could and was determined to find an independent doctor for a home birth.



When Sophie was born I very quickly saw that my daughter was different. I remember that moment when I looked at her clearly for the first time, searching for family connection. She turned her head and I saw an *otherness*, something familiar yet unknown. The recognition that stunned me was that she had Down's syndrome. Exhausted after a long and difficult labour I was at first shocked and numb. The initial disappointment that she was not how she was 'meant to be' came with the heaviness of guilt that I could judge her as anything but perfect. I felt moments of anger at the thought that this chromosomal condition was a sentence that would curtail and limit her life and that there was nothing that I could do about it.

In those first few dark hours of night my anxieties and concerns struggled to make sense of unknown fears. Fortunately they endured but briefly however as after a good night's sleep nature's chemistry took over. I was thrilled with my beautiful baby.


Belinda Whiting

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Sometimes Sophie didn't find it as easy as other children to learn new things. She often had to practice lots of times before she could do them.

She didn't mind though and it didn't matter because she liked to find her own way of doing things and in her own time.

Sometimes she got cross when I didn't understand the things that she wanted to do but mostly she was happy and full of laughter.

I was also reminded (by the wonderfully supportive doctor who had delivered her) of the extraordinary gift that such a child was; that she would enable me to experience a range of emotion that I might not otherwise have had the opportunity to know. As I gazed down at that new little being I was able to experience the true reality of her presence and all too soon was enchanted and seduced by it into the most intense feelings of love and tenderness towards her. She herself *was* perfect.

But in the weeks that followed I was forced to take a long, hard look at myself, re-evaluating expectations for myself as well as Sophie. I was forced to face up to my fears, failed expectations as well as my own prejudices, but it was as if I was dealing with two babies. One was the theoretical idea of a baby with Down's syndrome; hard to accept and full of doubts and what if's: the other was the real life experience of Sophie herself. Being confronted with the actuality of this wonderful little human being made a mockery of any disappointment that could have been felt in her. She was a delight from the beginning, not only to me but to all the friends and relatives who met her. Her difference was a uniqueness peculiar to her.

On a Christmas visit to family in Oxford, before her second birthday, Sophie became ill with meningitis. In hospital she recovered quickly despite early warnings that she might not pull through. It was at this point that a serious hole in her heart was discovered, that had gone unnoticed in previous routine health checks. Major heart surgery was considered imperative. It felt like another sort of bereavement; another major adjustment to be made.

I had no way of knowing at this time that the hospital unit where she was destined to have that operation was already known as 'the departure lounge' by those medics in the know.

We had to wait over a year for heart surgery. When the letter finally arrived with a date my heart sank to realise that it was the day before Good Friday, which I felt was extremely inauspicious. Sophie had her third birthday and two weeks later we drove to Bristol Royal Infirmary. On the morning of the operation I handed her over to the surgical team and was advised to go out for the day away from the hospital. I had never left Sophie for more than an hour or so in those three years.

Later that evening she died in the operation when the heart bypass machine was finally turned off and she couldn't pull through.

My world turned upside down. Rather I seemed to watch myself from a distance with a strange objectivity going through certain actions as if in a slow and terrible dream. The surgeon came and explained something of what had gone wrong. I felt

On the morning of the operation Sophie had some medicine to make her sleepy. We sat together in the sunshine that came in through the window and listened to the music that she used to listen to when she was a little baby.

She felt very peaceful being cuddled and hearing the sounds she liked and she fell asleep in my arms.

utterly and completely trapped by a reality that my mind would not contain or accept. I was consumed with an overwhelming longing to move beyond this restraint to reclaim my lost daughter, as well as an accompanying terror that it was forever impossible.

Later I held her for some hours. She was still warm. I was not allowed to move her as the hospital required an autopsy which couldn't be completed until after Easter. The following morning she was cold and stiff. I recognised the impossibility of her return yet she also seemed to be with me in some other way. In the Chapel of Rest I felt I could have stayed for ever beside her, somehow deeply consoled by a sense of some fundamental connection that was timeless. I was spellbound. Away from her I went to a church three times that weekend in the hope of finding some word of consolation but came away empty.

In the weeks and months that followed I went deeply into the loss I was experiencing. I went to Scotland to take part in a residential workshop with Elisabeth Kübler-Ross: immensely helpful days that put me in touch again with a love of dancing that had been lost to me for over 25 years. At home again I used this as a therapeutic tool to work through my sadness. I danced and sang and danced and wept and danced and shouted. Sometimes I fell into a great pit of despair in which I knew I was out of reach of any help. Yet even there I knew that too would not last. I carried on dancing and made art work and read many helpful books on the subject of death, but I often felt like someone who was drowning at sea. Waves of grief would overwhelm and submerge me. Then I would come up for air again before the next engulfing wave, maybe minutes later or hours. Gradually it became days and I started to feel that something was changing. The process of bereavement was taking me to new places. No longer drowning I stumbled up the shoreline to a new location.

Some months after Sophie's death, I met a friend of hers who enthusiastically asked if she could come round and play with her! Having to explain that Sophie was no longer with me, I felt incoherent to answer her repeated question 'But when is she coming back?' How to explain *gone* and *never coming back* to a three year old? In the days that followed I realised that I wanted to find a way of making sense of this terrible event but in a wider context that would encompass a life, albeit short, rather than just an ending. A tribute not an epitaph.

I still wanted to go on experiencing that reality of Sophie even in her absence and I needed something physical and tactile. So I started to make a book: the process was painful yet redemptive. It was natural to use photographs. They were the closest thing to show who Sophie was. There! Look at her! Vital and alive! The words that accompanied the photos were to assist an engagement with the images so that a child could relate to the ordinary everyday events of playing, eating, pets, laughter, playgroup. I wrote it in the language I had used to speak to Sophie, so that a child could understand and identify with it, and I also wanted to incorporate into the story something of how much she had meant to me.

I completed the book but put it away for some time when I became pregnant with my second daughter. I trained to work as a volunteer with Cruse, motivated by my own grief work to want to work and share with others. It was a couple of years before I showed my hand-made book to a friend who suggested that I should try and get it out to a wider audience because it might be a helpful resource.

I applied for a South West Arts award and when I was short-listed I had the good fortune to meet a curator and writer on photography, who at that time was putting together a major international exhibition, called *The Dead,* first at The National Media Museum in Bradford, then in Denmark and Montreal. This brought together photographers and video-makers to explore what death meant to them, and *Sophie's Story* was included. A copy of the original book was laminated and attached to a desk. Many people saw the book in Bradford and later at galleries in Denmark and Canada. And so it became visible to a larger public in a way that far exceeded any ideas I had had for it. I was immensely heartened to feel that somehow Sophie was still making her presence felt in the world.

This sense didn't stop there, as a year or two after the exhibition, a television director who had seen the book in Bradford included film of *Sophie's Story* and the reasons for making it in the third of his documentary series for Channel Four, *Vile Bodies,* which explored how contemporary photography was challenging taboos about the human body. The story was also written about in the book *Vile Bodies: Photography and the crisis of looking*, which accompanied the television series.

In the years that followed I continued to believe that Sophie's story had been told. It had seemed to have a life of its own, many people had experienced it and it had reached a far wider audience than I could have anticipated. In the next decade many other things preoccupied me and I concentrated on bringing up my new daughter and coming to terms with loss through my art work.

It wasn't until my daughter was preparing to leave home however that I started considering *Sophie's Story* again and the feeling that in fact this narrative needed a conclusion. Many people had encountered it but nobody could own a copy or hold one and read it. So last year I decided to publish it, in the hope of getting it into the hands of those people, (particularly children), for whom I believe it might be helpful.

She only lived for three years, but Sophie changed my life profoundly. In that short time, the experience of her taught me so much: she opened my heart and mind in ways that I could never

Commentary, by Jane Moss

Belinda Whiting offers an honest and compassionate account of her reaction to her daughter Sophie's short life and death. Her account is both a celebration of Sophie's life and an illustration of the way writing and the creative act of making a book can be an instrumental aid on the journey through grief.

The creative arts offer powerful means of expression after bereavement. Activities such as writing the life story or using a journal and personal memoire can enable the bereaved person to understand the experience, reflect upon it and create something lasting as a record or tribute. In this instance the making of a book from photographs and words has enabled Belinda to celebrate and ensure her daughter's continuing presence and influence in her life and in the lives of others.

Writing offers a diverse choice of tools and techniques, among them the containment of forms in poetry and prose, and the power of metaphor to describe thoughts, moods and feelings that seem inexpressible. Belinda uses a telling metaphor, comparing herself to someone submerged in waves of grief before being washed up on the shore, 'no longer drowning'. Her choice of image is all the more effective for the way it captures the process of change, from failing in the waves to arriving on the safer shore.

The instinct to write in grief does not occur to everyone, but when it does it can be as if light is being cast on a subject that is impossible to describe verbally or in thoughts. Belinda's urge to create a book for Sophie was driven both by the need to explain, and the need to hold on to the reality of her life and personality. She describes the process as 'painful yet redemptive'; the sense that the act of creating a tangible object may be part of the process of accepting loss as well as memorialising the life.

Like memory boxes, books and albums offer the opportunity to weave together the significant facets of a life. Belinda's choice of photographs as a starting point is fruitful; photographs and other personal items such as letters and postcards provide a trigger for stories. They bring others literally into the picture – an account of a family event, a favourite home or place – and provide a chronology for the telling of a life story whether short or lengthy. They provide opportunities to remember happier occasions and to acknowledge that the life being celebrated was about more than mishap or illness and eventual death.

The choice of whether and how to share writing is an important and highly individual consideration. Writing in the context of bereavement is often acutely personal and private, yet those who choose to share their writing in a therapeutic or public environment will often describe the sharing as helpful and even essential. In a therapeutic setting, whether in one-to-one support or group work, the sharing of writing requires sensitive and non-judgmental facilitation. It requires the writer to consider the effect their writing may have on others in a group, but if there is trust and a supportive bond, the effect of having the writing witnessed and affirmed by others, can be powerful and positive. In one-to-one support the sharing of a journal, story or poem may open up themes and stimulate further reflection that had been blocked.

In Belinda's case the making of a book for Sophie begins as a personal act, enabling her to make sense of her loss. The decision to share it is made later and with the aim of offering it to others in the hope that they may be helped by it; an element of instrumental grieving perhaps, in the sense that there is comfort and purpose to be found in the idea that others will be helped. The passing of time and other life events – in Belinda's case the birth of her second daughter – play a part. The decision to publish more widely can only be made when the writer is ready. Belinda is in good company; Poet Laureate Ted Hughes published Birthday Letters, his collection of poems written for Sylvia Plath, more than 30 years after her death.

Hughes T (1998). Birthday letters. London: Faber and Faber.

Recommended reading

Bolton G (1999). The therapeutic potential of creative writing. London: Jessica Kingsley.

DeSalvo L (1999). Writing as a way of healing: how telling our stories transforms our lives. Boston, Mass: Beacon Press.

Moss J (2012). Writing in bereavement: a creative handbook. London: Jessica Kingsley.

Neimeyer R A (ed) (2012). Techniques of grief therapy: creative practices for counseling the bereaved. New York: Routledge.

Jane Moss is a creative writing tutor and bereavement group leader. She is author of *Writing in bereavement: a creative handbook* (see review on p92).

have envisaged. I consider it an immense privilege and a great fortune to have been her mother.

While I experience the absence of her everyday in my life and that is inevitable, more importantly, and increasingly these days, I am aware of her deep presence within me and I still want to go on celebrating that aspect of her in my life. So I am grateful that in this book I finally have a tangible vehicle that might allow me to share something of that celebration, with the people who cared about her, and hopefully beyond them to others who might be touched by her story. ■