

A Lone Bird Sings

She lifts her hand as I descend the stairs. I turn my head, drink in the sight of the frail form propped in a sea of pillows and wave back. The role has reversed. Whose is the reassuring hand?

My mother has come to a place of resignation after five long years negotiating Motor Neurone disease. I am heading off today. I have been here a week this time and must return home.

A week of watching and waiting. This dying business has a shoreline but no grassy edge to define where land might meet sea. Together we take surreptitious, tentative steps toward the lapping water, but ultimately we all travel on alone.

I feel like a child in this abandonment, but also a surging towards adulthood as her dependence grows. She has, over five years, crumpled to this fading form, one that can no longer walk or talk and hardly eat. Every major watershed of dying has been breached.

The real beginning came with tripping. Tripping over pavements and small stones. I listened when she told me but, to my chagrin, never took much notice. You don't when you are young. Life goes on. I never imagined it so very significant, that falling in this way might signal something so sinister. I just got on with bringing up my family while she, stoically, had tests and extensive spells in hospital. Some hard part of me chose to ignore it.

One day however we knew. They said, 'Yes, it is bad news.' She has this terrible disease and there is no cure. Even then, how do you imagine something you know nothing about? We go on living but now we are watching, all of us. Our antennae are up and waving about. We watch the signs. We note every detail. We call each other and listen more attentively to what she tells us.

Mum has never been afraid of dying. She had held dying to be just the passing from one state to another; very simple. Now it is real. Now it is creeping up and none of us knows what it will look like. I choose to ignore the nasty stories, I choose not to find out. We wait.

The day comes. No more walking. She, who has walked the Downs every day; that chalky landscape, those rounded hills that are part of the fabric of her living. She has dug and hoed, trod and tilled the unyielding flint till it has grown verdant borders that keep her imprint long after she has departed.

Now, her only access to those folded sweeps is on a buggy. We all praise it's wonderful abilities whilst quietly agonizing over its portent of closure. Its sturdy form is seen, gadding up the tracks, small dogs scattered round it like snapping ants. A glorious moment as it crests the hill, but then it too becomes silent.

We mourn its passing.

The wheelchair arrives. Once again, positive to the end we coo and praise, its enviable properties. Mum is not convinced. 'You can come and visit me in Scotland now' I trill. 'BA "do" wheelchairs too and it will be easy... It will give you wings Mum'. None of us comments that in truth, her wings have already been cut. No chair will bring them back. These metal wheels are no compensation for what has been before.

I sit at her feet, watching the fire. We are still downstairs and the absence of speech brings a peace and sharing that is profound. The clock ticks and we rest after a day of circumnavigating tiny crustless sandwiches, mini cups of soup and well meaning visitors.

Conventional communication has become well nigh impossible. The tap of computer keys lies in wait pending each question and then, as our eyes meet, I decipher the confused script. Office skills never were Mum's strongest point.

She is determined to sort out her affairs while she can. For her this means writing letters to those that she cares about and selecting readings for her funeral service. In the following weeks it is not uncommon to see us, sitting round her like fledgling birds on the edge of the nest, singing out the chosen hymns. Over and over we sing until we have a repertoire that meets approval. Somehow this comforts her.

A carer comes. This time she stays. No chance of relief now. Night and day we need help. So does Mum.

Then a machine arrives. It can talk for you, uttering long stilted sentences that sound as if we have a new male relative in the house. He talks of intimacies in a dominant base incongruent with the frail woman who initiates them. The poorly typed letters are a thing of the past. All that needs to be said has been said, now we just need to interpret the fundamentals of life. It no longer matters that the picture is hung crooked, or that her glasses have been left upstairs. It is a matter of eating. Can you? Do you want to?

As a novice carer, I stumble around full of youthful zeal but ineffective with the minutiae that make life comfortable for a vulnerable dying person. It is indeed a steep learning curve. Her oldest friend comes daily like a reassuring angel, her peaceful hound trotting in her wake. She is very experienced in accompanying dying people and she brings humour and realism to this increasingly unknown situation.

'Now sweetheart, any visitors today... How many? Who?' We have passed through the valley of the frivolous, we are onto whether a boiled sweet will help the mouth ulcers. How about a commode? The real nitty gritty of life. Living with dignity. No shirker, my mum sits it out. Even the dread of being force fed, hospitalised and a cabbage. 'No more visitors please.'

'Remember me as I was'. 'Ok' we say. The drawbridge up, we muster forces and carry on. Each day a gift and also a challenge. A momentous challenge. As the barriers of dignity drop we bow to the human quality of living. The moment comes we all dread. She needs to have her bottom wiped. That brings us close and opens the heart to infinite love. And compassion.

The curtains belly in the breeze and a lone bird sings. Inside, outside, life and death is connected. Mum's attachment to life is decreasing now and she is easing out day by day. Her presence is withdrawing till sometimes it is hard for her to connect at all. However it is apparent that the distress of mouth ulcers, aching limbs and anxiety about what might be yet to come are not dissipated. The fear is real. Not of death itself that is sure, but of how it will happen.

We wait. Her breath rasps and heaves in its desperation for life. We hang on each one. She draws each breath in fear of death, of letting go. I massage her feet. Easing out the toes and bringing life back to their paleness. I feel her body soften under my tender touch. It brings with it a precious moment of shared intimacy as through my hands I feel our old deep connection, just as the warmth returns to these stagnating limbs.

Each day unfolds with new challenges, new highs and lows but moving inevitably in one direction only. We are in the domain of soft clothing, warm light coverings and the fragrance of lavender oil. Heady flowers from the garden fill the room and a candle burns.

We turn her.

Tempting morsels appear on trays. She is quite beyond eating but sometimes it adds structure and a measure to the day. The fragrance of jam, the familiarity of toast. A sip of tea maybe? Just a sip? No? A soft sponge dunked in water suffices. We need more than tea and toast but have no stomach for it.

Inevitably life goes on. I return home to my children. Ironically I leave a child waving feebly from the bed, 'See you soon darling'. I leave my siblings to carry the load of pain and grief, and as it turns out, her passing - I am not there when she dies.

When I come home the following week I sit at the end of the bed. My first dead body. I sit and gaze, breathe in this extraordinary moment. Her dog will not enter the room but I am happy to hold this time, to be with it. A precious interlude, never to be repeated. She needs to rest and so do I.

I have dreaded this moment since my own first breath, that breath that nearly cost her life. She hung onto existence then against all odds and thereafter I hung onto her.

A lifetime's fear of losing this precious being and now, as I sit, I know that all my anxiety was unfounded. Her body lies spent upon the bed, but this beloved woman is no longer here. That seedpod is empty now and she herself is flying free once more. So certain am I of this truth that never since has death held fear for me. I knew from that time that the body no more holds life than does the air we breathe. A container for it yes, but a cage, never.