

Low energy, high creativity – discovering writing through chronic illness

First published in *Writing in Education*, 62, Spring 2014

Maria C. McCarthy was far too busy for creativity before she became ill. Loss of health, work, relationships and financial security brought deep grief and a loss of identity. And then she started to write.

This article, adapted from a presentation to Kent Writing and Wellbeing Network in July 2013, focuses on how Maria manages to write and writes to manage with chronic ill health, her ongoing attempts to balance activity, creativity and rest, and her frequent inability to follow her own advice.

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In the mid-'90s I had a responsible job, co-ordinating a small charity. I had been married for sixteen years, had a house, a car, and two children. My mid-life crisis came at the age of 36, when I succumbed to temptation – having been a good girl all my life – and had an affair. I'd married too young; I'd married someone to whom I was not suited; I had been sleepwalking for years. I felt trapped by duty and other people's expectations of me, and I wanted out.

What followed was a crazy time. There's no doubt that relationship breakdown is painful, but I relished being free from my marriage. I went into an overdrive of socialising and working, as well as looking after my daughters and the house. I was playing superwoman.

I made a successful bid for a Lottery grant, and the small organisation I worked for grew by 300%. I was suddenly in charge of this, without training or support, and adding management onto an existing workload. Alongside this, I was negotiating single parenthood, changes in my financial circumstances and a new relationship. I also had family problems going back to childhood, which I was beginning to address through counselling. I should have seen the STOP signs, but it took a fire, a burglary, a car accident and the death of a pet, all in a short space of time, to bring me to a standstill.

I was first diagnosed with anxiety and depression, but the overwhelming symptom was extreme fatigue. I had been a sharp-minded, busy person who was there for everyone. I became a slow, scared, isolated person who, when a form needed completing, held on to a pen and couldn't work out what the pen was for, let alone what to write. My employers, ironically for the trustees of a mental health charity, were unsympathetic. They thought I was putting it on, and wanted me back at work to serve their needs. I did return to work, after three months, but the promised support and understanding were absent, and after fifteen

months, I broke down again. On the day that I walked out of the office, in July 1999, I knew that I could never step back into that place of work again.

It was a time of great loss – of work, health, relationships, financially and most of all a loss of place in the world. I had defined myself by my work, particularly during the years that my marriage was not fulfilling me, and that was gone.

There was a paring down of friendships. Some had liked the Maria who danced at the front when we went to gigs; they could not cope with who I had become, and neither could I cope with having lively, chatty people around me. Visits and phone calls exhausted me. My voice was weak, and even holding a phone was too tiring.

One of the greatest losses was that of words. I couldn't read for long, or watch a film without losing concentration or falling asleep. I struggled for the right words to describe things I saw – everyday words.

I looked and sounded different. I gained nearly three stone, whilst eating very little. My voice diminished to a high-pitched, breathy tone. The self I knew had disappeared.

During the first two years of my illness, I had a poor GP but a very good Community Mental Health Nurse. Both persisted with the anxiety and depression diagnosis, explaining that tiredness is a companion to depression. I was convinced it was the tiredness that was making me depressed, but mental ill health proved a sticky label, and the trouble with the medical profession is that they only see things through their own specialism's spectacles.

The change came when my nurse applied for Disability Living Allowance on my behalf and, when it was awarded, she felt that we should appeal for a higher rate. The Independent Tribunal Service sent me all the papers relating to my application, and my GP's statement was just one word – 'Depression?' Some of my old fight returned. I refused to see him again, so my nurse intervened and found me a better doctor. The new GP ran a number of blood tests, and discovered that I had a severely under-active thyroid, which explained

many of the symptoms I had, including poor cognitive functioning, sleep disruption and weight gain. The new GP also said that he believed I had Chronic Fatigue Syndrome.

Someone once told me that not being believed can make you feel that you are going mad. Being diagnosed, being believed, was an awakening. I remember being on Chatham High St and hearing an opera singer, a busker, singing Ave Maria, and it felt symbolic, like he was greeting me back to life.

But diagnosis does not equal cure. Although medication for my thyroid led to improvements – I lost the weight I had gained, looked more like my old self – the fatigue persisted, and has done so until this day. I am now in the fifteenth year of my illness.

Discovering writing

I could only tell the first part of my story in a detached way – this happened, that happened. Perhaps this is because, at that time, language had left me. I was functioning enough to stay alive and carry on for the sake of my teenage daughters. I wasn't carrying on for myself. I constantly thought of ending my life. I walked by the banks of the River Medway, close to my home, and imagined walking down the concrete steps into the water, just stepping down below the waterline until the waters closed over me. There is a poem I wrote about this, a few years later, when I was on my way to the new self that replaced the old one that I knew.

On Rochester Bridge

Sleep, like a distant relative, visited
rarely. You yearned for the bridge,
like the lover you could not forget
as you counted the clicks of the clock.

You sped there on the sponge beneath your feet,
too busy to rest; chasing thoughts of scores
to settle, people to pay and to repay
those who had trespassed against you.

*I want the river to cover my head,
its tides to carry me when I am dead,*

But the high tide spoke, *Not you, not yet*,
and kept you on the edge.

Twin mirrors saved you from the waters.
Your face reflected in both your daughters.

My daughters and I acquired a secondhand computer, and I signed up for a distance-learning course. I was too ill to sit in a classroom, but could manage ten minutes at the computer. One of the exercises was to type a paragraph, save it, then open it again, make some changes and save a second version. No suggested text was given. I sat by the machine wondering what the hell to type. My thoughts were, ‘what do I have to write about? Who am I anyway?’ Then out of nowhere came my first poem.

The poems I wrote at that time came out of grief and misery, but also because writing poems suited my energy levels. The poems were short; I could draft one, longhand, without getting exhausted, at one sitting. I could type up the draft another day. This has remained my process since I started writing: a notebook for free writing and drafts, then onto computer later.

I never got any comments on the poems I sent to the course tutors; they were only interested in whether I had saved version 1 and version 2. Then, for the desktop publishing part of the course, I produced a pamphlet of poems and images. I took the pages to the printers at the end of my road, and asked them to collate and staple twelve copies, which I sent to friends and family. It was the first step to becoming a published poet, and later a publisher-poet. It was like a new vocation, a job. I got some lovely feedback, but some were not so pleased. My sister told me to stop upsetting people by sending them these poems. It was an early lesson in audience – who would want to read my work – and in using material from a shared past. It was also about secrets. We were told as children that we should not talk about certain things outside the house. I had broken the family code. I was speaking out and healing past hurts through writing.

Here is a writing prompt I learned from Patricia Debney, who later became my creative writing tutor.

I would like to write about...

But I am afraid to because...

Nevertheless I shall...

When I put this exercise to members of Kent Writing and Wellbeing Network, some were reluctant to write difficult personal material, even though this was not to be shared with the group. Others felt they could only approach this by means of metaphor. I remember holding back when writing a story based on the night before my first wedding. I showed a draft to an Arvon tutor. 'This girl is walking to her doom,' she said. 'She's sleepwalking into this marriage.' I burst into tears, said I couldn't write about it anymore, particularly as my daughters might read it and recognise the characters as their father and me. She urged me to 'unlock the door and look into the bloody chamber'. I did. I worked through the pain, wrote through it, and the story is now in my collection, *As Long as it Takes*.

The end result of cathartic writing does not have to be self-pitying and miserable. I recently attended an evening with the poet Martin Figura, performing *Whistle*. Martin Figura's father killed his mother when he was a child, and *Whistle* tells this story. The resulting poems are funny as well as moving; even the moment when his mother dies at his father's hands is dealt with so lightly that you barely notice it.

I do write straight memoir, but prefer to distil my experiences through fiction and poetry – I can write better outcomes, cast characters as better people than they actually were, or tell my truth in all its misery. Processing this stuff through writing is hard, but eventually I no longer feel the pain, and leave the readers to experience the feelings instead of me.

My father died a year into my illness. My role in the family had always been to act as a listener, an emotional sponge, particularly for my mother. She continued to make demands on me at this time, despite the fact that I was too ill to attend my father's funeral. It was time to shake free from the familial taboos and emotional blackmail that had constrained me all my life. I decided to separate from my family. Writing through these issues helped me to come to this decision.

I suffered tremendous guilt, at first; there was a pull to be there for my mother and siblings when I needed to look after my daughters and myself. I only remained in contact with my younger brother. The separation from my three other siblings lasted five years, and continues to this day with my mother. She cannot forgive me for becoming a different self, nor for speaking my truth. There is a poem called 'Story' in my collection, *strange fruits*. It is addressed to my mother. The final lines are, "I know this story; // it's yours not mine. I've stopped listening."

I know that my mother was grieving for the daughter I had been. Her love was conditional on me being well, pretty, clever, hard-working, successful, married, and in her words, 'No trouble at all'. She sees herself as the victim of a daughter gone bad. Whilst I understand this, it is hard to accept that she could only take from me, and is not capable of giving the love and support I need.

Writing is what brought my estranged siblings and I back together. I wrote and broadcast a column for BBC Radio 4's *Home Truths*, about growing up in an Irish family in England. I wanted my siblings to hear it, to share my success and to hear some of the better things about our childhood. I got in touch, one sibling at a time. None of them quizzed me as to why I kept away for so long, nor did they turn me away – it's not the family way to confront. I have a much better relationship with each of them than before the separation. I am my own person, no longer seen as how I relate to them.

Managing creativity with limited energy

I was brought up with a work ethic that's hard to shake. My dad was a builder's labourer; my mum was a nursing auxiliary in one of the large asylums in Epsom, built in the days when troublesome relatives were tucked out of sight in the country. My dad only got paid when he worked – there was no such thing as sick or holiday pay. I remember my mum taking to her bed only once; my dad never did.

Creativity was applauded, but not seen as a means to a living. Relaxation was often seen as being lazy; this included reading. As a child in my household, if you were seen 'lazing around' you were given something to do. As a teenager, I worked after school and on Saturdays in Woolworth's. I continued working throughout my O and A Levels, as well as having chores to do at home. I remember, even then, being exhausted – too tired to go out on a Saturday night to wear the new clothes I'd bought with my own money. Someone once told me that working class people work themselves to death.

I still find it hard not to be working, not to be economically active. I still think of myself as lazy, even when exhausted.

In the time since my illness began, I have strived to achieve. I have taken two part-time courses, and gained a certificate and an MA in creative writing, both with distinction. I was on Income Support and had to pay fees for both courses – I searched for charities that would help with bursaries, took out a Career Development Loan. I took small steps to work towards my goals. In the case of the first writing course, I waited a year until I could manage the energy to travel to college and sit in a classroom for two hours. I was also fortunate in winning a short story competition, run by the University of Kent, which paid half my fees for the first year of the certificate course. This was for the first short story I had written since leaving school.

I have also become involved in artistic projects, both solo and as a member of groups, including Medway Mermaids women's writing group, running poetry workshops, and organising an arts day in my village. In 2011, I set up a small press, Cultured Llama, with my second husband, Bob Carling.

At my best, I work sensibly:

- I take small steps, mind-mapping them. Mind-maps are less daunting than lists
 - I can pick a task rather than working through a list
- I find support. This can be practical, emotional, or sometimes telling people that I need concessions, as I had to do when studying for my MA.
- I work in small chunks of time

Old habits die hard, though:

- I work too long and too hard, leading to exhaustion and relapse.
- I don't look before I leap – I get great ideas and jump straight in, without thinking of the work involved, the financial implications and how my health will be affected.
- I fail to get support. Either by not asking for, or not accepting help
- I say yes to everything that is asked of me
- I become overloaded, withdraw from groups and further projects, and say no to everything.

But I have come up with a few helpful pointers:

- A to-do list with one thing on it
- Seeking and accepting help

- Remembering that I have a body as well as a head, and taking gentle exercise, eating well and resting
- Socialising – avoiding isolation, but not packing too many things in a week
- Helping other people, but not so I am left with no energy for my own writing
- Being selective about projects, organising and delivering courses and events

As a general rule, I take on one project every three months. Cultured Llama, the small press that I run with my husband, publishes four books a year, and there is a rhythm to my involvement in their publication, which allows me to work sensibly.

Once in a while, I make a list of writing commitments and stick them up by my desk.

Here are a few from my latest list:

- I shall write every day
- I shall not share my writing too soon
- I shall write what I like, not what others ask me to do
- I shall not allow my illness or ability to work as defined by others to cloud my true calling as a writer

Try making your own list of writing commitments.

When I worked around disability, I was often astonished by the achievements of people with limitations. Many were determined to do things that I, as an able-bodied person at that time, would not attempt. If you've always been an achiever, that doesn't go away, it just has to be managed within your limitations. It is ironic that Sally Evans, in a review of our press in *Poetry Scotland*, said, 'A huge amount of energy has gone into launching these new publications, and it has obviously come from Maria C. McCarthy.'