

MS: My Story

Helen Boden

In autumn 2014 I facilitated an 8 week course at the Multiple Sclerosis Therapy Centre Lothian. Up to then, the Centre had offered physical and complementary therapies but not counselling or creative activities. Having identified a clear need for the latter, project worker Louise Liddell set up a Writing for Wellbeing course, and MS: My Story was born.

And with it, a paradox: At their preliminary meeting with Louise, several prospective participants expressed their wish not to be identified with MS or their symptoms, and to be free to write about what they chose. For them, 'my story' was not limited to their experience of MS. However, we'd also planned a 'My Story' publication, an 'outcome' which would celebrate the achievements of the participants, inform others, and raise funds for the Centre. I designed the course with all this in mind.

Eight people signed up, three of them wheelchair users. Some preferred to type, some to handwrite, and some to use voice recognition software. Some already had creative writing experience, and had published memoir and poetry. Others – highly skilled professionals, unable to work because of their condition – hadn't previously had the opportunity or inclination to write creatively. My challenge was to attempt to meet all their needs: both to provide a grounding in creative writing techniques that they would be able to build on later if they wished; and the opportunity to tell their stories – with as much or as little 'MS' content as they chose.

After sessions using visual and textual prompts, and relaxation and breathing exercises; and before a concluding collaborative session, I inserted two classes specifically on life writing. I circulated in advance some excerpts from memoirs and autobiographies, although I was keen for these writers to tell their own stories in their own words and not be beholden to models. Indeed, I sometimes avoid using text prompts with Writing for Wellbeing groups: what can inspire one person can intimidate another, especially if they do not perceive themselves as having literary talent, or have had bad 'eng lit' experiences at school. So in this case I just invited those who wished to comment on, or ask questions about, the examples before we started writing.

As a warm-up exercise we did a five-minute free-write starting with 'I remember'. Next, Life

Lines: this involves making a literal personal time line. Ideally this is done on a large piece of paper – maybe a sheet of A3 per decade – with coloured pens, so that highlights and low points and other key experiences can be colour-coded. People can spread out and work on the floor if they wish. In this instance, there were two restrictions. First, our room was quite small. Initially, we met in the Centre's open plan group area, but this proved noisy when people were trying to think, write or read out their work. After a session in which I introduced Mindfulness techniques as a precursor to writing, and everyone became mindful of noise and disturbance, we asked to move to a more private, but much smaller, treatment room. This generally proved far more suitable for our work. Second, the clients' mobility problems meant that it was best for them just to work with / on the writing materials they were already using. Where such restrictions apply, it can be good idea to provide an example of the larger format work, especially if there are other contexts, e.g. at home, where they could make their own version. And, of course, the facilitator will need to be able to respond sensitively if anyone becomes upset that they are no longer able, say, to work on the floor with crayons.

We shared and discussed the 'lines' before I suggested a number of ways of generating writing from them. As at all of our two-hour sessions, attendees were encouraged, but not required, to develop their work between classes. Despite symptoms, and family and other commitments, 75% of this set did, which is probably the highest I've ever encountered for writing at home during a therapeutic course.

The suggestions included:

- Be yourself at a chosen age / life stage; or observe yourself in the third person.
- Write a letter to or from yourself at that life stage.
- Write a memory . . . which of the senses seems to be most dominant?
- Write about rooms you remember and clothes or accessories you remember, from different points in your life.

In the second explicitly autobiographical session, we started by hearing work written in the intervening week, as was now our custom, though it wasn't one I'd planned at the onset. This was viable and useful because of the way these particular clients committed to their writing. Then I invited them to re-name their life stages in a way that was personally meaningful, thinking about how these might look as chapter titles in an autobiography. Finally, I asked the question 'is there a recurrent theme or "dominant story" to your life?' We considered how far, or not, the MS story dominated each person's life.

Obviously, one can design a whole course around life-writing, working, for example, with objects and photos that relate to various points in a life. Due to time restrictions, I simply invited this group to bring in such an item to share in our closing session, where we also made a collaborative poem to celebrate the course. There's something to be said for compression, as well as expansiveness. It suits my style of facilitation. In this case, I wanted to give the clients a taster of a wide range of approaches, aware that not everything would appeal to everyone, and to honour their desire not to be defined by a set of symptoms, and to fulfil the brief to produce writing for a publication. I did wonder if I'd spent proportionately a little too long giving background information about the history of autobiography (originating in the religious confession; in more secular times often used as a vehicle for minority or marginalised people to make their voices heard) – especially given my previously stated reservations about the potential of models to inhibit rather than inspire individual expression. However, these were a highly able and intellectually curious set, and I hope I chose and delivered a course (in both senses of the word) appropriate to and for them. A lot of my Writing for Wellbeing experience has been in mental health settings, and with carers, where I'd take things more slowly. I think the most important thing is to remain attentive to the needs of any given client group and its individuals, and adapt where necessary – but not to shy away using creatively stimulating exercises originally designed for 'mainstream' client groups, suitably customised.

Contact me at helenboden@talktalk.net
helenbodenliteraryarts.wordpress.com

Move to resource lists – leaflet availability might be useful in later editions

Resources

Life story, Memoir and Autobiography:

Jean-Jacques Rousseau, *Reveries of a Solitary Walker* (1776-8)

James Joyce, *Portrait of the Artist as a Young man*

Stephen Spender, *World within World* (1951)

Audre Lorde, *Zami: A New Spelling of my Name* (1982)

Derek Jarman, *At Your Own Risk* (1992)

Example of course leaflet – Louise made a great wee advertising and descriptive leaflet, which could be used as an example of good practice? I'll fwd separately. You'll need her

permission to include. She's also written a conference presentation about her experience of the project – if this is in the public domain, it would be good to include a link to it.

I'm sure you've already got these listed . . .

Killick and Schneider, *Writing for Self-Discovery*

Nina Jackowski, *Write for Life*

Lapidus Scotland / Hidden Voices pdf

Manjusvara, *The Poet's Way*

Peter Sansom, *Writing Poems*

Paul John Eakin, *How our Lives Become Stories: Making Selves* (Cornell UP, 1999)

Elaine Scarry, *The Body in Pain*

Hunt and Sampson, *Writing, Self and Reflexivity*

Bolton et al, eds. *Writing Works*

Bell and Magrs, *The Creative Writing Coursebook*