

To the Last Breath
a workshop for nurses
working with persons with life-limiting conditions
by Sarah Whiteside

For a person with a life-limiting illness, getting in touch with what is meaningful in life can make all the difference to how suffering and loss are experienced. Exploring meaning, a person has the chance to regain a sense of hope, even in the midst of debilitating disease, and even when facing death. Coming to see that this is the case, we used a recent invitation to facilitate a workshop for a group of Macmillan nurses to explore themes of hope and meaning further. We thought we would share something of the session here; a lot of what emerged has to do with creative uses of words and we hope that this will resonate with creative writing practitioners working in a range of settings.

When people suffer, it's tempting to focus on what's wrong and try to fix it. Sometimes this is a good idea! However, not all suffering is fixable and, more importantly, the pain and loss patients experience are never the whole story. Our job – as non-medical practitioners working in a medical environment – is, at least partly, to keep in mind the wider context of a person's life. This is not about ignoring suffering. It is about recognising that a person is bigger than his or her symptoms. Nothing is denied, but there's always the invitation to articulate a bigger story.

During the Macmillan workshop, we used Cicely Saunders' concept of 'total pain' as a theoretical background to aid discussion¹. Total pain describes that toxic mix of physical symptoms, emotional distress, social losses, and loss of hope that can entrap people at the end of their lives. It is a truism that to remedy total pain requires 'total care'. Our work in palliative care invites us to go more deeply into the complex and multi-layered losses that illness can bring and in doing so to help people reconnect with inner resilience, creativity and wisdom.

¹ Saunders, C. (1995) *Living With Dying: A Guide to Palliative Care*. 3rd Ed. Oxford: OUP.

We began by discussing with workshop participants what kinds of things give each of us hope, assuming that our own experiences would tend to reflect those of patients. This is the list we came up with:

- Having an impact
- Singing
- Appreciating our lives
- Small things that make a big difference
- Normality
- Happiness despite suffering
- Humour
- Courage
- Friendship
- Trust
- The attitude we take to our lives

In our work in palliative care, a person may want initially to talk about current difficulties, troubling symptoms and fears about the future. Given time and space, though, he or she often begins by find a way to talk about the wider context, which is likely to include reflection on what is good in life and may also include an engagement with life meaning. This is a creative process that seems to happen naturally. Often it feels like making explicit what is, on some level, already known. Our task is to facilitate the process by listening and by expressing curiosity, making connections and drawing out themes, as well as suggesting appropriate creative art forms to contain what is said. At its best this can feel like collaboration, with our roles as patient and professional becoming less important than our shared humanity.

During the Macmillan workshop, we asked participants to talk in small groups about things that give meaning to their lives and between us we turned these into a poem:

Things that Matter

Family, family, family
family and friends
a happy family –
loved ones and memories.

Being individual
being mindful
being uninhibited
beekeeping.

Enjoyment of nature
especially April showers.
Enjoyment of the arts.

Taking time out
ease, reflection
being loved.

Climbing hills
real and imagined.

- things that mattered to participants
at the Macmillan Study Day,
Copthorne Hotel, Aberdeen,
22nd May 2014

We hoped that giving a form to the different ideas that emerged from the discussions would help participants to see them more clearly. Similarly, in our work with patients, life writing and storytelling allow people to reflect on and celebrate their lives, while poetic images, symbols and metaphors can help them clarify ephemeral ideas and feeling states.

We all narrate our lives, to ourselves and to others. *I'm this kind of a person. I like these things. This is what scares me. This is what happened when I was five.* Often we repeat old stories, reinforcing them with each retelling. Bringing consciousness to our words – telling them, seeing them on the page, or hearing them read back to us – can take us outside habitual territory towards an immediacy

of feeling and a new way of seeing things. At a first meeting it's not unusual for a person to say that she's had an ordinary life and doesn't have much to tell; it can be very moving to see a this perception start to change.

The psychiatrist Irvin Yalom talks about this change in his book, *Staring at the Sun*². He suggests that we introduce the concept of 'rippling' to patients who struggle with regret or emptiness at the end of life. He says: 'the belief that one may persist, not in one's individual personhood, but through values and actions that ripple on and on through generations to come can be a powerful consolation to anyone anxious about his or her mortality'. This approach invites patients to consider the positive effects their lives have had on the lives of others. The idea that we leave something, even beyond our knowing, that bears an imprint of our good actions can be a powerful antidote to the experience of total pain. Telling the stories of our lives can help us to see the ways we have affected others; and giving our stories to loved ones in written form is itself a form of rippling

Towards the end of life there's a real opportunity, it seems. Because time is short, there is often a more than usually pressing need to reflect on life, as well as to celebrate and enjoy it. There may be a sense of 'now or never', but it's also that there's no longer any reason not to – pretence is at an end. It's common for the people we work with to take the risk of trying something new – picking up a paintbrush, writing a poem, or finding a new way to see or say a thing. The fact that person after person is willing to take the risk of going into the unknown like that – at a time when energy is often low, physical symptoms troublesome, and life uncertain – is testimony not only to the importance of creativity *in extremis*, but also to the resources we find within, just when we need them.

Sarah Whiteside is a writer. Kathy Kindness is a clinical psychologist. They both work in palliative care in north-east Scotland. sarahwhiteside@nhs.net

² Yalom, I. (2009) *Staring At The Sun: Overcoming the Terror of Death*. London: Piatkus.