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Cancer and chronic illness: A brief report

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This brief report provides an annotated bibliography and narrative perspective on poetry therapy resources for working with people living with chronic illness (physical and/or mental).

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Working with people who are facing life and death issues calls us to bring all of ourselves—our courage, presence and compassion—into facilitating writing, reading and listening together. The obvious is also true: such work can show us perhaps more than we always wish see, more about our own stuck or broken places when it comes to confronting deep loss, hard change and long mourning.

For the past 2 years, I've facilitated poetry therapy sessions in two major hospitals, at retreat centers, for support groups, and one-on-one with individuals just facing diagnosis or starkly seeing recurrence of their cancer. I have also moved through my own cancer story in living through breast cancer, chemotherapy and three surgeries, and in losing my father to cancer. Like many of us committed to poetry and poetry therapy, the experiences and perceptions we have replenish the well of what we can offer others. It also brings unexpected gifts: the vivid glimpses of being fully alive, the flashes of terror or pools of sadness that are part of the healing process, the strength we can witness in others that mirrors some of our resources.

Yet I see that the particular poetry prompts and writing exercises, while extensively valuable in helping people find their words and voices, are a small part of what I need to continually cultivate as a facilitator:

- how to be present with such painful and wordless moments;
- how to continuously open my heart to really be a good witness to people reading their words or talking of how another's words affected them.

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In other words, the lessons that continually unfold in the life-long art of facilitation bring their own goodness.

I offer this annotated bibliography of resources not so much for writing ideas, but as a way to help facilitators work with people living with severe mental illness, chronic illness or any serious limitation. Some of these books may not seem like the usual suspects in facilitating poetry therapy, but I find them immensely valuable in bringing to our groups our greatest capabilities.

Summoning compassion, being present

Over the last 20 years of facilitating groups, I have learnt what many good facilitators of such groups already know: so much depends on paying attention. To that end, the work of Pema Chodron, a Tibetan Buddhist nun, has been extremely helpful to me, both in my life and in the workshops I lead. *When things fall apart: Heart advice for difficult time* (Chodron, 2000), *Start where you are* and *The places that scare you: A guide to fearlessness in difficult times* (Chodron, 2001) are of particular value when it comes to learning more about how to wake up into the moment, be one with what comes to us, and continually soften and open our hearts.

Chodron writes often of cozying up gently with what scares us or hurts us in life, and then befriending whatever we feel, in the process cultivating greater compassion for ourselves and others. While she advocates meditation as the training for the warrior of the heart, she also points toward continual practices of loving-kindness, joy, compassion and equanimity. Most of all, she writes of groundlessness or the in-between state, that moment when what we thought was solid in our world falls away—a state all-too-familiar to someone who has heard that she has a terminal disease or that it has returned, or that there is no clear path to remission:

> Anxiety, heartbreak, and tenderness mark the in-between state. It's the kind of place we usually want to avoid. The challenge is to stay in the middle rather than buy into struggle and complaint. The challenge is to let it soften us rather than make us more rigid and afraid. Becoming intimate with the queasy feeling of being in the middle of nowhere only makes our hearts more tender. When we are brave enough to stay in the middle, compassion arises spontaneously. (Chodron, 2001, p. 120)

Groundlessness is also part and parcel of working with people living in the in-between state. There is no clear sense of how to proceed, what to say, how or what to fix. Yet being present, serving as a witness for whatever people living with serious illness are facing, imbues the room of the workshop or consultation with a sense of respect, caring, acceptance. Just being a witness can help a person making a huge adaptive change in their life enter more fully into that change.

Another Buddhist writer, Sharon Salzberg, has several books on cultivating loving-kindness in ourselves and our work. Her newest book, *Faith* (2003), speaks most to the qualities I find it necessary to grow in ourselves as poetry therapists

working with difficult situations. In this part-memoir, part-guide, Salzberg, a long-time meditation teacher, speaks of the importance of helping people enhance their own sense of faith. Salzberg writes, 'The therapist's love can nurture healing, but it is our faith in that possibility that impels us to show up and take each new step into the darkness' (p. 16).

In writing about her own horrendous childhood, and her struggles through losses of loved ones and illusions, she concludes about what we can learn from being present with the sorrows and suffering we encounter, in ourselves or in our writing groups:

> Our passion, our joy, our calm and our confidence are all rooted in this offering of our hearts to an expanded vision of who we truly are and the love and awareness we are capable of. With this understanding, we don't have to approach our suffering as though cut off from love and the pulsing of life. We can remember that suffering doesn't have to close us down and lead us into despair . . . Holding this vision, we can emerge from whatever suffering we encounter, not broken and embittered, but with an ever-replenishing wellspring of unwavering faith. (Salzberg, 2003, pp. 172–173)

Another important source is the work of Stephen on Ondrea Levine, Buddhist teachers who have extensive experience working with people with terminal illness. *Who dies? An investigation of conscious living and conscious dying* (1989), called 'the bible of the conscious dying movement' by *Harper's Magazine* and praised by Elisabeth Kubler-Ross, was particularly valuable to me in better understanding (beyond what experiential understanding I had) the loss of control, loss of dreams, loss of a future that many people with advanced stage cancer or other serious illness must face. The book is full of meditations, reflections, true stories, and other ways of knowing and sharing end-of-life possibilities—all in the name of showing up with all of ourselves and paying attention to what happens.

The right balance of hope

A new book, Jerome Groopman's *An Anatomy of Hope* (2003), tells of tending hope from the point of view of a Harvard Medical School professor and oncologist with 30 years' experience. What's particularly valuable in this book for a poetry therapist is how Groopman illustrates the problems caused by trying to instill too much hope (to the point of leading the patient toward unrealistic expectations that take the patient's power away from him or her) and the problem of being too negative about the disease. While poetry therapists aren't in the business of assessing anybody's survival percentages, Groopman's exploration shows us the importance of choosing poems open enough for our clients to find the right balance of hope for their lives on their own terms.

Studs Terkel, always an inspiring oral historian, looks at hope as well as faith in *Will the circle be unbroken? Reflections on death, rebirth and hunger for a faith* (2002).

Like many of Terkel's other books, this one is a collection of oral histories, many of which cut across class, race, religion (particularly important here), sexual orientation, illness and addiction, and other great divides in American culture. One thing Terkel does better than just about anyone is to really highlight the class differences in this country, and how class shapes our mindsets, expectations, abilities to hope and find meaning, and even what kind of hope and meaning we find. However, this book also reaches out beyond meaning to explore the lives of people who had lost children needlessly (as it would always be in such losses), or people who had simply come to the ends of words and faith, and yet, through the interview process, found them anyway. Reading it surely enlarges our capacity to glimpse a wider human experience.

In helping our clients or workshop participants glimpse their own human experience more fully, there are several anthologies on living with cancer that are particularly provocative and empowering. *The Cancer Poetry Project: Poems by cancer patients and those who love them*, edited by Karin B. Miller (2001), is composed of stirring poems, evoking the fear and uncertainty, and also the hope and love of living with cancer. The poetry, by cancer patients and their loved ones, are also categorized into easy-to-access sections: accepting a new body, accepting death, angle, celebration, understanding and compassion, coping and perseverance, denial, facing death, fear and desperation, grief, hope and joy, and questioning. This is an invaluable source for someone diagnosed with cancer or interested in working with the cancer community.

The Cancer Monologue Project, edited by Tanya Taylor and Pamela Thompson (2002), came from these actresses' passion for helping people create monologues of their experience for themselves, their family and community. Topics people wrote about ranged from honoring the body as a temple to experiencing cancer as a physician. Many people wrote of the trauma of receiving their diagnosis, fear of treatment and hope for the future. This collection gives us another model for helping people find their words and share those words with others. Finally, it illustrates what Groopman discussed about finding the right balance of hope—a hope not buried in denial or despair.

Entering the life of another

Memoir is probably the quickest route, short of personal experience, or sitting someone down and having them tell you their life story over many weeks, to learn what it is to live with serious illness. The memoirs below are just a small sampling of what's out there, but each conveys an inside-out view of what it means, one moment at a time, to get through the days and nights with a life-threatening illness.

Dawn Nelson's *Making Friends with Cancer* is a remarkable book, unlike anything else I have found when it comes to studying cancer treatment and reading cancer stories. Nelson, an expert in therapeutic touch with the elderly, advocates that what people with serious illness must do most is make friends with the enemy, just as she did with her very serious ovarian cancer. In addition to a well-told story about

undergoing surgery and chemotherapy, and lessons on building a strong support system around her, Nelson over and over again makes the case for us to embrace what grabs hold of us, and transform it and ourselves in the process. Her bottom line is that making friends with cancer, or any serious challenge, means practicing forgiveness and gratitude in every action. This book also challenges us to give up the conventional ways we talk about cancer and cancer treatment (using war terminology such as 'fighting cancer'), and find new language and greater healing.

Despite the odd title, *Mom's Marijuana*, written by Dan Shapiro (2001), a professor of integrative medicine and psychiatry, is one of the most marvelous and life-affirming memoirs I have encountered. Shapiro, who faced cancer as a teenager, plus two more recurrences, writes with great compassion and insight about what it is to live with a life-threatening disease as a teenager, a young man, a newly-wed and a father (he ends up marrying one of his nurses). He is brilliant at exploring the effects of cancer on the family and various communities, including the academic and medical communities. He conveys so effectively the effects of harsh treatments, including some of the fiercest chemotherapy of the time. The title, which comes from his mother's growing of marijuana to help him with the side effects of chemotherapy (when he first underwent treatment, some 20 years ago, the drugs to control nausea weren't as advanced as they are now), also alludes to the lengths people will go to for love (his parents generally abhorred all drugs).

Marion Woodman's *Bone: A journal of wisdom, strength and healing* (2001), combines journal entries with quotes and reflections, taking the reader on a tour through Wood's spiritual core as she copes with cancer in her physical core (uterine cancer). Woodman, one of the foremost writers of mythology and healing, collages together ways of writing about, and seeing fear and loss, including diagnoses of the cancer being terminal (later refuted by another doctor), as well as yearning and hope as she makes her way through the medical maze and emotional hinterlands. The writing is riveting, and the story compelling, especially how she draws on great writers (Emily Dickinson, William Blake), great art and great spiritual traditions to give her sustenance. As Blake writes and Woodman quotes, 'No bird soars too high if he soars with his own wings'. This memoir gives me a great view of how some people soar, and what gives them height and grace. It's a marvelous illustration of how writing—and keeping a journal—can strengthen healing and there's plenty here to bring into workshops.

For a witty and whimsical ride through the valley of death, there's Joni Rodgers' *Bald in the Land of Big Hair* (2002). Rodgers' story of going through chemotherapy in Texas was funny, but it also was a strong piece of writing with regard to dismantling some of the myths about cancer and serious illness, as Rodgers tells story after story of doing it all her own way. Her message, most of all, encourages cancer patients to make their own choices with their eyes open. As she writes:

> I advocate life. I recommend joy. I endorse forgiveness, and I suggest you seek until you find whatever it is you need, be it straight allopathic medicine, alternative methods, or mulligan stew. Because the oncologist

> and everyone else from priests to pathologist—they're just Ground Control. You're Major Tom.

This book is a wonderful tool for reaching people who find any of the more touchy-feely approaches to discuss cancer off-putting and I can see using excerpts of this in the future.

Finally, there is a wonderful collection of autobiographical essays by Nancy Cobb (2000)—*In lieu of flowers: A conversation for the living*, in which Cobb reflects on moments of great transition, including the deaths of her parents, friends, the child of a friend and other losses. She also looks at many ways of dying and their effects on the living—her mother dies slowly in a nursing home, her father (after he is diagnosed with Alzheimer's) commits suicide, a close friend dies from cancer, a child of a friend dies in an accident. What stays with me the most, though, was the wise advice about palliative care and what actions can honor a person in death, as well as help the survivors to go on surviving: talking about what's happening, giving everyone space and support, providing small, but important sensual pleasures to the dying and the surviving, finding spiritual support through the loss, and taking into account the mysteries of the grieving process and how individual this process always is.

In all these memoirs, and surely many others, some of the psycho-oncology we could read about in studies and reports is rendered human: the stories each writer tells makes the risks and the revelations real. As poetry therapists, reading and hearing such stories surely helps us not just to know more about what to expect when working in the cancer community, but how to pay attention and be good and true witnesses, as humans who have faced or will face serious losses, and as poetry therapists helping people to reflect on, and read and write about what it truly means to be alive.

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Editor's Note

The *Journal of Poetry Therapy* includes reviews of books of interest to poetry therapists. Of special interest are thematic poetry anthologies that deal with personal issues and experiences, as well as books about any aspect of the therapeutic use of literature and writing. Please note, however, that chapbooks and self-published poetry books will not be considered. To be considered for review, books should be sent to: Charles Rossiter, PhD, C.P.T., Book Review Editor, *Journal of Poetry Therapy*, 705 S. Gunderson Ave, Oak Park, IL 60304, USA (E-mail: ccrossiter@juno.com).