

From narrative wreckage to islands of clarity

Stories of recovery from psychosis

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Postmodern times may be pandemonium, but they are not a void. Illness stories provide glimpses of the perfection.

Arthur Frank¹

Medicine is a narrative art based on science. Narrative training, according to Dr Rita Charon, a general internist with a PhD in English, improves clinical skills in medicine. Charon defines narrative medicine as “medicine practised with narrative competence, that is, the ability to acknowledge, absorb, interpret, and act on the stories and plights of others.”² As family doctors, we *act on* the narratives presented to us daily by patients, their families, and other health care team members.

The late Dr Miriam Divinsky, family physician, wrote in the February 2007 issue of *Canadian Family Physician*, “Stories offer insight, understanding, and new perspectives. They educate us and they feed our imaginations. They help us see other ways of doing things that might free us from self-reproach or shame. Hearing and telling stories is comforting and bonds people together.”³ Narratives of recovery from psychosis can also be disturbing and awakening.

Narrative medicine has interested me for the past several years. I have twice attended the amazing international interdisciplinary conference, Narrative Matters, held in Canada, and I traveled to Columbia University in New York, NY, in 2003 to attend a world-class colloquium on narrative medicine hosted by Charon.⁴ Most recently, I immersed myself in the literature on narrative in order to better understand a critical issue in my best friend’s family life—a daughter with psychosis. As a medical practitioner, I am not alone in doing so.

An article in the *Globe and Mail* told the story of how his son’s illness spurred Dr John Roder, a researcher at the University of Toronto in Ontario, to shift his own scientific research from cancer to schizophrenia.⁵ The diagnosis devastated the Roderes. “You have hopes and dreams for your kids and they don’t include schizophrenia,” said Maria Roder, Nathan’s mother.

“At the center of narrative ethics is the wounded storyteller. What is ethical is found in the story, and the story depends on the wound.”¹ Personal illness stories or those of a close friend or relative describe the wound. Dr Rachel Naomi Remen writes of her life with Crohn disease:

My illness has been one of the great forces in my life, ... the inner process of illness rather than the outer process of cure. I realized that this search for healing that was awakened in me also was awakened in others when they were challenged with a disease. It is this search that has driven my career. Not healing just for me—because something just for yourself is hardly worth pursuing—but healing for us all.⁶

Remen, physician, medical educator, and Clinical Professor of Family and Community Medicine at the University of California San Francisco School of Medicine, is the cofounder and Medical Director of the Commonwealth Cancer Help Program.⁷ She believes doctors need to reconnect with story to transform health care systems into healing systems. “Story,” according to Remen, “is one of the most potent containers for meaning.”⁶

Arthur Frank, a professor of sociology at the University of Calgary in Alberta and a survivor of both cancer and myocardial infarction, writes:

Becoming seriously ill is a call for stories in at least two senses. ... Stories have to repair the damage that illness has done to the ill person’s sense of where she is in life, and where she may be going. Stories are a way of redrawing maps and finding new destinations. ... The second and complementary call for stories is literal and immediate: the phone rings and people want to know what is happening to the ill person. Stories of the illness have to be told to medical workers, health bureaucrats, employers and work associates, family and friends. Whether ill people want to tell stories or not, illness calls for stories.¹

Narrative is ubiquitous, omnipresent, and inescapable. Nowhere is this call more critical than in the struggle to understand, support, and heal those who have been diagnosed with psychosis. The diagnosis cuts to the heart of story itself: psychosis is a disruption in the balance of body-mind-environment; “profound narrative disruptions”⁸ result in a lack of coherent life narrative. In short, psychosis is narrative wreckage.⁹

Stories of recovery from psychosis

Psychosis involves a combination of an individual’s unique genetic, neurologic, psychological, and environmental factors. The course varies widely and fluctuates, often

with cycles of remission and relapse. Recent research indicates that about two thirds of those affected will recover or substantially improve with treatment (which includes both medication and psychosocial approaches).

Recovery is an arduous biological, psychological, social, and spiritual journey—a gradual process of restoring connections and health. It is a personal process of growth and change that typically embraces hope, autonomy, and affiliation as elements of establishing satisfying and productive lives in spite of disabling conditions and experiences.¹⁰

Significant recovery is a real possibility. Recovery is a natural process that can occur gently in a sane, healthy environment and can be fostered through authentic relationships. ... Recovery is facilitated only when a genuine sense of friendship is fostered among caring people, both staff and clients. Recovery requires community. A healing community is one that promotes the well-being of each of its members.⁹

What is the inner process for healing from a psychotic illness? Many aspects of illness can be known only from direct experience. The narratives of those who have recovered from psychosis come from voices not often heard. Like chronic pain, psychosis is often a silent, inner, and invisible experience that leaves observers guessing.

"Recovery-focused psychotherapy ... calls for a non-hierarchical dialogue in which clients are not supplied with a narrative but assisted in creating their own."¹¹ Processes of re-authoring one's life story are actually integral components of recovery itself.¹²

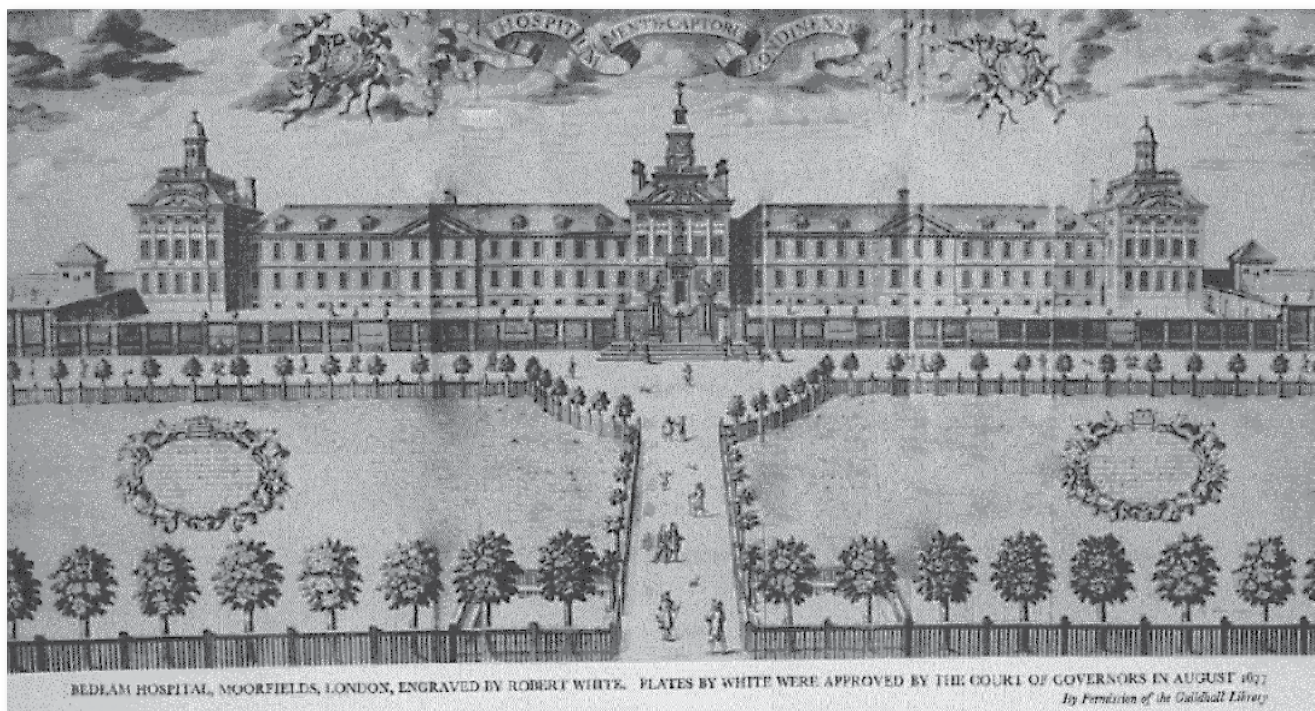
It is important for people recovering from psychosis, their caregivers, and their loved ones to appreciate the narrative aspects of recovery:

As wounded, people may be cared for, but as story-tellers, they care for others. The ill, and all those who suffer, can also be healers. Their injuries become the source of the potency of their stories. Through their stories, the ill create empathic bonds between themselves and their listeners. These bonds expand as the stories are retold. Those who listened then tell others, and the circle of shared experience widens. Because stories can heal, the wounded healer and wounded storyteller are not separate, but are different aspects of the same figure.¹

Empathic healing from psychosis happens in support groups and family meetings as well as through creative writing or other arts.

"Disease interrupts a life, and illness then means living with perpetual interruption. ... Telling an interrupted life requires a new kind of narrative. ... The stories are uncomfortable, and their uncomfortable qualities [are] all the more reason they have to be told. Otherwise, the interrupted voice remains silenced."¹ Narrative ethics and politics involve deciding whose voices are heard or not heard.

Arthur Frank described 3 main type of illness narratives: the restitution narrative, the chaos narrative, and the quest narrative.¹ Restitution involves a sickness which fully resolves, leaving the person "good as new." The chaos narrative is the opposite of restitution; it has no order and provides no answers. It



provokes anxiety in its revelation of vulnerability, futility, and impotence in the face of suffering. Finally, quest narratives meet suffering head-on. "They accept illness and seek to use it. Illness is the occasion of a journey that becomes a quest. What is quested for may never be wholly clear, but the quest is defined by the ill person's belief that something is to be gained through the experience."¹ Something transformative (learning or personal growth) happens through this type of illness story, even if healing is impossible.

First-person narratives of life before, during, and after psychosis are compelling and can inform treatment and recovery. The following 2 stories of recovery from psychosis involve aspects of both restitution and chaos; yet, ultimately, they are quest narratives. The first story is from published journal accounts of John Perceval⁹ who lived in the 19th century, while the second is taken from the writing of Dr Patricia Deegan, alive today.

Perceval's courage

John Thomas Perceval lived from 1803 to 1876, the son of a prime minister of England. His 40-year struggle with insanity showed that recovery was possible. Placed in an insane asylum against his will at the age of 29, Perceval single-handedly saw through his illness during the first year of his hospitalization. Although not released for another 2 years, he later devoted his life to telling the truth of recovery. He kept a daily journal of his experience and published it, providing an in-depth understanding of a psychotic mind.

Before his illness, Perceval had been an upper-class gentleman, described as moral, humourless, prudish, and austere. After experiencing a spiritual crisis, he renounced daily life for a life of prayer, study of the prophets, and fasting. He became obsessed with religious doctrine, experienced fits of depression because of visions of the destruction of the world, and left the military to pursue religious studies at Oxford. He was involved in a religious sect, which led to a mind-altered state and a mental implosion with command hallucinations.

In the asylum, Perceval was put in a strait-jacket in a small room with a guard; such forced restraint caused his condition to become worse. He longed for fresh air, and it took him many years to forgive this harsh treatment. He also endured bloodletting, physical brutality, and ice baths. In spite of the hopelessness, humiliation, and despair felt in his dismal life at the madhouse, Perceval reported powerful flashes of indestructible intelligence and moments of clarity and freshness. He described in detail how he

worked with his mind to become more insane at first, then later, less so. Nightmare, hellish qualities of his experience included visions, voices, spirits, rapidly streaming thoughts, and mental processes solidified. He felt desynchronized from the outside world, possessed, confused, and chaotic. He recognized cycles of confusion in his own mind: "in short, he discovered that wildness of thought and disordered sensations together create hallucination, but only when one enters into dialogue with [them] does one become truly insane."⁹

Perceval discovered that recovery from psychosis was possible with effort and courage. Moments of recovery, delight, and confidence were occurring all the time, sudden islands of clarity in the midst of oceans of psychosis. One at a time, the voices gradually weakened and stopped. It took tremendous willpower: "Keeping my head to my heart and my heart to my head."⁹ He found that fighting against the delusions created new delusions. He developed insight into his mind and the strength to face his delusions in order to cut through them; he learned to say no to internal fascinations. He renounced emotional attachment to the voices and took command of his thoughts.

The presence of other people helped cut down Perceval's self-absorption. He also found that cultivating environmental awareness helped him "come to." Noticing that he and others were stripped of humanity in the asylum awakened compassionate outrage in him; his allegiance shifted toward health, with interest in food, exercise, and religion. The awakening of compassion was a crucial turning point in his recovery. He kept his journal hidden. He was finally released from the madhouse at age 31, after relentlessly badgering the authorities. He moved to London to recuperate, feeling fragile, ragged, and worn out. He later married and had 4 daughters. He recalled his vow, the mainstay of his recovery, to break the system of madhouse care, the "villainy, cruelty and tyranny of the doctors."⁹ He wrote and studied reform of asylums. Few could speak for the insane, analogous to those in concentration camps.

Perceval founded and for 20 years led the Alleged Lunatics' Friend Society for former patients or their relatives; this marked the birth of the patient advocacy movement. He worked diligently and sowed seeds for later reform. He reconciled with his family, whom he had resented for having placed him in the asylum. He lived to age 73. Perceval said, "I open my mouth for the dumb, who simply cannot speak for themselves."⁹

Patients making "personal medicine"

Like Perceval's mission, Patricia Deegan's lifework involves telling the truth of recovery. "It is important to understand that for most of us recovery is not a sudden conversion experience ... recovery is a process, a way of life, an attitude, and a way of approaching the day's challenges. It is not a perfectly linear process. At times, our course is erratic and we falter, slide back, re-group and start over again."¹³

Deegan is a psychiatric survivor, first diagnosed with schizophrenia as a teenager. She spent 5 years at home on a couch smoking cigarettes. She later received her doctorate in clinical psychology from Duquesne University in Pittsburgh, Pa, in 1984. Deegan is an activist as a user of mental health care, as a survivor, and in the ex-patient movement and is cofounder of the National Empowerment Center Inc, a federally funded, national technical assistance organization run by consumers and survivors in the United States. She is also an independent consultant and speaker, specializing in developing training and lectures on the concrete application of the concepts of recovery and empowerment. She has traveled and lectured widely.

Deegan writes about the importance of "personal medicine," meaning those activities, interests, and personal strengths that give life meaning and purpose and that serve to raise self-esteem, reduce symptoms, and avoid unwanted outcomes, such as hospitalization.¹⁴ Personal medicines for the daughter of a friend were playing rugby and playing guitar. Deegan observes that, when psychiatric medications interfere with nonpharmaceutical personal medicine, patients often fail to adhere to treatment.¹⁵ Deegan also speaks about mentalism, the oppression of people who have been diagnosed with psychiatric disorders. Like other kinds of oppression, mentalism occurs at cultural, systemic, interpersonal, and personal levels.¹⁴ Stigma from others as well as self-stigma abounds.

Deegan also speaks of the positive power of relationships. She wrote the following in the Recovery Journal on her website:

I have had the privilege of interviewing many people about their journey of recovery. One of the most consistent themes ... in these recovery narratives is the importance of relationships. Relationships are the cornerstone of the recovery process for most people. Relationships that are marked by kindness and compassion can heal.... In a culture steeped in the

belief that there is a "pill for every ill," it can be important to remind ourselves of the healing power of human relationships.¹⁴

She noted elsewhere:

We do remember that, even when we had given up, there were those who loved us and did not give up; ... they did not overwhelm us with their optimistic plans for our futures but they remained hopeful despite the odds. Their love for us was like a constant invitation, calling us forth; ... the miracle was that gradually ... I began to hear and respond to this loving invitation.¹³

Remen has also identified the need for community:

[T]o recognize community as a healing tool ... seems obvious now, but this idea was seen as pretty radical and crazy years ago. I remember being told in medical school that we should discourage patients from meeting and talking to each other about their diseases and experiences because they will frighten one another and share misconceptions and inaccurate information. Of course, just the opposite is true; ... people heal each other. And they heal each other in very powerful and simple ways—by listening, accepting, believing, caring, and understanding what it's like to live with a serious illness. By healing the loneliness that robs us of our strength.⁶

Deegan also mentions John Perceval on her website:


We can and often do direct our own recovery. From a historical perspective there are many examples of this. One need only read the story of John Perceval's recovery in the early 1800's. In this fascinating first person account of self-directed recovery we learn of the wide variety of coping strategies that Perceval discovered in order to find his wellness. Among other strategies his voices taught him a form of meditation in which he attended to his breathing.¹⁴

Deegan's current projects include researching a recovery-based approach to using psychiatric medication at the University of Kansas, developing recovery-based competence for mental health practitioners, helping to restore forgotten cemeteries at state hospitals, and helping consumers win money for new housing through the sale of state hospitals.

Sailing to islands of clarity

“Sanity is always present even within psychosis. Moments of insight, common sense, or compassion continually interrupt mental turbulence. These experiences, however brief, are like awakening from a dream. They are ‘islands of clarity’ that must be recognized as the seeds of recovery.”⁹

Themes in recovery from psychosis, such as stigma, discrimination and loss, islands of clarity, healing relationships, and community, are universal and apply in the context of many illnesses and recovery journeys. Unconditional love and acceptance; loving care and commitment from family, friends, and professionals; plus genuine support and caring and true compassion are the necessary vehicles on this personal path. A deep sense of belonging and a sense of community restore personal and social connections. Psychosis is a small part of who a person is; there is a need to accept oneself as, and to be accepted by others as, a person who exists beyond the psychosis—a whole person in a physical and social environment.

We are in danger of losing the story of medicine, and that it is a way of life. Our story is about compassion, service, and integrity. About kindness to all and a reverence for all life. About love. It is a very important story for our time. We are trading that story for the story of science. That’s not a good trade. It is not a trade that can sustain us and our commitment to the world in which we live. Just as people with cancer need to know their story in order to find meaning in their struggle to be whole, we need our story in order to find meaning in ours. We need to stay connected with who we are and what matters.⁶ 

Dr Gold is a family physician in Halifax, NS.

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None declared

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For further reading

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