

BOOKS *et al.*

MEDICINE

The picture of health

A new series of graphic novels features intimate portraits of illness

By Arthur W. Frank

That a major university press would publish a series of graphic novels may come as a surprise to those who think of these works as comic books on steroids, offering plots about superheroes to younger readers. This image of the graphic novel became definitely outdated in 1986 with the publication of Art Spiegelman's second-generation Holocaust memoir, *Maus: A Survivor's Tale*. *Maus* won a Pulitzer Prize, was the subject of a show at New York's Museum of Modern Art, and has been translated into 50 languages. The next most acclaimed graphic novel might be Alison Bechdel's *Fun Home*, published in 2006, which inspired a musical currently enjoying an extended run on Broadway. Bechdel was a 2014 winner of a MacArthur "Genius" Award.

Within the graphic-novel genre, first-person accounts of both illness and clinical practice are an established subgenre. The new "Graphic Medicine" series, launched this spring by Pennsylvania State University Press, not only provides another publication outlet for such works but also lends them greater legitimacy. That counts when, for example, clinicians recommend books to patients or when assigned readings are being selected for health humanities courses. All of which brings us to the two books under review: What are they about, for whom are they written, and how



A strained relationship takes on new depth when a son moves in with his ailing father in *Things to Do in a Retirement Home Trailer Park*.

The reviewer is professor emeritus in the Department of Sociology, University of Calgary, Calgary, AB T2N 1N4, Canada. E-mail: arthurwfrank@gmail.com

Downloaded from www.sciencemag.org on November 19, 2015

might such books change the ways that health care research is practiced?

Aneurin Wright grew up in the American west, where *Things to Do* is set. Like *Maus* and *Fun Home*, *Things to Do* is a family drama. The story begins when Wright's father, who has emphysema, breaks the news that he has been certified by his physician for hospice care. Wright is not sure what "hospice" means but soon gets the message: His father is expected to live for less than six months. Wright decides to move in with his father, caring for him until he dies. Father and son have a troubled history together. The story is about their reconciliation, the progress of a terminal disease, issues of home care, and, ultimately, death itself. Writers from Simone de Beauvoir to Philip Roth have written about their parents' deaths; a research literature on palliative care abounds. What can graphic novels do, distinctively, with this material?

Reading *Things to Do*, I felt I was going through an experience with a real person, not a clinical or social-scientific typification of a person. That person reacted differently than I think I would, but I was brought close enough to the experience to feel how I might react and measure that against what Wright does. That does not, in itself, distinguish *Things to Do* from first-person prose accounts. The graphic-novel medium allows the reader to experience flashbacks, fantasies (such as stamping out a neighbor who has a particular talent for saying the wrong things), dreams, and distortions of reality that make the narrator's point of view compelling. We see both Wright—or his drawn avatar—and what Wright sees and imagines. The reader is both spectator and participant in Wright's frustrations and in his eventual sense of having done something of great value.

We readers care for Wright, the avatar narrator, because we care with him, and we care with him because the images in his head become our images. We share his struggles to care for a father who in the past has been at least threatening and perhaps abusive and who remains difficult to care for in the present. Eventually, we share Wright's sense of loss that manifests as both a feeling of liberation from the work of caring and a void that leaves Wright in need of care himself.

In the end, a serious joy pervades *Things to Do*. In my decades of reading the hospice and palliative care literature, I cannot think of a single book that would be a better companion for family members beginning on this particular work of caring. The book is equally valuable for home-care health workers, whom Wright depicts

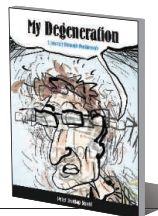
Things to Do in a Retirement Home Trailer Park ... When You're 29 and Unemployed

Aneurin Wright
Pennsylvania State University Press, 2015. 320 pp.



My Degeneration: A Journey Through Parkinson's

Peter Dunlap-Shohl
Pennsylvania State University Press, 2015. 106 pp.



as vivid characters, each doing his or her work with dedication and expertise.

Peter Dunlap-Shohl's *My Degeneration* is a shorter book, less ambitious in its existential themes than *Things to Do*, but a model of how to fill a particular niche. The book is an extended and more engaging version of the patient-information booklets given out in clinics and support groups. We learn some elementary neural chemistry, how the drug Sinemet works, and when it fails. We learn about deep brain stimulation, what it achieves, and its limits. But unlike educational booklets, such information is contextualized within a highly personal story. Dunlap-Shohl was an editorial cartoonist with the *Anchorage Daily News*,

a position he apparently had to give up because of his illness, diagnosed when he was 43. He has now been living with Parkinson's for more than a decade.

Like *Things to Do*, *My Degeneration* is written for both patients and clinicians. In one of the funniest segments, Dunlap-Shohl presents a series of drawings of bad doctors: "the gimlet-eyed skeptic" who accuses her patient of making up his symptoms, the "cheery prophet" who forecasts inevitable physical decline, "the blithe know-it-all," and several more. For patients, these irreverent archetypes validate their experiences. Clinicians, too, stand to gain a better appreciation of how they might appear to their patients.

The narrative line in these books is often fragmented, incomplete, alternating between surreal fantasy and reality. That is how life is experienced. The books under review reconfirm my belief that personal accounts of illness—both prose and graphic—should provide the starting point and benchmark for what academic health research aspires to say about the experience of illness. More immediately to those who are ill and who work to care for the ill, these books are companions that will both validate and challenge ways of acting and reacting. I hope copies of both will become fixtures in clinical settings and in health care education.

10.1126/science.aad5288



Parkinson's disease gets personal in Peter Dunlap-Shohl's *My Degeneration*.

CREDITS: (FACING PAGE AND RIGHT) COURTESY OF PENNSYLVANIA STATE UNIVERSITY PRESS