

The publication of this booklet was made possible through the generous support of Community CarePartners, Thoms Community Care Foundation and the University of North Carolina at Asheville. All photographs and personal narrative in this publication are copyrighted and may not be reproduced or stored in any form without the express written permission of the authors, Heidi Kelley and Ken Betsalel. Information regarding republication and/or exhibition of photographs can be directed to the authors at:

Liberal Arts Learning & Disability Services
CPO #1930 • UNC Asheville
One University Heights
Asheville, NC 28804-8508

E-mail: hkelley@unca.edu · Phone: 828/251-6980



That the mind's fire may not fail.
The vowels of affliction, of unhealed not to feel it, uttered, transformed in utterance to song.

Not farewell, not farewell, but faring

— Denise Levertov, epigraph to Naomi Shihab Nye's **Fuel**

s an anthropologist, I was used to observing, not being observed. As a teacher, I was used to explaining, not being the object of explanation. On August 29, 1998, I experienced a massive stroke, leaving my right side paralyzed and leaving me totally aphasic, utterly speechless. Since then, I have had to fashion "a whole new life." I was a cultural anthropologist and Director of International Programs at the University of North Carolina at Asheville. I made frequent trips to Galicia, a region of Spain where I did my fieldwork. I traveled to England, France, and Ecuador, and to conferences all over the United States and England. All that has changed.

Now, I speak slowly and walk with a cane. When I am brimming over with ideas (or tired or angry), my motor planning suddenly gets short-circuited. But, there is a sense where my life did not change. I am still a cultural anthropologist. In fact, my anthropological training also accounts, along with my age, for my rapid progress. I view my stroke as another culture to which I need to adapt. Specifically, my training in medical and psychological anthropology lends me the ability to see my experiences abstractly and see with empathy what other people must be going through.

Our exhibit is about our long journey through my rehab, through my stroke. My husband, Ken Betsalel, who also teaches at UNCA, took the photographs. I view our exhibit as a chance to educate other people about stroke, rehab, courage, love, and the need for community. Our

exhibit, our story, is not about overcoming my stroke, or even coming to grips with my stroke. We titled our exhibit *Mind's Fire*, from Denise Levertov's poem *F*, because it is about the powers of the imagination. It's about educating others about stroke. It's about healing other stroke survivors and using the mind's fire to heal "vowels of affliction," transforming them into song.

This photographic diary opens up with a picture of me taken in Paris six weeks before my stroke. The last photograph shows me attending a rally in support of the Americans with Disability Act in Washington, D.C., in October 2000. In between, the diary illustrates many of the different therapies I used, from the conventional to the more alternative. It shows me in a moment of despair—we wanted to demonstrate that stroke recovery isn't all smiles and sunshine. It shows me at home practicing my mouth exercises in a mirror and playing a word game with my stepson, Simon. Finally, it shows me back to work in my office, helping students, and in the classroom, teaching again.

I would like to thank my family, my friends, my therapists, everyone else involved in my recovery, and my husband, Ken Betsalel, for taking the photographs, for being such a loving person (at least, most of the time!), and for nagging me gently to write my story. This version of my story is only a beginning.

--- Heidi Kelley



A café in Paris, summer 1998, before my stroke



"In the depth of winter I finally learned that within me there lay an invincible summer."

— Albert Camus —



Working with occupational and physical therapists and other staff at Thoms Rehabilitation Hospital













"Two souls are serving each other, honoring each other, mirroring each other's hearts."

— Ram Dass —





Occupational therapy— working on small motor skills





Speech therapy at Thoms





Practicing speech therapy at home



Adjustments at home





Neuromuscular Developmental Technique (NDT) workshop at Thoms





Aquatic therapy at Thoms 🔻





Integrative therapy





Acupuncture





▼ Dr. Kuai: "Don't hurry!"









Multiple sclerosis yoga workshop





▲ Playing a word game with stepson Simon

"Yet we can't wait for the undamaged to make our connections for us; we can't wait to speak until we are wholly clear and righteous. There is no purity, and, in our lifetimes, no end to this process."

--- Adrienne Rich ---





▲ Preparing for disability studies seminar

Back at work 🔻





Meeting with students





Students learning about disability





▲ Seminar on "The Culture and Politics of Disability" (Photo by Marilyn Ferikes, one of our students)

"What counts is to be in the world, the posture is immaterial." $\label{eq:world}$

— Samuel Beckett —





At a rally in support of the Americans with Disabilities Act (ADA), Washington, D.C., October 2000

A long the way to my recovery, Ken and I learned that we were not alone. There is a beautiful, proud, resilient — and at times even defiant — disabled community out there! The following is a short list of books and Web sites we found useful in thinking about disability and disability culture:

Simi Linton, Claiming Disability (New York: New York University Press, 1998).

Nancy Mairs, Waist-High in the World (Boston, MA: Beacon Press, 1996).

Robert Murphy, The Body Silent (New York: Henry Holt & Company, 1987).

Joseph P. Shapiro, No Pity (New York: Random House, 1993).

Disability Social History Project

http://www.disabilityhistory.org/dshp.html

Center on Human Policy

http://soeweb.syr.edu/thechp/chp.htm

Disability World

http://www.disabilityworld.org/

Western Alliance Center for Independent Living

http://www.westernalliance.org

Heidi Kelley is a cultural anthropologist who teaches at the University of North Carolina at Asheville, where she also serves as Director of Liberal Arts Learning and Disability Services. **Ken Betsalel** is currently Chair of the Department of Political Science at UNCA. Together they teach a course entitled "The Culture and Politics of Disability."

Did you know...

Every 53 seconds, someone in America has a stroke. Every 3.3 minutes, someone dies of one.
 At least 700,000 people suffer a stroke each year.
 Stroke is the number three cause of death in the U.S., behind heart disease and cancer.
 Stroke is a leading cause of severe, long-term disability.
 North Carolina is number two in stroke deaths in the country.
 Strokes kill twice as many women as breast cancer.
 Risk of having a stroke increases after the age of 55.
 Incidence rate for first stroke among African-Americans is almost double that of white Americans—288 per 100,000 African-Americans, compared to 179 per 100,000 whites.
 About 4,400,000 stroke survivors are alive today — just over half are women

Resources for more information on stroke

Thoms Rehabilitation Hospital 828	-274-2400, ext. 6235	www.thoms.org
Mission St. Joseph's Stroke Team	828-213-6163	www.msj.org/neuro_stroke.html
Community Stroke Support Groups for Sur	vivors & Caregivers	828-213-6163
American Stroke Association	1-888-4-STROKE	www.StrokeAssociation.org
National Stroke Association	1-800-STROKES	www.stroke.org
The Brain Attack Coalition	301-496-5751	www.stroke-site.org
International Clinical Educators, Inc	1-888-665-6556	www.StrokeHelp.com