

## Independent Living - What is it?

**I**ndependent Living is a phrase attached to many things of vital interest to people with disabilities today. It is associated with programs and centers, legislative acts and grant money, information and services. However, first and foremost it represents a movement and a philosophy.

At the core it is an expression of civil rights for people with disabilities. Judy Heumann of the Berkeley Center for Independent Living wrote in 1977, "To us, independence does not mean doing things physically alone. It means being able to make independent decisions. It is a mind process not contingent upon a normal body."

In 1978 this philosophy became part of American law with the addition of Title VII to the Rehabilitation Act of 1973. This title was called "Comprehensive Services for Independent Living" and authorized federal grants to support Independent Living Centers. The goals of such centers are: to help persons with disabilities to live as independently as possible; to maintain the highest level of functional independence as possible; to live as fully integrated into the community as possible, and; to live each day in the same manner as nondisabled persons of the same age and background as much as possible.

Today there are Independent

Living Centers (ILC) in every state and they offer broad and valuable services to every family living with disability. In addition, ILC's are different from many other service organizations because people with disabilities are substantially involved in the decision making, management, and service provision of the center. This emphasis on control by people with disabilities stems from the belief that consumers know best what services and supports they and others in similar situations need.

Centers can have many names and are frequently also referred to as Centers for independent living or CILs). Most CILs are private, nonprofit corporations that provide services to maximize the independence of individuals with disabilities and the accessibility of the communities they live in. Anyone with a disability is eligible for the services of a CIL. Centers are funded, in part, by the U. S. Department of Education. A complete list of all CILs can be found on the internet at [www.ilru.org](http://www.ilru.org).

### Core Services

The core services of centers for independent living include:

**Information and referral** - Centers maintain comprehensive files on locally available accessible housing, transportation, employment, personal care

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## My First Installment

*by Jeffrey Weisel*

So I packed everything essential into my '76 Nova and left. It wasn't so hard, being a change-liner. I was intrigued to be landing in Boston and the open arms of friends I barely knew. I never could have intuited from my free-floating state that I was about to seek out the friendship/partnership that would define my service and sustain my life for the next eleven years. Nothing other than my enslavement to educational institutions has lasted so long.

Tom has muscular dystrophy. Not poetic. But the effort to co-create a quality of life worth living has offered more moments than can be noted. For a personal care attendant and a man whose abilities have been physically reduced to electronic devices via voice and a two-way chin switch, there have been a steady flow of enlightening moments. And all the power outages, emergency room visits, doctors' appointments, life threatening illnesses, long nights, triple, even qua-

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**INSIDE**  

FROM THE CENTER

RESOURCES

FROM OUR READERS

**Spring 1999**

It is no coincidence that Judy Heumann's definition of independent living, cited in the article in this issue, was given in 1977, the same year the Information Center for Individuals with Disabilities was incorporated, after a period as a pilot project. Information empowers those of us with disabilities that compromise our performance of routine, daily tasks in self maintenance and social participation. Nor is it a coincidence that Judy Heumann was involved early in the Independent Living Movement and disability political activism, and now she is Assistant Secretary of Education in the Clinton administration.

While it often appears that the heroes of the Independent Living Movement are all Californians like Judy (a New York transplant), Massachusetts has also been in the independent living vanguard, and we have our own set of IL superstars. Fred Fay, the political activist and recent Betts Award recipient, gives new and contradictory meaning to the term "home-bound;" Fred was in on the founding of the Boston Center for Independent Living, the first CIL in the eastern United States. His Justice for All listserve has in recent years made him a national presence. You could say that Fred is the highest embodiment of the IL concept, influencing national politics from a prone position in his Concord home.

Other local IL heroes also include Elmer Bartels, long-time "Commish" of the Mass. Rehabilitation Commission and, Dr. Paul Corcoran, an innovator in medical rehabilitation who both were in on the founding of BCIL with Fred. But *every* person with a disability, maintaining himself/herself outside an institution, is an IL hero! Whether the disability involves mobility, sight, speech, hearing, thinking, learning, or the psyche, it 'ain't' easy to survive in a world designed by and for able-bodied, able-minded people. But, as we get out there and demand accommodation, that world will become more user-friendly for all. Where there's a ramp beside a set of steps, almost everyone uses the ramp!

Not only does Massachusetts have ten IL Centers, we have a personal care assistance program that has long led the nation in its emphasis on consumer control and in access to PCA services. The Commonwealth program allows working persons with disabilities to "buy into" Medicaid coverage and thus qualify for the PCA services that the private insurance coverage offered by employers never covers. PCA services, now more politically correctly termed personal assistance services (PAS), are at the very heart of independent living, providing assistance with whatever personal and social tasks we simply can't do all by ourselves. **(Ed. PAS will be the main subject of our next newsletter.)**

The IL Centers are grassroots, nonprofit organizations that operate on a membership basis. You should consider getting involved with your local ILC/CIL as a member and/or as a volunteer. Maybe "independent living" would better be termed "interdependent living," because we all us need some kind of help at some time, and we all have something to give back to others. The name of that game is Life, and each of us needs to "get a life." Independent living, or interdependent living is the winning strategy. Read about it here.

*Ray Glazier, founding Trustee, wheelchair user, disability policy researcher at Abt Associates Inc., Cambridge, MA Nature Made*

## Medicare Savings for the Quick

If you act quickly you may take advantage of a new federal program, known in Massachusetts as the MassHealth Buy-In Program, that will pay for your Medicare Part B premium which costs \$45.50 per month. The program will not cost you a penny, if you are accepted, but the number of people who can get into it is limited - so act now.

If you: 1) have Medicare; 2) have a monthly income between \$708 and \$947 for an individual or between \$943 and \$1,245 for a couple, and; 3) have assets (excluding your home) of less than \$4,000 for individual or \$6,000 for a couple - you may qualify.

To apply for the MassHealth Buy-In Program, call the MassHealth Enrollment Center, toll-free, at 1 (888) - 665-9993 (voice) or 1 (888) 665-9997 (TDD), and ask them to send you a MassHealth Buy-In Application.

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President: Nancy C. Schock  
Editor: J. Archer O'Reilly III

# Independent Living Centers, Programs, and Services in Massachusetts

## Independent Living Centers

According to the federal definition, independent living centers (ILCs) are community-based, consumer-controlled, and cross-disability nonprofit organizations that provide independent living services and advocacy to persons with disabilities. Information referral, peer counseling, skills training, and individual and systems advocacy are available through all ILCs. For more detailed information about services offered, please contact one of the local ILCs listed below.

### Ad Lib

*Serves: Berkshire County*

215 North Street, Pittsfield, MA 01201

(413) 442-7047 (Voice); (413) 442-7158 (TDD); (800) 232-7047/MA (Voice/TDD)

*/also/* 85 Main Street, North Adams, MA 01247

(413) 662-2650 (Voice/TDD)

### Boston Center for Independent Living

*Serves: Boston and Metro - Boston area*

95 Berkeley Street, Suite 206, Boston, MA 02116

(617) 338-6665 (Voice); (617) 338-6662 (TDD)

### Cape Organization for Rights of the Disabled (CORD)

*Serves: Cape Cod area and the Islands*

1019 Iyannogh Road (Rt. 132), Hyannis, MA 02601

(508) 775-8300 (Voice/TDD); (800) 541-0282 (Voice/TDD)

### Center for Living and Working

*Serves: Central Massachusetts*

484 Main Street, Suite 345, Worcester, MA 01608

(508) 798-0350 (Voice/TDD)

*/also/* c/o MRC, 100 Medway Road, Suite 102, Milford, MA 01757

(508) 473-2271 (Voice); (508) 798-0350 (TDD)

*/also/* 76 Summer Street, Fitchburg, MA 01420

(978) 345-6331 (Voice); (978) 345-1568 (TDD)

### Metrowest Center for Independent Living

*Serves: Ashland, Dover, Framingham, Holliston, Hopkinton, Natick, Needham, Sherborn, Sudbury, Wayland, Wellesley, Weston*

63 Fountain Street, Suite 401, Framingham, MA 01702

(508) 875-7853 (Voice/TDD)

### Independence Associates

*Serves: South Shore and Cape Cod*

10 Oak Street, 2nd Floor, Taunton, MA 02780

(508) 880-5325 (Voice/TDD); (800) 649-5568 (Voice/TDD)

### Independent Living Center of the North Shore & Cape Ann

*Serves: North Shore and Cape*

### Ann area

27 Congress Street, Salem, MA 01970

(978) 741-0077 (Voice/TDD)

*/also/* 298 Washington Street, Gloucester, MA 01930

(978) 283-4000

### Northeast Independent Living Program (NILP)

*Serves: Northeastern Massachusetts*

20 Ballard Road, Lawrence, MA 01843

(978) 687-4288 (Voice/TDD)

### Southeast Center for Independent Living

*Serves: Fall River and New Bedford area*

170 Pleasant Street, Fall River, MA 02721

(508) 679-9210 (Voice/TDD)

### Stavros

*Serves: Hampden, Franklin, and Hampshire counties*

691 South East Street, Amherst, MA 01002

(413) 256-0473 (Voice/TDD); (800) 804-1899/MA (Voice/TDD)

*/also/* 262 Cottage Street, Springfield, MA 01104-4002

(413) 781-5555 (Voice/TDD)

*/also/* Hayburne Building, 55 Federal Street, Room 210, Greenfield, MA 01301

(413) 774-3001 (Voice); (413) 772-2556 (TDD)

### Independent Living Programs and Services

There are many organizations throughout the state that do not fit the strict federal definition of independent living centers (for instance, they are not cross-disability, serving only a single disability population) but do

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# Independent Living Programs in Massachusetts

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provide many independent living services. The following is a list of independent living programs, as well as organizations that offer independent living services and state agencies (indicated by \*) that can direct you to independent living programs or services.

## **The Arc of Cape Cod**

*Serves: Persons whose primary disability is mental retardation, on Cape Cod*

171 Main Street, P.O. Box 428,  
Hyannis, MA 02601

(508) 790-3667

## **The Arc of Franklin County**

*Serves: Persons whose primary disability is mental retardation, primarily in Franklin County*

111 Summer Street, Greenfield,  
MA 01301

(413) 774-5558; (800) 343-5558

## **Charles River Association of Retarded Citizens - Community Living Program**

*Serves: Persons whose primary disability is mental retardation, in the Newton/South Norfolk area*

P.O. Box 920169, Needham, MA  
02492

(781) 444-4347

## **D.E.A.F., Inc.**

*Serves: Individuals who are deaf or hard of hearing, from any language background, primarily in the Greater Boston area*

215 Brighton Avenue, Allston,  
MA 02134

(617) 254-4041 (Voice/TDD);  
(800) 886-5195 (Voice/TDD)

*/also/* 154 Water Street, Danvers,  
MA 01923

(978) 762-4735 (TTY only)

*/also/* 105 Grove Street,  
Middleboro, MA 02346

(508) 947-5402 (Voice/TDD)

*/also/* 105 Williams Street, Room  
25, New Bedford, MA 02740

(508) 990-1382 (Voice/TDD)

*/also/* 184 North Street, 3rd  
Floor, Pittsfield, MA 01201

(413) 447-8135 (Voice/TDD)

## **Department of Mental Health \***

*Serves: Individuals anywhere in Massachusetts who have any kind of mental illness*

25 Staniford Street, Boston, MA  
02114

(617) 727-5500 (Voice);  
(617) 727-9842 (TDD)

## **Massachusetts Commission for the Deaf and Hard of Hearing \***

*Serves: Individuals anywhere in Massachusetts who are deaf or hard of hearing*

Administrative Office and  
Eastern Massachusetts Regional  
Services, 210 South Street,  
Boston, MA 02111

(617) 695-7500 (Voice);  
(617) 695-7600 (TDD);  
(800) 882-1155/MA (Voice);  
(800) 530-7570/MA (TDD)

## **Massachusetts Commission for the Blind \***

*Serves: Individuals anywhere in Massachusetts who are legally blind*

88 Kingston Street, Boston, MA  
02111

(617) 727-5550 (Voice);  
(800) 392-6450/MA (Voice);  
(800) 392-6556/MA (TDD)

## **Massachusetts Rehabilitation Commission \***

*Serves: Individuals with disabilities, anywhere in Massachusetts*

Fort Point Place, 27-43 Worm-  
wood Street, Boston, MA 02210

(617) 204-3600 (Voice/TDD);  
(617) 204-3868 (TDD);  
(800) 245-6543/MA

## **Minute Man Arc for Human Services**

*Serves: Persons whose primary disability is mental retardation, in Acton, Bedford, Concord, Littleton, Maynard*

1269 Main Street, Concord, MA  
01742

(978) 371-1543

## **Renaissance Club**

*Serves: Persons with chronic mental illness, in Greater Lowell*

176 Walker Street, Lowell, MA  
01854

(978) 454-7944

## **South Norfolk County Association of Retarded Citizens/Lifeworks**

*Serves: Persons whose primary disability is mental retardation, in Canton, Dedham, Foxboro, Medfield, Millis, Needham, Newton, Norfolk, Norwood, Plainville, Sharon, Walpole, Wellesley, Weston, Westwood, Wrentham*

789 Clapboardtree Street,  
Westwood, MA 02090

(781) 762-4001 (Voice/TDD);  
(888) 339-0239

*The Information Center has available a current Fact Sheet on Independent Living Programs in Massachusetts which may be requested by writing to the Center at P.O. Box 750119, Arlington Heights, MA 02475.*

*A complete list of Independent Living Centers across the United States, as well as other related information, can be found on the internet at [www.ilru.org](http://www.ilru.org).*

# The Information Center's Annual Appeal for Your Support

*To make more effective use of our limited resources, and of your valued contributions, we have elected to include this appeal in the newsletter. This saves us printing, and mailing costs which we can devote to more important services. We hope our loyal readers will understand this choice and take no offense.*

Dear Valued Friend;

People working at and for the Information Center for Individuals with Disabilities are pleased to report to you that we are making substantial progress in restoring the Center's service, and are again asking for your support.

Thanks to the generosity of hundreds of contributors who are providing financial support, and the dedication of volunteers who have taken on the tasks necessary for carrying out our mission, we have been able to reestablish our regular quarterly publication of **Disability Issues**. Our thousands of readers continue to find the contents of **Disability Issues** useful and informative, and are sending messages of appreciation in increasing numbers. Many who live or work with disability are offering to contribute articles which are pertinent and enlightening. We make the publication available, without charge, to everyone who requests a copy.

In addition, we have established a task force to make our web presence truly effective and it is planning to add to the website our newsletter articles; our fact sheets, which are prepared responses to frequently asked questions; and annotated connections to other sources of information. This service will be available for individuals with disabilities, their families, friends, and the dedicated professionals who serve them.

We are currently an entirely volunteer-run organization with no paid staff, so all our resources go into information services. Although we are not yet able to receive or process telephone requests for information, we are responding, as our volunteer resources allow, to written requests. It is our expectation that, as our fund raising successes increase, we will begin to phase-in responding to calls for information and assistance. The need continues to be very great.

Recently, we received donations from the Bushrod Campbell Foundation, and from the volunteers at Symmes Hospital. These funds are helping us pay for supplies, mailings, and general operating expenses. We do continue to need additional support from you.

Will you be kind enough to consider a contribution of \$100, \$50, \$25, \$10 or whatever you can afford to help us move forward. Thank you for considering our request.

Sincerely  
Nancy C. Schock President

**Yes, I want to help the Information Center continue to provide services to the community of people living with disability.**

Enclosed please find my tax-deductible contribution of \$ 100 \_\_\_\_, \$ 50 \_\_\_\_, \$ 25 \_\_\_\_, \$ \_\_\_\_\_ .

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_, State: \_\_\_\_\_ zip: \_\_\_\_\_

Make check payable to: **Information Center**  
and mail to Information Center, P.O. Box 750119, Arlington Heights, MA 02475

Please send us the names and addresses of any friends or colleagues who would enjoy **Disability Issues**. We will be very happy to add them to the mailing list.

## Coping with Disability

by Benjamin J. Cantor

There are millions of Americans suffering with disability of one form or another. However, they all have one thing in common, i.e. moments of depression. The question is how can they cope with or overcome these periods of melancholy?

### Plan

One way is to anticipate each day, e.g., make a plan or schedule of things to keep occupied with, keeping so busy that there is little time to give heed to one's disablement. With a scratch pad and pencil next to the bed, one can jot down any things that come to mind which should be added to the next day's agenda. It may be that the schedule is so full there is isn't time to finish all the things planned. That is fine! The trick is to be involved with so many activities that, even if they create other problems, one's handicap, or disability, takes a "back seat."

### Hobby

Another way of coping - with whatever handicap one may have - is to have some sort of hobby. One of my hobbies over the years has been collecting funny cartoons, jokes, riddles, and unusual photographs. When friends or relatives visit, I show my "humor album" and we have a helluva time. I have found that humor gives one an opportunity to look at the comical side of life - which many of us fail to do - and allows us to wear a cheerful countenance and convey a smile to others.

### A Smile

- A smile costs nothing, but gives much. It enriches those who give it. It takes but a moment, but the memory of it sometimes lasts forever.
- None is so rich or mighty that s/he can get along without it, and none is so poor that s/he cannot be made richer by it.
- When people are too tired to give a smile, give them one of yours. No one needs a smile as much as s/he who has none to give.
- It can perk up the weary, bring cheer to the discouraged, sunshine to the sad, and is nature's best antidote for trouble.
- Yet it cannot be bought, begged, borrowed, or stolen, for it is something that is of no value to anyone until it is given away. \*

### Cheer

I have learned that if you want to cheer yourself up, you should try cheering someone else up.

Those of us with disabilities should promise ourselves to be so strong that nothing can disturb our peace of mind.

### Support Group

To cope with the many problems affecting them, people with disabilities will find joining a support group a great help. It offers the opportunity to talk with others, to share experiences, feelings, and suggestions, and to grapple effectively with one's disability.

\* *Source is unknown*

*Benjamin J. Cantor is cofounder of the Boston Area Ataxia Support Group and a reader of Disability Issues.*

## Nature Made Accessible

by Ray Glazier & Celeste Andrade

The Broadmoor Wildlife Sanctuary owned and operated by the Mass. Audubon Society in Natick has just opened a quarter-mile trail designed especially for persons with disabilities, including wheelchair users and those with visual impairment. As the trail's first wheelchair tripper, I was really impressed with the 8' wide well-packed path with its 4' wooden rail on one side and a 4" lip on the other; our party of 5 enjoyed the experience without falling over each other. The trail was conceived by Broadmoor's Director Elissa Landre to make the nature experience accessible to all. Five years in the planning and one year in habitat-friendly construction, the new trail was built at a cost of \$300,000, funded by members and donors.

What really blew this writer away was the experience of being out over the marsh on the trail's 500' boardwalk, right there among the dragonflies, frogs, and turtles, and a few inches above the water lilies. For an old Ohio boy who misses hiking through the woods. This is a place I'll want to return to in every season (except in rain or snow) in order to relax from the exigencies of independent living.

Broadmoor is on Route 16, just west of Wellesley College. The Nature Center is super accessible, including the bathrooms. The sanctuary is open from 9:00 to 5:00 Tuesdays through Sundays. There is HP parking in the level lot, paved with packed crushed stone. The experience is free to Mass. Audubon members, and costs \$3.00 per person for non-member adults and \$2.00 each for seniors and children.

# Independent Living - What is it?

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attendants, interpreters, recreation and much more. Also the personal experiences of staff with disabilities enhances the information available. If you are away from home and need disability related information, the nearest CIL is always a wise place to begin.

**Independent living skills training** - Centers provide training courses to provide skills required to live more independently. These may include using public transportation, managing a budget, dealing with insensitive behavior of the public, supervision of personal care providers, and much more.

**Peer counseling** - Through a center, a person with a disability can work with others who are successfully living independently with their disability in the community. The ability to exchange ideas and work out options and opportunities with others who have managed the same or similar challenges is

an important resource for individuals dealing with disability, particularly if the situation is new or evolving.

**Advocacy** - Centers provide two types of advocacy: Individual advocacy which involves staff working with persons with disabilities to obtain support services from other agencies in the community, and; community advocacy which involves staff, board members, and volunteers initiating efforts towards change in the community to make it easier for all persons to live independently. These efforts for change may affect legislation, policy, housing, business, transportation, health care, employment opportunity, access or any other issue affecting the lives of people with disabilities.

As the Independent Living movement has taken root over the past twenty plus years, a number of independent living-like programs have been developed outside of the official CILs. Therefore, if you, or someone you know, needs the kind or support and services described above and you do not have a nearby CIL or it does not offer exactly what you need, there may be another organization or state or local agency offering similar programs. Some of the independent

living like programs in Massachusetts are listed elsewhere in this issue and may give you ideas for where to seek the same in your community.

Centers for Independent Living in many states have taken an active role in the advocacy for and management of Personal Assistance Services (PAS). Where a CIL is involved, the person seeking PAS contacts the CIL and skill trainers perform an assessment to determine eligibility. If eligible, skill training is provided to help the person with a disability in areas necessary to manage the PAS system. Once completed, the center processes the application for services. The user of the services finds, hires, trains, supervises and, if required, fires their own PAs. If necessary, a surrogate may be used for these functions if they are outside the capacity of the consumer. If your local CIL is not providing all or part of this service, they should be able to refer you to the appropriate resource.

Regardless of the type of disability which affects you or your family, an independent living center is always a good resource for connecting you to services and to the disability community in your area.

Subscriptions to **Disability Issues** are available to all who find this publication useful and interesting. There is no fee, however, contributions to help defray the cost ensure the future of our efforts. Your tax-deductible donation, in whatever amount you can manage, will be greatly appreciated, and put to good use.

**Please send *Disability Issues* to:**

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Make donation checks payable to the **Information Center**  
P.O. Box 750119, Arlington Heights, MA 02475-0119

# ***Information Center***

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## **Memory**

*by Carl Grenier*

Re: How Technology Can Help with Memory and Organization (*DI Vol. 19, No. 1*) - I feel some of the solutions are too costly for someone in my income range. I have found an inexpensive way to have my "reminders." It was by accident after I had the Bell Atlantic Voice Mail installed that I went into other personal options. There are several features included. Reminder options can be set up to 30 days in advance. You send yourself voice notes to remind you of appointments, medication times, wake-up, etc. You can also send programmed messages to other people to remind them.

## **Accessible Trail**

*by Tom Schock*

If you like to walk in the country, there's a trail you may want to check out. It's called the "Battle Road Trail" and is part of Minuteman National Historic Park. The trail meanders through 5.5 miles of wooded areas, marshes, and farms in the towns of Lexington, Concord and Lincoln, Massachusetts.

I've been on the trail several times and really enjoy it. I was very pleased that I could easily

access such attractive countryside from my wheelchair. The trail allowed me to get close to nature more easily than any other trails I've tried. In my estimation, the trail would be accessible to almost all wheelchair users. The surface is dirt mixed with fine stones. It is uneven in a few spots. I wouldn't recommend that wheelchair users travel along the trail when it is very wet because you could get stuck in the mud. As yet, there are no rest rooms.

For those interested in history, the trail follows the road the American militia used during the battles of Lexington and Concord in 1775. The trail is dotted with buildings dated from before the American Revolution. The Minuteman Visitors Center and restored Hartwell Tavern are located along the trail.

Minuteman National Historic Park is located 22 miles west of Boston. Take Rt. 2A West, Exit 30B off I95/Rt. 128. For more information call (978) 369-6993 or (781) 862-7753 or e-mail [mina\\_info@nps.gov](mailto:mina_info@nps.gov).

## **Installment**

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druple shifts (even more, sometimes!), girlfriends, cat chemotherapy, home redecoration,

Christmas shopping, therapy groups, videos, backgammon, arguments, old westerns .... I think the greatest light has arisen in our heart of hearts.

I've heard the tale of a fully physically disabled adult, then heard it again, and yet again. He has needed to share it as much as he has needed to heal it. With acceptance being one of the most important healing strides, especially when living with what is presently still an incurable, progressive congenital condition, I've tried to commit to being present from the first morning bathroom run to bedtime toothbrushing. I've challenged myself to continue in a fresh way when I throb with boredom and my low back threatens an attack. It helps to remember that Tom never gets a day off. And while my mind and body may occasionally ache, I almost never doubt my usefulness and purpose.

Recently I reduced my hours to part-time to allow for exploration and variety. Tom and I understand each other and I have nothing to prove. Even though I've needed a change, I have no plans to leave. There are moments that the last eleven years feel as if they were merely the first installment.

*Jeffrey Weisel is a veteran PCA*