



Designing Solutions for Aging in Place

Part 1: Boothbay's Awesome Seniors' Initiative—First Year

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NETTING IT OUT

We all know that the demographic trend is inexorable. We—the human species—are living longer and getting older. This trend is particularly evident as the huge bubble of baby boomers moves through our “retirement” years in developed countries. I believe that the next twenty years will reshape our economy and spawn many new services designed *by and with* people who want more control over the quality of their lives as they age.

There are big business opportunities as well as huge economic costs associated with our aging demographics. Government organizations, non-profit organizations, and for-profit entities are all investing in tailoring services for our rapidly aging population. What many designers of services for seniors aren't paying enough attention to, is that it will be the seniors themselves who will drive the transformation of how and where people will live and thrive as they age; not their adult children, nor the many non-profit and for-profit corporations that are busily designing and evolving products and services for seniors.

On a rural peninsula, in coastal Maine—which happens to be home to the most elderly population in the U.S.—a group of “Awesome Seniors” are trying to design their own affordable solutions to help them age gracefully in place, while contributing to their community.

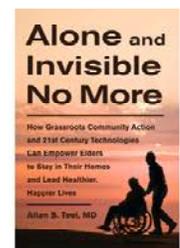


June Phillips

SENIORS DESIGNING SERVICES FOR SENIORS (& OTHERS)

Awesome Seniors Thriving in Place Design Team

Inspired by Dr. Alan “Chip” Teel, the author of *Alone and Invisible No More*¹, who a talk in Boothbay Harbor in October 2013 about how to help elders thrive in their homes, group of local seniors decided to form an “Elder Empowerment” committee to coordinate



¹ See my book review: [Customer Co-Design for Elder Independence: Approach for Elders to Age in Their Homes](http://dx.doi.org/10.1571/br06-14-13cc), by Patricia B. Seybold, Customers.com Press, June 13, 2013, <http://dx.doi.org/10.1571/br06-14-13cc>

Direct link: <http://dx.doi.org/10.1571/cs12-04-14cc>

existing senior services and to design new services for themselves and for others on the Boothbay peninsula in midcoast Maine. One of the compelling points that Chip Teel made in his speech and in his book is that if you harness all the brain power of all the seniors in any region, you will have an organization that probably has more manpower than the largest company in that region.

This committee, which soon dubbed itself the “Awesome Seniors,” consists of about 30 seniors, ranging in age from 65 to 97. Twenty-five of these seniors are year-round residents on the Boothbay peninsula. Five of them are seasonal residents (they live here for five months/year). Five of them are low-income (eligible for MaineCare and local Food Pantry). Thirteen have chronic diseases, including four with cancer, one with disabilities due to Lyme disease, two with COPD, three with asthma, four with diabetes. One is confined to a wheelchair. Another has limited mobility. Three are also caregivers for family members who are older or more disabled than they are. They are the designers, volunteers, and eventual recipients of a comprehensive set of services they are coordinating, designing and rolling out for themselves and their peers. They have been meeting and working since September 2013 to design and coordinate services that will keep people healthy and happy in their homes. In Part 1 of this case study in progress, we’ll describe the first year of our journey towards true elder empowerment.

What many designers of services for seniors aren’t paying enough attention to, is that it will be the seniors themselves who will drive the transformation of how and where people will live and thrive as they age.

WHO ARE WE? SENIOR CITIZENS WHO LIVE & VACATION ON A COASTAL PENINSULA

Demographics

Year-Round Residents. There are approximately 7,000 year-round residents on the Boothbay peninsula (in the towns of Edgecomb, Boothbay, Boothbay Harbor, and Southport) of whom 62 percent are over, or nearing, 65. So 4,340 year-round residents are nearing or past 65, forming what is now referred to as a “naturally occurring retirement community” (NORC). Although, truth be told, “retirement” is not something that people in this region of the country do. Many of these seniors are still working, and many plan to do so until they die. I heard this conversation at the grocery store check-out counter between two senior men: “How are you enjoying retirement?” “Me? I’m not retired. I left my job at Bath Iron Works and now I sell cars at Hawke’s Motors.” “Wow, that’s great! Me, too. I put another 100 lobster traps in this season. I don’t see any reason to stop fishing.” Many of the hardworking local seniors keep working as long as they are fit.

The majority of these seniors live in their own homes—which range from mobile homes to classic New England farmhouses. There are also four subsidized apartment complexes on the peninsula—each with a capacity for 30 to 40 residents. Apartment residents include younger families, but the majority of the apartment dwellers are over 65. There is one retirement community on the peninsula: St. Andrews Village. It provides independent living apartments, nursing home care, skilled nursing care, a small dementia unit, and 12 cottages that are owned by residents. For low-income seniors, Dr. Teel’s nonprofit, Eldercare of Lincoln County, runs two small independent living homes—Edgecomb Green and Boothbay Green—for low income seniors. Each home accommodates six to eight seniors. These are men and women who need a safe, supervised environment, but do not yet require skilled nursing and who prefer to live in a place that’s more like a home than an institution.

Seasonal Residents. During the five months between May and October, these 4,000+ year-round seniors are joined by approximately 7,000 additional seniors, as the total seasonal population on the Boothbay peninsula swells to 24,000. The approximately 7,000 seasonal senior citizens are the anchor tenants for the multi-generation vacation homes sprinkled up and down the peninsula and on the nearby islands. Most of these seasonal seniors have been spending their summers in this part of Maine since they were babies, as did their parents and grandparents. Many of these seasonal residents become year-round residents as they retire from their “city jobs.” That’s one reason that the number of seniors on the peninsula continues to grow. People who die are quickly replaced by those who shift from being seasonal residents to being year-round residents.

Health Status

How healthy are we? Not very. In the 12 months between July 2013 to July 1, 2014, 1,928 of these seniors (65 and over) have been identified as having chronic disease(s)², including cancer, COPD, congestive heart failure, and/or diabetes. Helping these people stay as healthy as possible, out of the ER and the hospital, and ideally living in their own homes, is one of the Awesome Seniors committee’s biggest priorities. Preventing the rest of our seniors from becoming disabled or ill is an equal, or even higher, priority.

Because seasonal residents’ medical care is typically coordinated from their winter residences, it’s difficult to gather statistics about the diseases and illnesses that afflict our seasonal visitors. Medicare reporting is done by zip code, based on your primary residence. But anecdotal evidence and interviews with local physicians and hospitals tell us that our seasonal residents bring with them the same constellation of illnesses as the year round population: heart disease, cancer, respiratory diseases, diabetes, and mental health and behavioral health issues.

Income

As you can imagine, there is a fairly large income disparity between the year-round senior residents and the seasonal senior residents. The median income of the typical year-round senior resident is below \$15,000/year. The median income of the typical seasonal senior is about \$60,000.

IDENTIFYING NEEDS

The Awesome Seniors Committee has spent over a year collecting seniors’ stories, talking with them, and observing what they/we need. Our findings are not unique. Based on the literature about aging in place, these are the same needs that seniors have across the country and around the world.

Seniors Want to Remain Independent

Whatever living situations our senior residents enjoy, they almost all share a cultural norm: “I don’t want to be a bother to anyone else. I want to do things myself.”



Seniors prefer living in their own homes with their pets and memorabilia around them.

² Data provided by Maine Health InfoNet in July, 2014.

What takes away independence? Illness, disability, and/or loss of the use of their own car.

The refrain of “not wanting to be a nuisance” may be particularly pronounced in Maine, where people pride themselves on their independence and their ability to make do and get by.

Seniors Need Flexible Transportation

Losing the ability to drive your own car is a huge change in lifestyle. All of a sudden, you're no longer free to do as you please on the spur of the moment. Seniors who live in Boothbay Harbor or East Boothbay who can walk around town to run errands and visit are able to preserve that sense of independence at least during the summer months. But most of us live a few miles from local stores and community amenities, like the library, post office, gym, so we need a car to get to those places, and many seniors who can no longer drive have to rely on family, friends, and neighbors to provide those rides. During the long winter months, many of our local seniors become close to shut-ins. They're afraid to walk in the ice or snow for fear of falling, and they hate to impose on family, friends, or strangers for all but the most necessary rides (medical appointments, grocery shopping, hair appointments, church activities, important hobbies). In addition to the “necessary” outings, there are so many things that seniors used to do that are no longer easy for them to arrange: things like running errands, taking a pet to the vet, volunteering, going to an exercise class, going to concerts, movies, and town meetings. All of these daily and weekly activities tend to fall away without easy transportation.

To age in your home with dignity, everyone should be entitled to a few hours a week of personal care and housekeeping services, regardless of income.

Seniors Need Help Navigating Medical Services

As you grow older, you have more ailments. Preventing and treating conditions often becomes daunting, confusing, and time-consuming. Understanding your medical conditions, your medications, and how your body is responding to treatments is difficult. Most of us need an advocate who can go with us to medical appointments, take good notes, help us get and keep our medical records organized, and coordinate among specialists. Today's primary care physicians are simply too busy meeting with enough patients to cover overhead costs to spend as much time as would be necessary coordinating patients' care with a number of specialists. Our seniors have found that they need and *want* to become much better informed and involved in managing their own health and care.

Although Medicare provides coverage for most hospitalizations and doctors' visits, seniors and their caregivers still have to navigate the confusing regulations and limits on coverage. For example, Medicare only pays for a few days of acute care in a hospital setting, after which you need to move to a nursing facility or rehabilitation facility, where you are entitled to a certain number of days. Physical and occupational therapy is covered for a period of time and then expires. Skilled nursing care runs out. After you're discharged from a hospital or nursing care facility to your home, you're entitled to visits from a Home Health Care nurse. But that care is limited. Coverage for prescription drugs depends on your income level and your insurance plan. Sorting through the labyrinth of entitlements and making sure that you (and your insurers) are not being over-charged for services can be a full-time occupation.

Seniors Need Help with Errands

As soon as you no longer have control over your own transportation, running errands becomes problematic. Doing grocery shopping, going to the Post Office, buying gifts for family members, getting pet food, going to the dump, recycling bottles—all of the small activities of daily life—become chores you can no longer do yourself. Seniors need “errand runs”—when they can get out and do these activities. Or, if they aren’t feeling up to getting out, they need people to do those errands for them.

Seniors Need Exercise

Once you become homebound, it’s hard to motivate yourself to exercise. People who are used to walking, riding a bike, playing tennis, dancing, doing yoga or tai chi really miss it once they become slightly disabled and/or can no longer drive. For many people, exercise is a group activity. Whether we walk our dogs together, do aqua aerobics together, play tennis, or work out on exercise machines, having other people around you exercising is both supportive and social. People who are recovering from disabilities or illness often need exercise buddies—people who will walk with them and spot them to make sure they don’t fall, or will exercise along with them, turning a chore into a social time. Once they’re relatively nimble again, staying fit requires regular exercise, two or three times a week. Studies, including one in the April 24, 2012 issue of the journal *Neurology*, have also shown that for people who are at risk of dementia and Alzheimer’s, group exercise in a social setting often slows the progression of memory loss.



97 year old walks and rests along scenic Maine coast.

Seniors Need Help in Their Homes

One of the biggest gaps we’ve found for low-income seniors in our region are people who can come and help around the house. If you can’t afford a housekeeper to clean and organize for you and you can no longer do everything yourself, your living space becomes a burden, not a joy. For many seniors, doing their own laundry becomes problematic, particularly if they don’t have a washer and dryer in their home. Cleaning the bathroom and changing sheets is a difficult challenge. Just putting things away and keeping them organized can be overwhelming. Dr. Teel has observed that the most important activities for seniors to engage in involve cooking and feeding themselves. As long as people are interested in making a meal for themselves, cleaning up after themselves, putting their grocery lists together, they are able to thrive in their homes. If those essential tasks are removed from them (for example, if a housekeeper or a daughter prepares all their meals), they begin to decline.

Seniors Need Personal Care

Once certain disabilities kick in, many seniors need help bathing or showering safely. They need help finding the right clothes and putting them on. They may need help shaving. They may need toileting help. These are the kinds of activities of daily living (ADLs) that cause many people to move into nursing homes. Yet, with as little as an hour or two a week of personal care, many seniors can remain safely in their homes. Often personal care services are combined with housekeeping services. To age in your home with dignity, everyone should be entitled to a few hours a week of personal care and housekeeping services, regardless of income.

Seniors Need Purpose

One of the “needs” we discovered in observing the behavior of the 12,000 seniors we’ve been studying and observing for a year isn’t something people explicitly talk about, but it’s clear in observing what they do. Our local seniors aren’t retirees. They’re doers. They contribute to their families and their communities in many ways. When it’s no longer possible for them to be of help to others in their community, or to serve a larger purpose, they begin to decline in health and vitality.

ASSESSING THE CURRENT SERVICES AVAILABLE

Organic Emergence of Safety Net Services for Seniors

Most communities are blessed with a patchwork of community service organizations. The Boothbay Region is awash with many such services. Most of these are several decades old and have emerged from church groups and other volunteer organizations. There are actually 55 thriving non-profit organizations on the Boothbay peninsula. These include churches of all denominations, the local library, a number of clubs (Senior Citizens’ Club, Rotary, Lions, Knights of Pythias, Garden Club, Hospital Auxiliary, etc.), our healthcare system (LincolnHealth—which is part of MaineHealth), Bigelow Laboratories (a marine biology lab), Maine Coastal Botanical Gardens, a thriving YMCA, the Boothbay Region Land Trust—in short, there are many, many organizations that provide services and activities that are powered by volunteers and funded by memberships and donations.

We Already Have Many FREE Services for Seniors

Specifically, there are a quite a few volunteer organizations that provide *free* services that our local seniors value and use. Many of these services are coordinated through a single umbrella service organization—the Boothbay Region Resources Council—which was formed about a decade ago by coordinating and combining a number of church-based outreach programs:

Transportation:

- F.I.S.H. (Friends in Service Helping) matches people who need rides to medical appointments with volunteer drivers.

Food:

- Warming Lunches – Volunteers provide free lunches and social time four days a week in four different locations: Our Lady Queen of Peace Catholic Church in Boothbay Harbor on Mondays, the Edgcomb Thrift Shop on Tuesdays, the Southport Town Hall on Wednesdays, and St. Columba’s Episcopal Church on Thursdays.
- Meals on Wheels – Low-cost meals are delivered to peoples’ homes five days/week.
- Food Pantry – Provides free groceries and staples for low-income seniors and families as well as community garden-grown organic produce. A grant also provides vouchers for low-income people to purchase locally-grown produce at our farmer’s market.

Heat:

- Fuel Assistance – Those who qualify can receive up to 100 gallons of heating oil.

- Woodchucks – Free firewood is made available to people in need. The wood is gathered and split by a group of local chain-saw wielding seniors.

Clothing:

- There are at least two free clothing closets as well as two very inexpensive volunteer-run used clothing fund-raising shops (one supports the local healthcare system and the other supports the local animal shelter).

Home Improvement:

- Rebuilding Together – Volunteers who provide carpentry and handyman help to people in need.

Health Care:

- District Nurse – Free or affordable (\$10 per visit) visits by a community-funded nursing service. Usually limited to one visit per week to check blood pressure, do wellness checks, and reconcile medications).
- Community Paramedicine Pilot Program – Our local Boothbay Region Ambulance Service coordinates with LincolnHealth and with other independent local physicians to provide wellness visits to the homes of patients who have been recently discharged from the hospital or those who suffer from chronic conditions.

Social Services:

- The Boothbay Region Community Resources Council provides a social worker who identifies and coordinates social services for people and families in need.
- Free Medicare and Medicaid counseling services are provided by the Area Agency on Aging, which is Spectrum Generations for our county.

Safety:

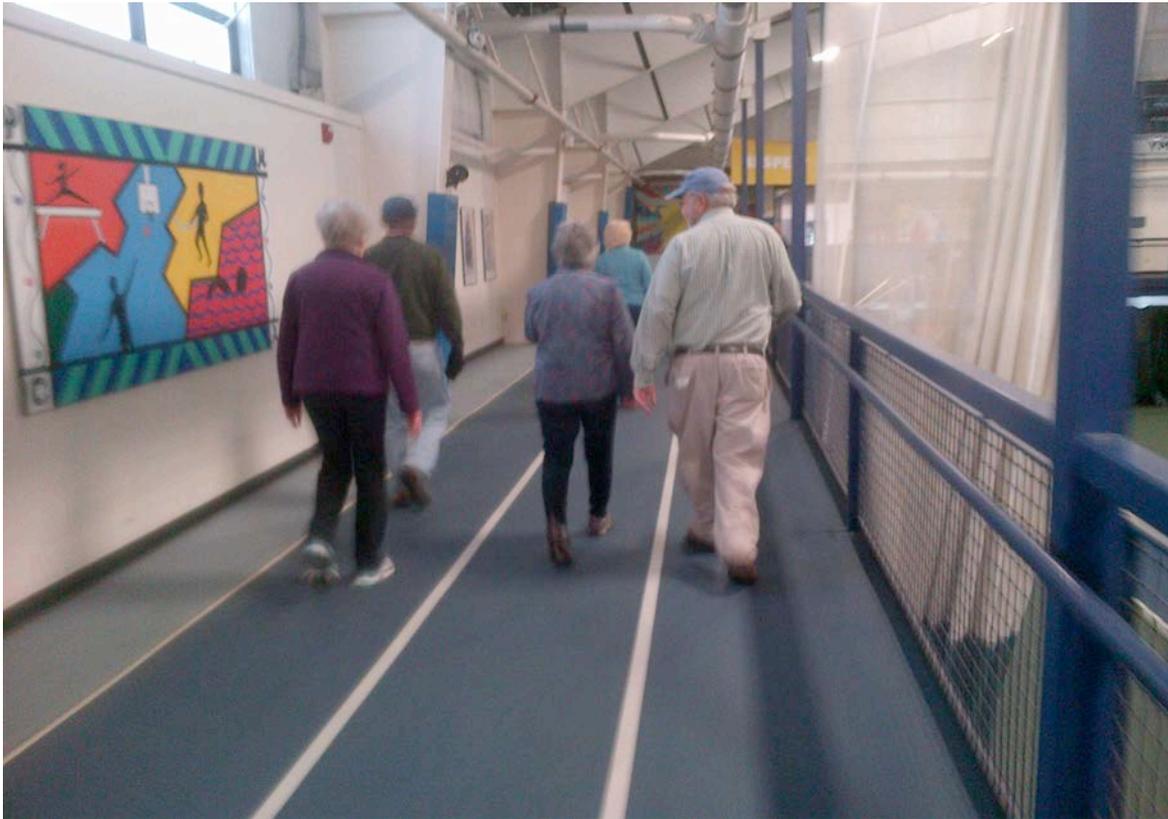
- Triad is an organization that includes all of the police, fire, ambulance and other emergency responders—which looks out for the safety of our seniors. This organization provides free 911 cell phones, alerts seniors to scams, and hosts an annual free luncheon and education session.
- The Boothbay Region Resources Council has just launched a “Good Morning Neighbor” program in which teams of three seniors each call one another each morning to check on one another.

CREATING NEW PROGRAMS

Seniors Walk Free at the Y

After surveying seniors about their biggest needs, the Awesome Seniors Committee tackled the “low hanging fruit” first. We didn’t want to duplicate any of the services already available. We were looking for a quick win in the middle of winter last year and decided that the highest priority need was to provide a means for seniors to exercise safely, particularly in the snowy and icy winter months. One of the first programs the group kicked off is a “Seniors Walk Free at the Y” program. So we approached our world-class YMCA and asked them if they would consider letting non-members use their indoor track. They said yes! We agreed to try a pilot program, which kicked off

Awesome Seniors Walk at the Y for Free!



Seniors walking at the YMCA track on Tuesdays and Thursdays.

last March. The YMCA management and board were concerned about setting a precedent for free use of Y resources for a specific group. Andy Hamblett, the Director of the Boothbay Region YMCA, emphasized that subsidies are available to defray membership fees for anyone who can demonstrate their need. The Y wants to be inclusive. We countered that our proposed program would be open to all (65 and over) and that applying for a subsidized membership is a barrier for many seniors who don't want to fill in yet another form and supply their tax returns.

The Y management was also concerned that this program might cannibalize existing paid programs. In particular, the Y offers a "Walk across America" program that costs \$35/month and encourages people to walk on the track, log their miles, and plot their course on a map to show their progress.

But they agreed to try the "Seniors Walk Free at the Y" out as a pilot program. Now, nine months later, it has become a core and valued community service program.

Anyone 65 or over is encouraged to come to the local YMCA and walk on the indoor track from 10 a.m. to noon twice a week, without needing to be members of the Y. Over 100 seniors are now Y Walkers. About 35 of them are regulars. The regulars come every time, and they support one another in staying engaged and in increasing the number of laps they walk each time. The majority of these participants are people who grew up on the Boothbay peninsula, attended the local schools, and, for the most part, raised their families here. But most of them never joined the YMCA, feeling that it was too expensive (despite the subsidies) and tailored more for "people from away" than for the locals.

Seniors Socialize as They Walk at the Y



The camaraderie of Walking Together at the Y is an important part of the program. If you skip a day, people comment on it and ask about you. Most of these folks went to elementary school together, but many had lost touch with one another over the years. This activity is reuniting them!

When we initiated the program, we offered to provide rides for anyone who wanted to come walk at the Y and didn't have transportation. We were planning to either use the YMCA van to shuttle people to and from their homes or have walkers in each neighborhood provide rides for shut-ins in their neighborhoods. To-date, only one couple asked for transportation, and, when they realized that it was being organized just for them, they declined.

The best news is that we have seen great results from the Y Walkers. As a group, they have increased their mobility and endurance. For example, Jeanne Foster, who uses a walker and carries her oxygen bottle with her, had trouble getting around a single $\frac{1}{8}$ th mile lap last Spring. Now she is walking $\frac{1}{2}$ mile twice a week. Harriet Chowdery started by using a walker, and now walks a mile each session without a walker or without even holding on to the railing. Even during the summer months, when it is pleasant to walk outdoors along the water, on a sidewalk, or on a trail in the woods, many of the regulars kept on coming. They enjoy the camaraderie as well as the ability to stride along without worrying about tripping on something or bumping into a dog or a kid. During the busy summer months, these stalwart regulars were joined by a new group of seasonal residents who started to take advantage of the program. At least 10 of our seasonal walkers came regularly throughout the time they were vacationing here.

Boothbay Region Awesome Seniors Walk at the Y for Free Program

	Totals	March	July	October
# of Senior Walkers	115	21	16	31
Avg. # Walkers per Session	31			
Age Range	65-97			
Average Age	74			
Average Laps (1/8 th mile) per Person		5.1	8	12.2
Average Miles per Person per Session		0.8	1	1.5

TimeBanking: Give an Hour, Get an Hour

It was Chip Teel who clued us into the phenomenon that many seniors in need of help won't accept help. But they *will* provide help to others. That got us thinking about how to reward seniors' volunteerism and let them "earn" services from others. After doing some research, we decided to try out an existing program—TimeBank USA—and, in particular, the Mid-Maine TimeBank.

Here's how it works. After you sign up and are vetted (references checked, criminal record checked), you can start logging your volunteer hours into TimeBank (or keeping track of them and we'll log them for you). Any time you spend on any kind of volunteer work counts—whether it is for a church organization, a nonprofit, a political group; if you serve as a Selectman or cook for the homeless; or if you help a neighbor in need (any non-family member counts) by doing their grocery shopping, walking their dog, or taking them out to do errands. As you donate hours to the TIME Bank by doing things for others, you are earning hours that are "owed" to you. Of course, there's no guarantee that someone will do exactly what you need to have done when you need it done, but the reciprocity does work out pretty well over time.

What works well about this program is that every one's time is of equal value. And it provides a great way for people who don't have much money to pay for services they need.

So far, we have only about a dozen local seniors signed up and logging our hours and swapping services. We're still getting the kinks out and trying to streamline the system to make it easy to sign up and easy for non-computer folks to log their hours and request services. The best approach seems to be to have a single coordinator who can call folks up, get their time sheets from them, enter their hours, and then chat with them about what additional services they need. That person is also likely to become the glue—to be able to match people who need services with people who have services to offer.



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HOME MY ACCOUNT MARKETPLACE

We link local Maine neighborhoods and communities in a statewide network based on good will, sharing our skills and resources to improve quality of life through reciprocity.

Welcome to the Time Initiative of Maine (T.I.M.E.)

Submitted by sysadmin on September 20, 2010 - 4:05pm

Upcoming Events
No upcoming events posted.

Featured Events
No upcoming events posted.

Recent Yellow Pages Listings
11 yellow pages

User login

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LOG IN

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Our hope is that we can expand the number of people who are TimeBankers on our peninsula and use our time as currency. Bartering is a cultural norm in rural Maine. Swapping my hours of volunteer work for your hours to chop my firewood, or weed my garden, or teach me how to play the piano, seems like a natural fit.

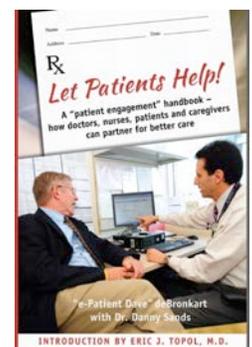
E-Patient Dave Gets Ready for His Presentation



Dave deBronkart, also known as e-patient Dave, came to speak to folks in the Boothbay region last July. His talk spawned a Patient Empowerment Study Group.

Patient Empowerment Program

Just as Dr. Chip Teel's presentation in the fall of 2013 lit a spark that spawned our Awesome Seniors' initiative, Dave DeBronkart's presentation in the summer of 2014 catalyzed another important grass roots effort. Known as e-Patient Dave, and a cancer survivor, Dave travels around the world as a professional patient advocate. He and his physician, Dr. Danny Sands, partnered on Dave's kidney cancer treatment and in writing a book, entitled [Let Patients Help!](#)³. In doing so, they broke new ground in participatory medicine. Dave's presentation in July was empowering and inspirational. One of the people in the audience was a local physician, Dr. Steven Cook, who had recently left the employ of LincolnHealth as an emergency physician. Steve really resonated with Dave's message about patients taking control of their own medical records and coordinating their own care. As an ER physician, he talked about how valuable it was when patients arrived armed with copies of their current medications, their current medical records,



³ See my book review, entitled: [Ten Steps that may Save \(or Improve\) Your Life: Prepare Now to Engage as a Patient or an Advocate for Someone You Love](#), by Patricia B. Seybold, July 10, 2014, Customers.com Press, <http://dx.doi.org/10.1571/br07-10-14cc>

and provided the background and grounding that he needed to make quick decisions and good judgment calls. Steve felt that when patients have, and understand, well-organized copies of their vital medical charts, their probability of survival increases dramatically. He also learned that relying only on accessing a patient's electronic medical records isn't sufficient. Often, those records are incomplete, and, alarmingly, they often contain erroneous information. Only by the patient taking control of their records, and verifying their accuracy, and ensuring that all of the specialists' information and medications are synchronized and reconciled, can you ensure a good and proper diagnosis and treatment.

So Dr. Steve Cook launched a Patient Empowerment Study Group. It's a group of about 20 people—almost all 65 and older. We meet in the local library once a week to learn how to access, organize, and understand our medical records. We are also learning how to do medical research, and how to work more collaboratively with our physicians.

THE AWESOME SENIORS' GUINEA PIG AND CHAIRPERSON

Who Is June Phillips and How Did She Become the Advocate for Awesome Seniors?

June Phillips is 76. She lives in subsidized housing and is now mostly confined to a wheelchair. Her four grown children—the closest one lives over an hour away—have told her over the past few years that she should be in a nursing home. But June doesn't want to be in an institutional/medical setting. She loves being in her own apartment with her books and her collections of English China and horse memorabilia. She is an environmentalist and a conservationist with a specialty in wetlands preservation. June and her daughter ran a riding stable in Massachusetts for many years and provided riding therapy, 4H club outings, pony rides, and, of course, riding and driving lessons. She also served on the Farm Bureau and served over 20 years as her county's land use supervisor.

June Phillips



A Year in the Life of a Vulnerable Senior

Here is June's story as she told it at the Annual Meeting of the Boothbay Region Health & Wellness Foundation where she sits on the Board.

"I'm an active member of the Boothbay Region Health and Wellness Foundation's Awesome Seniors Committee, and I believe my story illustrates the issues our committee is trying to address. There are many seniors on this peninsula, who, like me, want to be able to stay in their own homes. But there are lots of hurdles we need to overcome in order to do so. I tell my story in detail, not because it is unique but because it richly illustrates many of the unexpected issues that seniors living on their own encounter.

About 2 years ago this autumn, I was losing mobility. I started to use a Rollater. My Doc, after blood tests, said I was suffering from Polymyalgia from an unknown source. He knew I was using a walker. (I'll list the problems I'm telling you about only so that you'll understand the problems better.)

FIRST PROBLEM: *I had no instruction in Walker 101, so of course I goofed up and fell several times.*

June Phillips listens as another Patient Empowerment Study Group member talks about what she has learned to-date.

SECOND PROBLEM: Each fall, unbeknownst to me, was adding insult to injury to my spinal column.

THIRD PROBLEM: The apartment complex where I live had many units rehabbed, including mine, to make my apartment handicapped accessible. To accommodate this change, I packed all my possessions in big boxes, and movers moved me to another unit for a few months, and then back in again, leaving me with 60 large boxes to unpack by myself. My mattress was damaged by the movers, I think, and so, many times when I got out of bed during the night, I actually slid off the mattress on to my bottom and wound up sitting on the floor and unable to get up! I would have to call 911, and our local EMTs would come to “Lift and Assist” me. (That’s a free service for which they don’t receive reimbursement.)

Soon, I replaced the mattress. But I was quite weak and unable to drive by this time.

Finally, in December 2013, (after our local St. Andrews Hospital was closed, which used to have a 24-hr. ER 5 minutes from my apartment), I tangled my feet in the bedclothes and fell out of bed right on my face at 4 a.m. I hollered my head off and my neighbor heard me and called 911.

The ambulance arrived and the EMTs did a hospital run to the nearest ER at Miles Memorial Hospital—35 minutes north—rather than to the ER that used to be 5 minutes from my home, or to the Midcoast Hospital’s ER (a much larger hospital that is 40 minutes south). That was **PROBLEM #4**. By going north to Miles, as it turned out, I was lucky I survived the trip. I had lost precious time and added distance by travelling north, and when I got there and they did X-Rays, they discovered I had a spinal cord injury. Now, they had to get me to Maine Medical Center (90 minutes south) fast. So, by that night, I was at Maine Medical Center being operated on for a spinal cord injury.

Upon waking up, I couldn’t feel or move much of anything except my fingers. When I asked the surgeon, he didn’t know if I would recover motion and control or not.

*I can tell you that we need a coordinated
senior-to-senior volunteer program so that times, tasks,
and people are scheduled. The Awesome Seniors Committee
knows this and is working out a solution.*

~ June Phillips

PROBLEM #5: About 5 days post op, I was still unable to stand or manage control of arms and legs. But because of Medicare limits of coverage, I couldn’t stay at Maine Medical. I was moved to an Acute Care Nursing Home with only 1 hour of Rehab each day. I was making progress ever so slowly but Medicare coverage was running out.

As it turned out, **PROBLEM 6** was a Godsend: a bad case of the flu. I was terrified because I asked to be seen by a Doc and sent to the hospital. I wasn’t ever refused, but nothing happened for days. When I asked for a telephone, I was told it was broken. Finally, I started hollering my head off every time someone passed the door.

That worked! I was sent to Midcoast Hospital in Brunswick, ME. By the time I hit the ER, I was as mad as a wet hen. And I told everyone in sight that, in essence, I had been kidnapped. The Doc asked me if I would like to speak to someone from the State. I did and I did.

From Midcoast, everything improved. The docs there advocated for me to go to New England Rehab where I did lots of Physical Therapy. When I was released from there, I entered Hawthorn House in Freeport. All the time, insisting that I wanted to go home. I

was discharged in a wheelchair and given a walker I could use to move around in my kitchen and bathroom and to strengthen my legs.

PROBLEM 7: At home, all my stuff that had been moved back into my apartment was still packed in large boxes, severely limiting my mobility. It took me four months to unpack everything, and I am STILL unpacking now.

PROBLEM 8: There is not proper funding for household help. Medicare pays only for medical care, not housekeeping help. Home Health only comes for a while after you are discharged. And, while our local physical therapy is great, once the PT is over, you need to keep moving on your own, you need people who can escort you when you are trying to exercise, and walk, and shower.

PROBLEM 9: Within a week after I arrived home, I wound up back at Miles Memorial Hospital due to a medication error. They had not given me the proper discharge instructions and meds, nor did I have an immediate appointment scheduled with my primary care doc, so I had trouble breathing and had to be taken to Miles again. This time, they wanted to discharge me to a nursing home. I refused. I showed them I could walk a bit with a walker and I walked up and down the hall always objecting that I did not want to go to a nursing home. Finally, they gave up and discharged me, and Patty Seybold came to take me home.

I've been ever so lucky that the Foundation folks and some of my family helped me along the way. I provide phone calling services for the Foundation, and they shop, do laundry, and clean for me, but **PROBLEM 10**, sometimes the help isn't consistent. So for the last year, I've been a guinea pig to figure out what is needed. I can tell you that we need a coordinated senior-to-senior volunteer program so that times, tasks, and people are scheduled. The Awesome Seniors Committee knows this and is working out a solution.

Here's what we've been doing so far. I volunteer my time making hours and hours of phone calls for the Wellness Foundation. In exchange, I receive help with grocery shopping, laundry, household chores, and escort service. Sometimes I get that help. Sometimes I don't.

In addition to the volunteer work I do for the Wellness Foundation, a new opportunity arose in early August, when FISH (Friends in Service Helping) lost a key person—the person who takes the calls from people who need rides to medical appointments and locates a volunteer who can do each ride. I found out about this crisis, through the Foundation, and said, "I can do that," and within a couple of days, FISH was back in business, and I was busier, meeting a community need.

PROBLEM 11, For a while, the Community Paramedics (our local EMTs) were coming every week to check on me as part of our Pilot Community Paramedicine program. But then they stopped coming. After three weeks, I finally called and learned that they need a new doctor's referral to continue to visit me in my home. Or, I could switch over to being seen by our District Nurse, but I'm the one who had to figure all this out.

After the Community Paramedics resumed their weekly visits (once I got the Doc's referral), they were alarmed by my sudden weight gain and fluid retention. This is exactly what they're supposed to be watching out for—so I don't wake up not being able to breathe. The paramedics immediately notified the Community Paramedicine Program Coordinator at LincolnHealth who, in turn, contacted my doctor, but **PROBLEM 12**, instead of requesting an immediate consult with my doc, she sent in the information as an FYI. Two weeks elapsed with growing concern before I finally made my own doctor's appointment, arranged (thru FISH) for a ride to and from the doctor's office 30 minutes away, where they showed me their record of the FYI report from the paramedics. Someone had checked the wrong box. And nobody had really read the report. They just stuck it in my file. My doctor quickly adjusted my medication, and I'm now doing better, although I have to pee a lot, which is a problem for someone who lives in a wheelchair!

*On November 2, 2014 our region was hit with a large snowstorm. I had prepared by locating my emergency box, making sure that I had a battery-powered lantern handy as well as candles. I knew I had enough food and water. But, **Problem 13**, when the power went out, so did our heat and our phones. And, it stayed out for three days! I was afraid to try to get out of my recliner and navigate in the dark to my Emergency Box in the closet. So I stayed put. My phone service was out. My emergency cell phone (which only dials 911) was not charged and not within reach. Nobody came to check on me. Not the Residential Manager of our housing complex, not the local police. My friends finally came by the second day to check on me (they had had a car accident and were preoccupied with their own safety and recovery). They got new batteries for my lantern, brought additional flashlights and took me out to dinner to warm up. But there was no other place to stay that night that was handicapped accessible (the local motel was full) and we didn't know of any emergency shelter. So, once again, I bundled up and slept in my chair in the dark and cold. The next day, I was on duty at the polling booth collecting signatures for a Clean Election petition. My friend took me there, and I was able to be warm and sociable all day while doing something important to me. I informed the town officials of my plight, and, by now, they had discovered that the 35 residents in our housing complex had been without heat and power for 3 days and they were working with Central Maine Power to prioritize the restoration of service for our apartments.*

The following week, I attended a meeting of our Rotary Club's sponsored Elder Forum—a group of representatives from local non-profits, all of whom provide services for local seniors. I described my difficulties during the recent storm, and they all agreed that both our seniors and our community's first responders had been inadequately prepared for that early storm. We felt that more was needed, so the Rotary Club asked the Foundation to work with our local Red Cross to put on a "Disaster Preparedness Day," which we are doing.

These 13 problems represent a year in the life of a vulnerable, low-income senior citizen. I believe that because 1) I'm mouthy, and 2) because I have good, kind, friends and family that I've been able to stay at home with my cat and all my own possessions around me. I also believe we need improvements. Most people aren't as outgoing as I am.

Because I'm outspoken, willing to pitch in by being my own advocate, and to help others advocate for themselves. I'm able to answer the phone and coordinate with volunteers, I have been elected chairman of our Awesome Seniors Committee. Our committee plans to work this year to put in place a coordinated program that will rely primarily on senior volunteers working to help one another, to help people like me thrive in place."

*~ June Phillips,
Chairperson of the Boothbay Health & Wellness Foundation's
Awesome Seniors Committee*

Walking the Talk

Now that you've read her story, you probably realize what our committee realized: Who better to try to design and coordinate services for people like herself than June Phillips? Not only is June living and breathing all the difficulties (medical and logistical) of living alone with a disability, but she is a fearless advocate for herself and others like her. She loves to be of service and never turns down an opportunity to make phone calls, coordinate services, and/or to come to meetings and help people understand what's really needed. So June is now the Chairperson of the Awesome Seniors Committee, and she is also becoming the Awesome Seniors' advocate and coach, as well as the volunteer coordinator for senior-to-senior volunteer services. My hunch is that once she has figured out how to perform these roles herself, she'll be ready, able, and willing to delegate them to other strong volunteers.

TimeBanking Is Paying Off for June

Over the past several months, June has been a member of TimeBank, as have the rest of the Awesome Seniors committee. Each week, we log the hours she spends coordinating rides for medical appointments for FISH, and doing outreach phone calls for the Boothbay Region Health & Wellness Foundation. In exchange, volunteers buy her groceries (or take her grocery shopping), do her laundry, take her recycling to the dump, help her organize her vast collection of books, take her to community meetings, drop her off at auctions (one of her passions!), and one TimeBank volunteer is building her a set of custom shelves for her cookbooks.

Patient Empowerment Program Is about to Expand

After spending four months in “study group” mode, the Patient Empowerment group is now about to launch a series of public seminars in order to convey what we’ve learned to-date and to begin helping others become advocates for their own health. June Phillips was one of the few people in this study group who already had copies of all her medical records over the years. But, like the rest of us, she had no idea what to do with them. Now, she is beginning to have a well-organized set of current information, including up-to-date medications, dosages, and all of her tests, scans, and diagnoses.

WHAT’S NEXT?

Social Worker/Case Manager or Empowered Advocates?

Originally, the Awesome Seniors design group felt that each senior, regardless of income, should have access to a professional social worker/case manager who could coordinate services around his/her medical and non-medical needs. We felt that the role of the case manager would be to coordinate weekly with each person’s inner circle of family, friends, and neighbors to ensure that daily contact and support are provided. Now, after watching June Phillips in action, advocating for herself and building her own support network, we’re beginning to think that perhaps lay people—seniors themselves—can teach one another to become advocates and case managers.

Paid Professionals or Organic Volunteerism?

Our initial program design also called for a paid position of a Volunteer Coordinator: Someone who could both recruit and screen volunteers and also match volunteers to seniors needing services. Now we’re wondering whether we can combine TimeBanking with its technical match-making with caring people who check in with one another by phone to see what’s up and what’s needed.

Chronic Care Management? Health Coach? Patient Empowerment Coach?

As we’ve seen from our demographic overview and from June’s story, our population, like many others, includes a large number of seniors with chronic diseases who are at risk. There’s clearly a need to provide more proactive care for those suffering from chronic conditions and to prevent others from sliding into the same situation.

Our District Nurse and Community Paramedics are already in place in our community checking on at risk patients. Our local physicians are attempting to provide proactive outreach, but there’s still a long way to go.

24-Hour Health & Wellness Safety Net

Since our community lost its 24-hour ER and local hospital⁴, we believe that there's an unmet need in our community for a better 24-hour safety net for people with medical and safety issues and concerns. These problems often arise at night, when there's no local healthcare facility open. You can call your doctor in the middle of the night, but there's only one local physician—Dr. Oliphant, who is an independent practitioner—who will take patients calls directly. If your doctor is part of LincolnHealth, the doctor on call rotation will most likely not know you. They typically advise callers to wait until morning and call their primary care doctor's office to schedule an appointment, or to call 911 and have the EMT's come to check you out. We believe there may be a better solution. But we're hoping our seniors will design it themselves. Stay Tuned.

⁴ If you want more background, read "[A Community Fights for its Right to Healthcare: Customers Enlist Regulators to Improve Services in Boothbay, Maine](#)" by Patricia B. Seybold, August 22, 2014, Customers.com Press.