

Age-in-Place Senior Case Study:

24-Month Update

Background

This is a case study of an older woman who regained her health and quality of life following a serious disease. At this 24-month update, she has also avoided ER, hospital readmission, in-home caregiving and assisted living costs estimated at \$250,000.

The method she and her family used is described in *The NetworkSage: Realize Your Network Superpower*. Though not specifically written for older people, the principles in the book are universal. Why? Networks are essential to success throughout – and in each part – of life.

Through the *NetworkSage* lens, adults are supported by eight networks. The first five are called “birthright networks” because they are created by parents for children: a family network, a health and vitality network, an education and enrichment network, a spiritual network and a social network. As we grow up, we add to them, shaping them to be more to our liking and expanding our horizons of people and experiences. We never, however, outgrow our need for what these networks provide. Eventually, we mature into three additional networks called “coming-of-age networks”: a career network, a home and personal affairs network and a ghost network, that is, people we once knew who are no longer in our lives.

In each of these networks are people who care about us and who can help us – or not – with the needs we have. They teach, they play, they love. They are there to celebrate with us when times are good and to support us when times are bad.

The *NetworkSage* approach is based on more than a decade of research with hundreds of people of all ages, showing that when people become aware of their connections and manage

them well, it helps them be healthier, happier and more successful in every way.

The woman in this case study was an otherwise healthy senior experiencing today's longevity; she was living in her own home, aging-well-in-place and enjoying independence. She didn't need much support from family or friends. In fact, she supported them in a number of ways and was an active community volunteer.

Then, she became suddenly, seriously and mysteriously ill. Her story and the visualization of her network data are used with permission, with her photo and identifying information changed or omitted to protect her privacy.

Meet Janet

Janet (not her real name) has a spirit for adventure. As her story begins, she's approaching 86, has been widowed for more than 20 years and lives alone. A decade ago, she built a single-family home in an over-55, active-retirement community in Florida and relocated from the Midwest. She kept the house, picked fruits and vegetables at local farms, hosted dinner parties, and gardened. She enjoyed the arts and local university lectures. She helped others, driving 60- and 70-year old friends to medical appointments at major cities more than an hour away. Once each week, she ran a soup kitchen, working 12-hour days. As you might imagine from this description, her health was good and her energy levels, exceptional.

Then a sudden series of health crises changed that. What began as moderately annoying symptoms quickly became worse, leading to nearly two years of specialists, misdiagnoses, emergency surgery, life-threatening dehydration, 911 calls, frequent ER visits and two 10-day in-patient hospitalizations in isolation for what was eventually diagnosed as

c. diff, most likely contracted visiting friends in nursing homes.

Her family was able to help, but not as well as they wanted. Her son and daughter-in-law live nearby but were out of the country and could not be reached during some of the most harrowing days of her extended illness. Her daughter navigated from 1,000 miles away with contact information for only one neighbor. Throughout the weeks and months, it would appear Janet's health had improved; everyone would breathe a sigh of relief, only to then face sudden, unpredictable setbacks.

After ten months of frustration and during her second hospitalization, the family engaged nurse case-managers to intervene with doctors and hospitals, support Janet and coach the family about how to help. Those nurses helped get a correct *c.diff* diagnosis and then, secured her enrollment in a clinical study for an experimental treatment that successfully resolved the disease.

By the age of 88, she had recovered but was physically weak and emotionally shattered from the long illness. She also felt vulnerable; any moderately annoying symptom made her fearful *c. diff* had returned and that made her a twice-monthly user of the ER. To make ER-use worse, the local hospital built a free-standing ER just outside her gated community.

Needless to say, the experience was a "wake-up call" for everyone. Neighbors – approaching caregiver burnout – encouraged her to relocate to assisted living. To satisfy her curiosity, Janet explored options, but the cost was higher than she imagined, she feared it would exhaust her resources and felt moving there was an admission of incapacity. She was not about to "give up" and committed to doing whatever it took to remain in her home. Her family was supportive, treading lightly to allow her the autonomy she wants.

Network Analysis

Janet and her family used the Sage *Network Information Architecture* to gather all the data they needed to be more aware of Janet's current networks and develop a plan to help her remain independent in her home and avoid caregiving crises. The results follow.

Family Network. Janet was born into a large family of six siblings, most of whom had large families as well. Her husband's family was smaller, but nearly everyone in both families lived nearby. Vivid memories of big family gatherings obscured the reality of family life now. She and one brother are the sole survivors of their generation: her husband, siblings, in-laws, and even one of her children, have long-since passed away.

Today, her own family network is quite small. A son and daughter-in-law live nearby and are the only family with whom she has regular, face-to-face contact. Her daughter lives in a distant state, visits during holidays and keeps in touch daily via phone and email, as does her granddaughter. Her granddaughter is a military wife and arranges for longer visits, bringing her two children (Janet's great-grandchildren), when her husband is deployed.

It takes nearly a full day of air- and ground-travel for her daughter and granddaughter to visit, so they cannot provide her with either emergency or ongoing, hands-on support. She is not an *elder orphan* – a term used to describe seniors living without family support – but she lacks the kind of large family support she provided to relatives and in-laws.

Health and Vitality Network. Janet has been healthy all her life. Aside from birthing three children, she has never been hospitalized, nor is she a high utilizer of health care. Before *c. diff*, she needed only twice-yearly visits with a primary care physician to renew prescriptions for high cholesterol and high blood pressure and occasional visits for audiology/hearing aid care. The problems she experienced with her

primary care physician and specialists during her illness – particularly when did not take her concerns seriously and attributed the symptoms to mental health problems – eroded her confidence in physicians. In retrospect, she believes they were ageist and condescending towards her as an older woman.

As a result, she opted to find a new primary care physician and transferred her records, now resuming twice-yearly visits with him. In her *health and vitality network* are also students who provide dental care at a nearby School of Dentistry. Twenty years ago, she had a partial knee replacement resolving knee pain and allowing her to be more active. Since the surgeon told her she might need additional surgery, she keeps him in her health network.

Education and Enrichment Network. Some of Janet's enrichment life is solitary. She enjoys reading and does so daily in the morning and evening, but she is also extroverted and enjoys the company of others. In the past, she attended lectures in her community and at the local university and concerts in local venues with friends. *C. diff* prevented her from joining others for events during those months and contributed to social isolation, but now that she is recovering, she has begun to attend again and would like to meet new friends interested in joining her.

Spiritual Network. Janet was raised in one of the major religious traditions, but her social and theological views changed decades ago and since she no longer feels at home in that tradition, she has no formal, congregational spiritual network. A neighbor has suggested she attend a Universalist Church nearby and she is contemplating doing so, though she is not sure she wants to be part of a congregation at all. In the meantime, her spiritual life consists of attending lectures on Zen held in the local community and participating in a spiritual book discussion group, being in nature and tending her garden.

Social and Community Network. Janet formed close relationships with colleagues in her years as a teacher when she lived in the Midwest and they remain friends, although they are scattered across four different states. She communicates with them by phone and email, and occasionally they arrange visits. Locally, she formed high-quality friendships with neighbors. She also formed close relationships with other volunteers at the soup kitchen, but since *c. diff*, feels she should no longer work there and only sees them occasionally at social events.

Janet's gated community provides some social, cultural and fitness amenities. However, there is no local mass transit she can use to get groceries, run errands, keep medical appointments, or engage in community volunteer work. For that reason, she must be able to drive or prepare for the day she cannot by finding a driving service.

Home and Personal Affairs Network. Janet's home is in good condition and has been maintained well, but exploring her networks made it clear the many people and services involved in maintaining it. Even though her son helps out as her handyman and for large garden projects, she needs help from others, too.

This is true for her personal affairs, as well. Having managed the affairs of her brother, husband and son as they became ill and died, she knows the value of wills, powers of attorney and living wills and believed hers are in order.

Network Sage Assessment

Based on this initial assessment, it appeared Janet had prepared better for the eventuality of her death than she had for her goal of aging-well-in-place in her own home. Network mapping made next steps obvious to her and her family.

Janet's Age-Well-in-Place Plan

Janet's goal is clear: to live in her own home for the rest of her life. To succeed, she needs a plan

to address three key challenges that exploring networks brought to light:

- First, without traditional, large extended-family support and given the importance of being able to drive and be otherwise mobile, recovering her health and vitality is essential. She needs to restore the strength and fitness she lost during her illness.
- Second, understanding the value of social support for her physical and mental health

and the overall quality of her life, she needs to expand her social and community network to build connections with new people who can be companions for the activities she enjoys.

- Third, she needs to better organize – and communicate about – her home and personal affairs, so that her children and grand-daughter have information to help her manage – including from a distance – if the need arises.

Network	Janet's Action Plan
Health and Vitality	Goal: rebuild strength and regain confidence in my body <ul style="list-style-type: none"> ▪ Sessions with a strength trainer to learn how to lift weights ▪ Morning water exercise classes at the community pool ▪ Find friends who want to swim or water-walk at night
Social and Community	Goal: strengthen existing friendships and enlarge my social circle <ul style="list-style-type: none"> ▪ Attend singles' club events ▪ Strengthen connections with out-of-state friends and plan trips to see them ▪ Learn Facebook and use it to find old friends ▪ Find local friends who want to attend lectures and concerts ▪ Become a library reading volunteer
Home and Personal Affairs	Goal: create peace of mind for me and my family by sharing more information <ul style="list-style-type: none"> ▪ Organize all personal affairs paperwork ▪ Assure all HIPAA forms are signed so my new doctor can share information with my family and nurse case-managers ▪ Provide my family with contact information for each person in my networks ▪ Provide my family with password and other information for online and automatic bill-pay accounts ▪ Assure my family is listed as co-owners on all bank accounts ▪ Identify local driving services in the event I ever need one ▪ Explore food-delivery services in the event I ever need one ▪ Explore local service agencies that support aging-well-in-place

Janet's family has a goal as well: to support her intention to live in her home by empowering her with information and emotional support, particularly in the areas of her three most immediate: health, social life and personal affairs needs. Although they could be more assertive in taking charge, they felt doing so would rob her of the autonomy she wants.

As a result, their plan includes:

- Encouraging her to take the steps in her personal action plan.
- Finding ways to celebrate her accomplishments as she completes the steps.
- Knowing she values science and research, sharing medical studies showing the value of exercise and social networks for seniors.

- Monitoring for changes in her health and behavior that signal a need to consider intervention.

With clear goals and a plan in place, Janet and her family have greater peace of mind and feel more confident about the prospect of her living in her own place.

Three-Month Update

Janet's plan is well underway. She has a trainer, is lifting weights, has become an active member of the single's club and is on a committee to plan future events. She suffered a brief health setback caused by a too-high dose of an antihypertensive. Her physician responded to her concerns well, adjusted the dose and that helped restore her confidence in health care providers.

Unfortunately, that setback had social network consequences. It required she cancel a trip to see retired teacher friends in another state.

Even worse, soon after the cancelled trip, her emotional health suffered a major setback when she learned that three of her four best friends – people who moved to the neighborhood when she did a decade ago – were relocating to live closer to their adult children.

Her daughter helped her clarify that she was not depressed, but rather, was grieving the loss of good friends and their social support. Her daughter warned her to be careful when she spoke with her physician about it, since he might mistake normal grief for depression and prescribe an anti-depressant. The loss served as further encouragement for Janet to maintain her own health so that she could travel to visit these friends at their new homes.

Network	Janet's Action Plan Three-Month Update
Health and Vitality	Goal: rebuild strength and regain confidence in my body <ul style="list-style-type: none"> Continue with weight-lifting Find more friends to water-walk in the evening
Social and Community	Goal: strengthen existing friendships and enlarge my social circle <ul style="list-style-type: none"> Reschedule the trip to see friends now that I am feeling better Plan visits to see friends who are moving
Home and Personal Affairs	Goal: create peace of mind for me and my family by sharing more information <ul style="list-style-type: none"> HIPAA, banking all other paperwork is on the way to being organized. It can feel overwhelming, especially since I'm busy taking a friend for leukemia treatments and helping her get groceries. My daughter is going to help when she visits over the holidays. I found several paid and one free driving service that can help me if the time comes I can no longer drive.

Six-Month Update

During a holiday visit, her daughter reviewed Janet's legal paperwork and found each one was flawed. Her *Last Will* had not been executed properly and could not have been

taken to probate. Janet's deceased son was still named in her *Powers of Attorney*. Her *Living Will* – a checklist document given to her during a hospital seminar – gave her agent only the power to consent to a procedure, not the power to withdraw care. Having watched her

brother and her husband linger in comas, Janet was clear about her own wishes and wanted her children to be able to withdraw care if needed. It would take more than six weeks to find an attorney and draft new documents, and the waiting – and fear she would die in the meantime – were stressful for her.

During the holiday visit, Janet said she feared her hearing loss was worse and felt it was

impacting her cognitive abilities. No cognitive decline is apparent to others, so the differences are those only she feels. She asked her son to program her television to provide her with closed captions so she has the added stimulation of news. Her daughter got her a subscription to Netflix and showed her how to find the historical dramas she would enjoy to supplement her reading of European history.

Network	Janet's Action Plan Six-Month Update
Health and Vitality	Goal: rebuild strength and regain confidence in my body <ul style="list-style-type: none"> ▪ I've gained so much strength, I can do everything I want around the house and in the garden, and I'm able to make long drives to visit friends.
Social and Community	Goal: strengthen existing friendships and enlarge my social circle <ul style="list-style-type: none"> ▪ I do regular outings with the Singles' Club and now get invitations to dinners and events frequently.
Home and Personal Affairs	Goal: create peace of mind for me and my family by sharing more information <ul style="list-style-type: none"> ▪ My son found an attorney to do all the documents I needed, my daughter made a special trip back and we all met so I could review and sign the documents. Getting the paperwork done gave me the peace of mind I needed. ▪ I've given contact information for my friends, doctor and others who help me to my kids in the event they need it to help me in the future. ▪ I've also told my kids that I need contact information for people in their lives. Especially if my daughter, who is single and lives so far away. If she needed me to help, where would I begin?

Nine Month Update

Janet's brother died recently, making her the last survivor of her generation. She decided not to travel across country for his funeral and dealt with her grief by writing a very long letter to his kids, grandkids and great-grandkids, recounting memories from their childhood together. Now the matriarch of the clan, her nieces and nephews are traveling to visit her and that has been good for her emotional well-being.

She has taken even greater control of her health and recently saw her audiologist to address her hearing loss. At that visit, she learned her hearing was not getting worse but rather, both hearing aids were malfunctioning.

They were still under warranty and were replaced at no charge.

She had the inside of her house and garage repainted and, though she did not do the painting herself this time, she was able to do all the preparation required, boxing and storing items and moving some furniture for the painters. The carpeting in her home needed replacing, and she opted to have hardwood floors installed because they would be easier for her to continue to maintain on her own.

One-Year Update

Janet's health and level of fitness has returned, nearly to its pre-*c.diff* state. This allowed her to make plans for a month-long trip to see retired-

teacher friends in the Midwest. She prepared her home for the time away, made all the travel plans for a two-hour drive to the Orlando airport, the flight to her destination in Chicago and was ready well in advance.

Her departure day was especially demanding, as it was the last day Orlando airport was open before the arrival of Hurricane Irma. Her family wanted her to remain at home, since her son was nearby and prepared to address any hurricane-related needs. Over their objections, she kept her plans. The health, fitness and resilience she regained allowed her to manage the challenges of traveling during a state-wide evacuation, airport crowds and a 20-hour travel day.

Janet spent a month visiting friends and all the places she once lived and worked in the Midwest. The trip culminated in a 16-hour drive back to Florida, managed over two days. She shared the drive-time with a friend, tending the friend's dog along the way.

Her home was spared hurricane damage, but after a month away, the gardens were overgrown. For several weeks she spent early hours each day pulling weeds and trimming bushes until it was too hot to work outdoors. She used the rest of those days indoors, tackling a kitchen remodeling project.

Since the last update, new neighbors have moved into the homes vacated when her close friends relocated months ago. She's met each one and several have offered – and provided – their assistance if she needs it. One works at the gym and encourages her to work out more often.

It took some doing, but she's also become more accepting of help. In a recent example, she was unable to lift 50-pound boxes of tiles for the kitchen backsplash out of her trunk and carry them into her house. She counts asking a neighbor for help as a milestone on her journey and agrees that occasionally asking for help is far preferable to assisted living.

Eighteenth-Month Update

Janet began having difficulty sleeping recently. Her physician prescribed Trazodone to help her sleep, but it left her unable to function for all but two hours the next day. Her physician suggested taking it earlier in the evening, but that did not resolve the side effects, so she only moved those 'two good hours' to earlier in the next afternoon.

Under the next-day influence of the drug, she was no longer interested in exercising or socializing and had no 'good hours' left after she ran errands like grocery shopping. Nonetheless, her physician pressed her to continue to take it and said she would need it the rest of her life.

After several months, it became clear to her family that the drug created a downward spiral in her mental and physical health not unlike what she experienced with *c.diff*. Again, network insights helped.

Whatever the initial cause of her sleep problems, the next-day fogginess kept her from being around other people and doing the things she loved. She didn't exercise, visit antique shops, volunteer, see friends or engage socially. It was also harder for her to take care of her home and gardens.

She decided on her own to stop taking the drug. With great resolve, over the course of a month she successfully weaned herself off of it. Her physician never knew because he retired during that time. Janet said it was a good thing or she'd have "read him the riot act" for putting her on the drug without exploring better ways to address sleep difficulties or explaining the side effects and risks.

She's developed a formula for sleeping better that includes getting enough exercise and dealing with anxiety and grief. Exercise comes

from tending her gardens when the weather is good, cleaning house when it rains and going to the gym. She's even signed-up for "senior games," which required she learn how to use all of the exercise machines.

To deal with anxiety that any – even a mild – symptom means that *c.diff* has returned, she enrolled in a six-week program at a local college about GI health taught by a Gastroenterologist and is keeping careful notes about her diet and other factors that can impact symptoms.

Grief has been more problematic, however. Of the three friends who relocated months ago, two have since passed away, both within a few months of their move. Her family and other close friends are helping her deal with those losses by remaining close and making suggestions about how to honor their lives since she was unable to travel for their funeral services.

Twenty-Four Month Update

Janet celebrated her 90th birthday on a week-long cruise with her family. It was not her first cruise, but she was joined by her great-grandchildren for her first snorkeling experience. She is engaged socially, ushers at concerts at the local college, plans singles club events and continues to live independently.

She also found a new purpose, this time with a program for teenage girls at risk from poverty and family disruptions. At a recent meeting with them, she asked if any wanted a grandmother; every hand shot up. She is now designing an outing with them in which they will go to grocery stores where she will teach them how to shop for healthy food on a budget, combining math, nutrition and cooking lessons. Her goal is to help them prepare Thanksgiving dinner for their families next year.

Disrupting her life at this point are problems with her home. On two different occasions, she

discovered leaks (a problem now happening to others in her development as well) that caused damage to the walls of three different rooms in her home. For the most part, she was able to manage plumbers, insurance adjusters and reclamation people on her own. She's proud of her ability to do it herself, even though some of those involved were less than helpful.

Her comment at this update was, "I waited at home for two days for the insurance adjuster to come, he didn't, and he didn't call. At the same time, my regular tree trimmer promised to be here, but he didn't show up either and his wife says he's now too busy to help me. I've called several others and they're busy and not taking new customers.

"If seniors are going to live in their homes, they need to have people who can be reliable and show up to help when they're needed.

"They have pretty high standards for how we need to maintain our property and if we don't comply, we are fined. I'm waiting for the HOA to show up at my door to say the trees need trimming. I'll tell them I'll gladly pay if they can find someone to do it, because I can't."

