# The Full Life



Join Ann Hedreen for Breakfast on October 22 See back

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Fall 2015

## Discovering Power in a Powerless Situation

At Full Life Care's annual benefit breakfast on October 22, local writer and filmmaker Ann Hedreen will speak on behalf of those struggling to make sense of a life touched by Alzheimer's disease.

Ann is a passionate advocate for Alzheimer's research and author of *Her Beautiful Brain*, a memoir that details her struggle with her mother's younger onset Alzheimer's disease. With unflinching honesty and raw emotion, Ann reveals just how personal and consuming the disease is for both those who live with it and their family members.

The title refers to her mother Arlene Grundstrom Tocantin's beautiful and brilliant brain before it wasted away from a combination

of Alzheimer's and Lewy Body dementia. Alzheimer's silently crept into their lives soon after Arlene established her career as an English teacher at Roosevelt High School and should have been





Ann and her mother Arlene

enjoying her sprawling family of six children and 14 grandchildren. The telltale clues and memory lapses slowly piled up over the years, as did Ann's resentment over her mother's seeming

inattentiveness to their own struggles, joys and accomplishments.

As Ann struggled with a failed first marriage, found new love, and achieved accolades as an Emmy-winning news producer and documentary filmmaker, Arlene's detachment hurt. And as Ann became a mother herself, it became increasingly obvious her children would not have the grandmother Ann envisioned.

When the diagnosis was finally delivered, Ann

writes, "I wanted to get away because I was having the one thought I knew I should not be having at such a moment: I'm not up to this. Whatever this is."

What this turned into was a long, slow journey into the unknown that was both predictably tragic and unexpectedly joyful.

"Caring for someone with Alzheimer's disease is like parenting in reverse, removing one freedom at a

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# **Kindness is Part of The Journey**



Kevin on his 90th birthday



Jennifer and Kevin

When Gaffney House resident Kevin Kelly learned he was being interviewed about his daughter Jennifer he immediately said, "Jennifer is the most thoughtful and caring person I know. My daughter always goes out of her way to help people."

This brought tears to Jennifer's eyes. It was poignant not just because she felt closer to her father than ever before, but because helping people is the inspiration for her songwriting.

"This is the closest my family has ever felt to my father," Jennifer said. "I've been so inspired by the intimacy of helping him on this journey."

"The Journey" is the title of Jennifer's latest song inspired by her father and his experiences living with dementia.

"I think I'm going on a journey Jennifer," Kevin told his daughter one night from his hospital bed after surgery to repair a hip fracture. He had suffered a bad fall and broken his hip.

"It was a moment I'll never forget because we both intuitively knew he would never be able to go home," Jennifer said. The family made the tough decision to move Kevin to assisted living.

When he first moved into Gaffney House Kevin was disoriented and frightened. Jennifer's brother volunteered to stay with him the first night. But Kevin grew very distraught during breakfast.

"That morning when a bowl of cold cereal was put before him, I guess he became very upset," says Jennifer. "He didn't know what it was and said something about always eating a hot breakfast."

Rahma Abdi, a staff member at Gaffney House, quickly made Kevin a big hot breakfast. When Jennifer arrived a short time later she said he was "calm and radiant" and talked about the "beautiful woman" who made him breakfast. What he said next became lyrics in "The Journey": Have you seen the kindness all around me? I am no longer afraid.

"When we sing in the house it's true what they say about music. People laugh and smile and talk in clear sentences."

Jennifer is working on her second album of original music and continues to write songs focused on human experiences of love, loss and change.

"It is the greatest honor and privilege to perform and write songs that speak to people's suffering in a way that gives it meaning and connects them," Jennifer says.

Jennifer often brings her guitar to Gaffney House and enjoys singing with her father and other residents. She said he rarely sang publicly before he had dementia but she always knew he had a beautiful voice, just like his father.

"Dad, would you like to sing us your favorite song?" Jennifer asked. With a laugh and a smile, Kevin launched into a Pepsi jingle from the 1930s:

Pepsi Cola hits the spot / twelve full ounces, that's a lot / twice as much for a nickle, too / Pepsi Cola is the drink for you!

"When we sing in the house it's true what they say about music," says Jennifer. "People laugh and smile and talk in clear sentences."

#### Among Friends

# Building a Foundation for Friendship

By Laura Weiss Lutheran Volunteer Corps, 2014-15 ElderFriends Match Coordinator

If there's one thing I've learned during my time as the ElderFriends Match Coordinator, it's that meaningful connections are always possible. The manner in which a friendship is forged is often more important than having similar interests or experiences. This is the case with

volunteer Jen Watkins and her friend Diana Yorks, who have been matched for about a year. Despite their differences, a sense of acceptance has been fundamental in the growth of their friendship.

When asked what she appreciated about Jen, Diana exclaimed without hesitation, "I can feel confident with her about my story." Although it's clear they're good friends now, it wasn't always this way. These two started like any other pair of strangers: both curious and cautious, eager yet reserved. When Jen picked up Diana for their first meeting, they met in front of

Diana's apartment building and went somewhere else for lunch. This was the norm for the first six months as they got to know each other and slowly opened up.

One day, something changed. Diana invited Jen to park the car and meet *inside* her apartment. Apart from her feline companions, few had received such an invitation. Diana admitted she was nervous—it was a big step for someone to see her personal living space—but by this point Diana "knew she didn't judge me." They had built a foundation of trust into their relationship, which paved the way for even more meaningful conversations and shared experiences.

Storytelling is a trademark of Jen and Diana's friendship. As Jen remarks to her friend, "you like talking and I like listening to stories." With time Diana has shared more and more of her personal narrative, including her experience as a homeless woman and the purchase of her first home 14 years ago. She also shares stories about her first "pet baby," Boots, who passed away last year but had been with Diana since she first moved in. Jen has listened with

respect and an admiration for Diana's resiliency, inspired by her ability to maintain hope despite hardships. Diana feels increasingly comfortable with Jen as she's realized, "If she hasn't ran away from me yet, I don't think she will now!"

Many volunteers join ElderFriends with an intention to hear and learn from the rich life stories of older adults. What's often undervalued is the opportunity for volunteers to share insights from their experiences, as well. Diana has learned a few things from Jen this year, as she's shared about her efforts towards

Jen this year, as she's shared about her efforts towards wildlife conservation and restoration. They've discovered a mutual passion for nature and animals, including Jen's chickens. When Jen first brought her a batch of eggs, Diana was astonished to discover that "chickens lay colored eggs!"

Whether it's a tale from the streets or a strangely colored chicken egg, Jen and Diana have come to know and appreciate each other's unique stories. Although their life journeys have differed greatly, a simple sense of acceptance and understanding is exactly what makes this friendship so special.



Jen and Diana

### Beer for a Cause: a Record-Breaking Success

Thank you to the 500+ people who attended our Beer for a Cause fundraiser on Thursday, April 23, 2015

Over 500 Full Life supporters gathered on Thursday, April 23 for our Annual Beer for a Cause event. Guests enjoyed cold beer, cider, fine wine, and the roaring '20s feel of our new venue at Aston Manor. Amazing prizes were raffled including dinner at Canlis, an Oregon coast getaway and many more. Guests also participated in our "You Hold the Key" wall and made gifts in honor and memory of

loved ones. All of this generosity added up: we raised over \$36,000 to support our programs and participants. Special thanks to event chairs Frances Holtman and Cheryl Swartz, our event MC Brian Osborn, and our hardworking committee and event volunteers. We also could not have done this without our event sponsors including Slalom Consulting, Georgetown Brewing Company, and everyone else who helped to underwrite this event.

Visit www.facebook/fulllifecare to view more photos.

#### **THANK YOU Beer for a Cause Committee**

A few of the 17 committee members



Cathy Ayers and Cheryl Swartz



Frances Holtman (center) with revelers



Amanda McGowan (center) raises a toast

## **Discovering Power**

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time," Ann said in her 2004 awardwinning documentary film *Quick Brown Fox: An Alzheimer's Story.* 

The disease has its own "particularly insidious torture methods," Ann writes. One is the open-endedness of it. There is no timeline and no way to know how the disease will progress. Another is the painful realization that "once you've passed a certain point, you can no longer talk about it with the person who has it."

"There is no crying together about the awfulness of fate; there are no goodbyes." Ann writes.

Yet during nearly four years of extended grief, as her mother survived beyond the point of being able to communicate, Ann discovered she could volunteer for Alzheimer's research at the University of Washington's Alzheimer's Disease Research Center. Over the past decade she's had MRI brain scans, donated spinal fluid five times and returns every year

for a battery of cognitive tests.

Ann says it didn't make accepting her mother's dementia easier, but she found it "deeply meaningful and valuable."

"It can help you feel like you're doing something powerful despite being in a powerless situation," she said.

Ann will be the featured speaker at Full Life's Annual Benefit Breakfast, Thursday, October 22, 2015 at the Seattle Sheraton Hotel. See back page for details.

## Supporting Our Amazing Caregivers



By Nora Gibson, Executive Director

I recently visited Gaffney House and introduced myself to the daughter of a resident. I told her my mother lived there until she passed away.

"Oh so you know!" the daughter said, suspecting that we shared some secret knowledge.

"Yes, I know," I said, pretty sure we were on the same wavelength.

"This place has the best caregiving staff I've ever seen," she continued, confirming that we were, in fact, enthusiastic about the same secret.

My mom had 10 children. When she lived in Gaffney House, several years ago, I was the only one of her kids who lived in the area. But after her other children came to visit her here, they would return home with anecdotes, marveling

about the staff. One of my sisters said, "The caregivers make me want to be a better person."

As I was finishing my visit at Gaffney House I saw Haregwa, just one of the many workers who have worked there for a number of years. I noted to myself how she is always so cheerful, warm and affectionate. She was bringing a resident into the living room, and he was laughing and smiling as well. Haregwa and the other caregivers at Gaffney House loved my mother. It's the best feeling a daughter can have when you turn your parent's care over to others.

That same week I went to lunch with my father, who talked about Maria, a Full Life home care worker who helped my parents at their condo with shopping, banking, cooking, and personal care. When Mom moved to Gaffney House, Maria continued helping Dad. He remarked, "It is so amazing to think I was able to live in the condo for three years longer because of Maria's help."

That was also the week that a neighbor of one of our day centers took a moment to email us:

"I just wanted to take a moment to write. I am working from home today, which is across the street from [the North Seattle Adult Day Health Center] and the park.

"The staff just took the elderly clients out for some exercise and air in the park and I was just really struck by how great the staff are with them, so attentive and engaging. They are doing an amazing job."

The common theme in these stories is the compassion and skill set of all of these workers. The Gaffney House resident's daughter, my dad, and the neighbor are right on the money: the caregivers are amazing. They are also low-wage workers. They

are part of what might be the most important workforce in our country. And eventually they will be taking care of us.

The \$15 minimum wage in Seattle is a welcome start toward wages that will allow working caregivers to continue providing essential services to frail elders and people living with disabilities. I am a strong supporter, even though our government contracts have yet to keep pace with rising costs. I'm confident that SEIU 775 – the union that represents our employees – will continue to be a lead partner in

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"As baby boomers retire, the need for caregivers will increase dramatically – we fight every single day to improve wages, benefits and training for caregivers so that the folks who do this critical work are paid a living wage, have good health insurance and a path to a meaningful retirement, and are provided with training that ensures they are able to take excellent care of our community's most vulnerable people."

—Sterling Harders *Vice President, SEIU 775* 



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#### **Nora's Corner**

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our efforts to create and grow a superior long-term care workforce.

With the baby boom generation moving into older age, we will not be able to construct places for all of us to move to when we need support. Nor would we want that.

We need to successfully attract caregivers into the community-based workforce and provide training, compensation and supportive benefits that will keep pace with the cost of living.

And when your loved one needs more intensive care, I hope places like Gaffney House and Buchanan Place, and supportive services like adult day health and home care, are thriving in your neighborhood. If they do, you'll be able to sleep at night, knowing your loved ones are receiving the amazing care they deserve.

# YOU'RE INVITED! A Breakfast to Benefit Full Life Care

7:30 am – 9:00 am Seattle Sheraton, Downtown

Info: www.fulllifecare.org/breakfast Suggested minimum donation: \$150

RSVP by October 1, 2015: alexf@fulllifecare.org or 206.224.3749





FEATURED SPEAKER: Ann Hedreen

EMCEE: Dick Foley
CHAIR: Maneesha Lall
CO-CHAIR: Julie Lemery