

## **CPI *Unrestrained* Transcription**

Episode 10: Jan Zimmerman

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Host: Terry Vittone

Terry: Hello, and welcome to *Unrestrained*, the CPI Podcast Series. This is your host, Terry Vittone, and I'm joined today by Jan Zimmerman. Hello and welcome, Jan.

Jan: Hello.

Terry: Jan Zimmerman is a registered nurse and a dementia care specialist. She has been in the field of nursing for over 30 years, and part of Heritage Homes Assisted Living and Memory Care in Watertown, Wisconsin since its opening in 2010.

She brings a wide range of nursing experience from pediatrics to geriatrics, medical, surgical care to psychiatric services, and hospital to home health. She is a trained instructor in dementia care and has been a speaker at multiple conferences and workshops covering topics such as dementia, medications, and alternative medical therapies.

Jan has been instrumental in starting a grass roots movement to make Watertown a dementia-aware, dementia-friendly community. Watching those living with dementia and their families and friends struggle with the changes dementia brings led Heritage Homes to explore what they could do outside of their campus. "We saw a need to help people remain a vital part of the community, looked around, and saw very little resources out there. When asked why would a small town like Watertown start something like this, we replied, 'Why not?'" in Jan's words.

And I'd like to begin now with a question, Jan. How did Heritage Homes and Alzheimer's Speaks come together to create the Watertown Dementia Awareness Coalition?

Jan: The Lutheran Home Association, which is our parent company in Belle Plaine, Minnesota, had invited Lori La Bey, from Alzheimer's Speaks, to speak to our administrators at one of our administrator's meetings. That was my first meeting with her, and I was very impressed with her passion.

Since we opened in 2010 we realized that there was a great need in the community for education related to dementia. Family members, friends, community members would frequently contact us with questions related to dementia. Mike Klatt, who is our CEO of the Lutheran Home Association, suggested to Heritage Homes that since we did an annual education workshop that maybe we should consider having Lori be our keynote speaker. I thought it was a great idea, and we contacted her.

She agreed to present at our October 2013 Workshop and we started talking about how we wanted to focus the topic. I went to her website and saw that she had a number of webinars and videos for businesses to become dementia aware. That was very interesting to me. We had done programs for those living with dementia, their care partners, health care providers, but nothing specifically targeted to businesses.

I did an Internet search for other communities in the United States that were dementia friendly, or working towards becoming dementia friendly, but I couldn't find any. So all the references on dementia communities were in the U.K., New Zealand, Australia, Denmark, Holland; there was nothing here in the United States. I felt it wasn't right that the United States didn't have any initiatives started, so we decided to focus the 2013 event on the businesses and community awareness so that Watertown could become one of the first communities to become dementia friendly.

Lori La Bey was very helpful and supportive in launching this initiative. She's encouraged us to go forward and helped us in any way that she could with her advice, her immense knowledge, and her contacts. She pointed us to resources and friends that she's made across the nation and in countries. And when we need any kind of advice, resources, or just plain support, she's been there for us and has always been very supportive of us.

Terry: That sounds like a really productive collaboration so far. And Jan, weren't you exposed to the idea of a dementia-friendly community through a speaker from the British Isles at first?

Jan: Norm McNamara is very vocal on dementia-friendly communities. He is living with Lewy body dementia, and when I read a lot of his articles on the webpage, it very much inspired me—that this is the thing that we needed to do. It was the right thing to do.

Terry: And since you've partnered with Alzheimer's Speaks with this initiative for the coalition, how are businesses responding to you guys so far?

Jan: They've responded very well to us. Almost everyone we've spoken to has been touched by dementia in one way or another; maybe a parent, a grandparent, maybe a friend had or has a diagnosis of dementia. We've had ten businesses who have earned the Purple Angel. We have a number of pledges from other businesses who are requesting education. As the majority of our volunteers who are willing to provide education have other job responsibilities, it's been kind of a challenge that we don't have the personnel or time to

provide the education as fast as we'd like. Our goal is that one day we will have a full-time educator, but until that happens we're doing what we can to meet the requests from the different businesses.

Terry: So what sorts of businesses have joined you guys? Ten, that's a good start.

Jan: It is. We have businesses, such as banks, assisted living, skilled nursing, grocery stores, working with the library, religious organizations, emergency services, fire, and police.

Terry: I'm sorry to cut you off there.

Jan: That's okay.

Terry: You just led me to a question when you were speaking about the bank and it's related to the next one. Did you have another one to add?

Jan: Oh, the city government.

Terry: Really?

Jan: Across the board, legal, there are so many ramifications with those living with dementia in a community that it touches all aspects.

Terry: And that dovetails nicely into the next question here about what makes a business dementia capable. Now you mentioned a bank. Now I can see how that would be a place where someone with memory care issues would need some oversight and help for sure.

Jan: Working with numbers is like one of the first skills to leave with a short-term memory. With a bank, they can monitor to see how a client is handling their money. The bank down the street from us, the State Bank of Reeseville, was one of our first to get the Purple Angel for their business. And what they noticed was that individuals coming in were doing multiple withdrawals. And that was not normal. And so what they can do is when they see something like this out of the ordinary they can ask themselves, you know, do they maybe have some bills coming up that they are not aware of, or because they are more vulnerable, is there an issue with somebody possibly pulling a scam with them, and they are being frauded? Or is it just that they are forgetting that they have it? They are taking it home and hiding it, and then going back for more because they need money and they haven't withdrawn any, even though they just did.

So we talk to them about some of the different things that they might see related to memory loss. And then what do you do with that information? That's the big question.

Terry: Right.

Jan: There is privacy; there are legal regulations with it. And so what we encourage them to do is if they see anything out of the ordinary, anything they have concerns with, that they go talk to the bank manager. The bank manager can contact the person, contact the family members, kin, and contact Adult Protective Services to make sure that everything is going the way that it should so that person is safe and isn't being scammed or losing money.

Terry: Now what happens when a business joins the coalition?

Jan: When a business joins the coalition we ask them a couple of things. A business can decide first if they want their employees to become dementia aware, and if they want to join the Watertown Dementia Awareness Coalition organization, or they can do both. If they join the coalition, they will agree to have education provided to their employees about basic dementia, and how it applies to their specific business.

We don't expect anybody to become dementia specialists; we just do basic what is dementia and the physical changes that are going on so that they understand there is an actual physical change. It isn't somebody just being stubborn or difficult. And then we touch on what types of behaviors that they might see with somebody coming into their business. And then how they can communicate with that person, how they can approach that person, maybe in a little different manner so that they can help decrease some of the confusion that may be going on.

Terry: I see, so let me ask you—say I want to start a shoe store in downtown Watertown, and I call up the coalition and you guys. Is there a cost to me to join?

Jan: No, there is not. One of our goals is to keep this free to the community. We feel that this is something that is just the right thing to do, and we want to spread the awareness and education in any way we can. We are working on possibly getting some grants. We do take donations if somebody wishes to donate to us. We will be doing some fundraising. But our goal is that this is free to the community.

Terry: I see, and now as a business owner, then, I would take something called the Dementia Friendly Pledge. Is that accurate?

Jan: Correct.

Terry: Could you talk about that for a moment?

Jan: Sure. Our pledge is we agree to commit to becoming dementia aware by learning more about dementia, how we can help employees become sensitive to the needs of a person living with dementia and the people that support them. That is on our pledge sheet. And so by signing that, the business agrees to learn more about how to help employees become more dementia aware, and that they'll look around and assess the business

environment to see how it can be made more dementia friendly and maybe easier to navigate for a person with memory loss.

Terry: I see, and at some point then, I know you guys have a Purple Angel, and maybe you can talk about that.

Jan: Sure. Purple has long been associated with dementia and Alzheimer's related diseases. When we started, we felt we wanted a logo that people would immediately associate with dementia. And after a lot of discussion and searching, we decided on the Purple Angel, which is the symbol of dementia awareness and collaboration in the battle against dementia.

The Purple Angel stands for hope, protection, inspiration, and universal teamwork per the PurpleAngel.org.uk website. It's been adopted and shared by thousands of people across nations to indicate caring about those with dementia and wanting to help raise awareness. The Purple Angel acts not only as a guardian to those living with dementia, and their care partners, friends, family, but also as a helper to those who are working hard to raise the awareness of dementia around the world.

The original Angel was a caregiver called Elaine, who lived in I think it is Torquay—I think I'm pronouncing that correctly—in the United Kingdom. Her partner, Norm McNamara, the man I talked to just before, he's living with Lewy body dementia. And Elaine and Norman and their friends were instrumental in starting one of the first dementia-friendly communities. And the original Purple Angel was developed by Jane Moore from Camelford in Cornwall. Norm had raised a challenge for somebody to help create the Purple Angel.

So we chose this angel with a globe as we felt it's a universal endeavor that we hope will spread not only across Wisconsin and the United States, but join hand in hand with the other global nations that are also trying to raise the awareness. And so businesses that make the commitment to become more aware of memory loss, and obtain education for their staff, can earn a Purple Angel that they very proudly display in their windows or doors. And it's really meant to open honest conversations about dementia, challenges that it causes, and how communities can support the person with dementia and their care partners.

Terry: I see. So Jan, if we could go back now—say I'm a business owner with that shoe store. How do I earn that Purple Angel?

Jan: In order to earn it the Watertown Dementia Awareness Coalition has asked businesses to sign the pledge, committing to learning more about how to help employees become more dementia aware. We ask them to assess their business environment to see how it can be made more dementia friendly, easier to navigate. So simple things, I went to a restaurant one night and I needed to use the restroom. Well, after searching for a while and getting some kind of vague directions from the servers, I went down into the basement and found

them. Now on the door said, "Does and Bucks." I kind of figured out I was a doe, but if you have problems processing, that would not mean a restroom to you.

Terry: Right.

Jan: And so simple things (such as having the word *toilet*, women on the door, as well as the does and bucks) would have made a difference—and having clear signs to direct a person there. How embarrassing it is for us sometimes to have to ask for directions to the restroom. Well, if you have problems maybe with incontinence and urgency, and you're having to ask, they may not feel very comfortable having to ask somebody for directions to the toilet.

Terry: Right. That would be a huge change, just clear directions and then the appropriate restroom. Yeah, that would be big for someone with memory issues for certain.

Jan: Yes.

Terry: And you guys have something there called the Memory Café.

Jan: Yes we do. That started up on October 15th in 2013. It meets the third Wednesday of every month at a local coffee shop called the Connection Café, just down the street from us. And Lori La Bey who lives a very active café in Minnesota helped launch our first one. One of the challenges when a person is living with memory loss is that it can sever some social connections, and at the time when it's really needed the most. A lot of people have the stereotypical image of somebody with dementia that is very negative. They don't know how to interact with them. One of the women at the Memory Café told me that when she mentions that her husband has dementia, many people kind of mumble I'm sorry, look down, and then they start to drift out of their lives.

So people a lot of times become isolated, even through their own choice, because of the challenges being out in the community, or because sometimes friends and family members no longer try to see them or include them in social events because they're not comfortable talking with somebody with dementia who may be struggling.

Terry: And that leads to a lot of attrition for a lot of people.

Jan: Correct. The vast number of people with memory loss are living by themselves in their home, and they don't have a lot of support or contact from friends or family. So anything we can do to really decrease that isolation is what we are trying to do for them.

Now the Memory Café is one where people with memory loss or their care partners can come together to make new friendships and support one another. It's not a therapeutic group; it's a social group.

Terry: I see.

Jan: It's a social time where they can get together, and they don't have to worry about if they forget something, they can't find the right word, because everybody is in that same boat there. So it's not a group like some of the support groups where caregivers go in one room and those living with dementia go into another. They are there together.

Terry: And is that a pretty active ongoing group that participates?

Jan: Yes, we generally have between 10 and 12, but we've been down to like 6 or 7 at times. But it's very active when they are there. Somebody from Heritage Homes will be there to set up and sometimes, you know, get the ball rolling and things. But the direction of the conversation is really determined by the people attending. The conversation can be questions that somebody has related to dementia, or it might be reminiscing about something last one that we were at. We held a very hilarious conversation on what is shorthand. We had one younger person there who had never heard of shorthand, much less seen it. And then another big discussion of how you fold a cloth diaper. They had a lot of fun instructing this younger person on how it used to be with diapers.

So you just never know which way the situation is going to go. A lot of times there is a lot of laughter; sometimes there are tears. But it's always a feeling of not being alone.

Terry: That's important. So you feel like, about a year into this now, this coalition has got a real presence in Watertown.

Jan: Yes, we are getting there. One of my major accomplishments that I'm kind of proud about is we had a business and one day somebody walked in and said, "You know, I saw the Purple Angel on your window. My mom has dementia. I'm wondering if you could help me find some resources." So to me that means that people are starting to associate that Purple Angel with dementia awareness and caring.

Terry: That's a beginning, no doubt. Do you have any advice, Jan, you might give to a listener out there in another community who thinks that maybe a dementia awareness coalition could make sense where they live?

Jan: Yes, number one is just do it. Why? Because it's the right thing to do. Somebody has to start it.

Terry: Right.

Jan: And one voice can make a huge difference. Approaching businesses, organizations, on a personal level really encourages a willingness to change, because as I said, it was very rare when I went into a business to talk to staff or managers that somebody didn't know somebody with dementia. People are just hungry for information. You want to remember

that flexibility is really important. You try one thing, and if it doesn't work, then you move on with your new knowledge and be willing to make mistakes. Talking, just get out there and do the talking; that makes a big difference.

One organization may have started it, but I tell you, it takes a whole village, and we have the best volunteers. They are very passionate and motivated. And engage anybody willing to learn about dementia and help raise awareness and pull them in as some of your key people around your table.

What I suggest to people is just walk around the community. You know, are there people with cognitive memory concerns? Yes. I'll guarantee it. If you look at it from if you had a memory problem, would you feel comfortable going about in your community? Are there areas that make you uncomfortable? I've gone into restaurants where they've had a number of specials and they've rattled them off so fast that I had no idea. So if I had memory problems, I really would not feel comfortable with it.

Identify some small goals. It might be a community education event. Maybe identify one community service you feel would help those with dementia. And then kind of target those local businesses to start your dementia awareness initiative. It might be maybe you talk with banks. Maybe you talk with restaurants. And Watertown has kind of gone out and we're going, okay, we're hitting all the businesses. But if you're not sure how you want to do it, maybe you just start with one type of business, maybe like food service, and approach it and then expand from there.

Terry: So it sounds like those are all great ideas. Do you know, Jan, if Alzheimer's Speaks and Lori La Bey are available to partner with other communities?

Jan: Lori is always willing to talk to anybody.

Terry: Great, great.

Jan: She is a wealth of knowledge. She will share with anyone, and just an absolute pleasure to talk to.

Terry: And you too, Jan! I thank you very much for everything you've shared with us today about making Watertown a dementia capable society with the coalition. Good luck with that. And are there any takeaways you'd like to leave our listeners with today? You just gave me a great one, I mean. But I think I'll give you a last chance, if you wanted to say something to wrap up our interview.

Jan: Well, I just really want to thank you for giving me the opportunity again to get the word out there about raising awareness for dementia. But the number-one thing is just do it. You have to do some planning, but what we've found is that over-planning really bogs the

system down. So don't be afraid if you don't have this well-defined, "I'm going to cover everything" plan. No, just start and learn as you go along.

Terry: Excellent, excellent. That's great advice and hopefully it will be inspirational to some listeners to begin their own dementia capable coalitions in the communities where they live and work. Thank you, Jan.

Jan: Thank you.