



## **Transcript: Choosing the Right Nursing Home – Family Caregiver Advocate Interview**

**Barry:** Welcome to the Senior Care Corner Show. I'm Barry.

**Kathy:** And I'm Kathy. Thanks for joining us.

**Barry:** You'll find us online at SeniorCareCorner.com; a great resource for family caregivers of senior adults.

Well today we've got a really good show for you. Our feature segment is an interview Kathy recorded recently with an expert who advocates for family caregivers on nursing home placement. Kathy ended up taking that one solo so I thought I'd thank her by handling the other segments of the episode.

First we're going to turn to a couple of news items we've got for you today.

Our first news item today:

### **Americans Want Online Access to Doctors and Health Records; According to a Survey**

Many seniors who are internet savvy want to email their doctors and even add them as a Facebook friend.

A new study from the Journal of General Internal Medicine asked over 2,200 pharmacy customers who were frequent Facebook users about their health technology access.

They found that 37% of participants said they had emailed their doctors in the past six months and 18% reached out to them on Facebook.

Caregivers and patients with chronic illnesses are more likely to use email or Facebook for communications with their doctors but the largest group that reached out were younger than 45.

57% of participants reported wanting to electronically access their health information and 46% wanted to track their health progress via email.

Despite that fact that health records are available electronically, only 7% have used this source and another 7% have ordered their drugs by email.

Researchers feel that perhaps patients are unaware of online health services and we should do more to make secure web-messaging services available.

Our second news item:

### **Muscle Strength Fades after Just 2 Weeks of Inactivity a Study Indicates**

A new study has found that it takes only two weeks of physical inactivity for those in good physical shape to lose a significant amount of muscle strength.



As much as 30% of muscle strength was lost after that short amount of time in young people and active older people lost 25% of their strength.

Researchers state that the more muscle a person has the more they will lose when sedentary after an injury, illness or even a vacation.

The loss of muscle mass is more critical for older people due to the impact it can have on their general health and quality of life.

When active through exercise for six weeks following the loss of muscle, researchers found that their muscle strength didn't fully recover even in that time. They found that weight training in addition to cardiovascular activity helped to regain loss muscle mass but it will take three times as long to regain as it took to lose.

**Kathy:** We keep saying you've got to stay physically active. We really need to have our muscles so that we don't fall as we get older.

**Barry:** Now our feature segment and I'll turn it over to Kathy here.

*Start Recording*

**Kathy:** Today I have the pleasure with a woman who has a wealth of knowledge to share with caregivers. Joanna Leefer is a Senior Care Advisor and Advocate for the elderly and author of *Almost Like Home: A Family Guide to Navigating the Nursing Home Maze*. You can find a link to her book on our Bookstore and we hope you check out. And also on her website, we'll link that with our show notes during the podcast. Joanna has more than 10 years' experience in eldercare. She is the founder of Elder CareGiving a service that helps families find and get the best care for their aging loved ones.

Previously, she served for five years at the foremost advocacy organization for the elderly FRIA, which is the voice and resource for quality long term care. Joanna speaks often about nursing home care to the public, community groups and senior care professionals and she writes a monthly column on eldercare for the Community Newspaper Group.

Today she is going to share with us her expertise about nursing homes and how caregivers can become advocates for their seniors.

Welcome Joanna to Senior Care Corner!

**Joanna:** It's a pleasure to be here.

**Kathy:** Well great! We're looking forward to some great information. We'll start out with our first question. We usually start out asking our guests what motivated them to become advocates for seniors, usually there is a personal connection that drives all of us. Do you have experience as a family caregiver too?

**Joanna:** Absolutely! I think most people who go into the field at one time dealt with some kind of issues with their own parents or another loved one. And my experience came with my parents.



My mother started showing signs of Alzheimer's when she was in her late 70's. And we realized after a while that we weren't going to be able to care for her at home. Being what I thought was a very educated and methodical person I thought that this was going to be an easy task to do. Well, all I had to do was read up on how to find the right Alzheimer's facilities. What characteristics to look for, to consider and it should be a piece of cake.

However, when I started to look I realized that there are quite a bit of diversity between what some people call an "active Alzheimer's" facility and some that are really much less capable. The first place we went to was what they called "Active Alzheimer's"; or they had one room and all the residents sat around at a table putting together puzzles.

The second one we went to looked a lot better it was diverse. It had several types of activities for different stages of Alzheimer's there. They had things that Alzheimer's patients like to do like fold towels and cook. They would be stirring ingredients and such. However the room wasn't very large. And my mother who was in the early ages--stages of Alzheimer's used to walk out of the room all the time. So we always had staff members who were stopping and running out after her and bringing her back. After about 20 times of this, they finally suggested to me that we find another place.

**Kathy:** Hm.

**Joanna:** And finally, we found a wonderful facility in Brooklyn where I live which is a whole closed in floor and with lots of murals on the wall. A lot of brightness, a lot of different activities and at night my mother just spent the whole day walking around the whole floor and was perfectly happy; and was safe.

And that's when I began to realize that caring for loved ones and finding the right facility is really a lot more complicated than it appears on the surface. So I began to realize that this is something I really want to look into. Fortunately I was able to find a position part-time with an organization; an advocacy organization for the elderly which gave me a LOT more insight into what one's rights are.

**Kathy:** Mhm.

**Joanna:** And that between just daily caring for my mother and then my father and working with FRIA; I was able to understand and get a feel for what your rights are in a facility. And thus I came out with my book *Almost like Home*, which explains a lot of the regulations that affect the nursing home industry and how you can go about advocating for somebody in it.

**Kathy:** Well that's great! That's great. I think your book is a great resource for people who are experiencing this and unfortunately we're all going to head to this somewhere or another along the way, one relative or another. I believe our lives have been affected by Alzheimer's as well but there are choices that we have to make along the way and really none of us really want to think that our loved ones need to be in a nursing home but the reality is we're all going to make it there. And oftentimes, it's the best choice for them.



If a caregiver, yeah, if a caregiver is faced with that kind of a decision, what are some of the key criteria that you recommend to help them locate a nursing home while they're looking initially?

**Joanna:** Okay, what I consider: first thing a person should do is take a big map and figure what distance you're willing to travel to visit somebody in a nursing home. One of the first criteria for putting someone in a nursing home is to be able to visit them. So you want to be able to get to that place easily. So what I always say to do is take the map, put your home as the center of the circle and then from there draw maybe with a compass the distance you are willing to travel. Once that is done you can look in that area, you can put down the zip codes or whatever and find out what nursing homes are in that particular area that you would be willing to travel to and that's step number one because rule number one is you really; in order for somebody to get the best care you really HAVE to visit that person frequently. So that's number one.

Number two is to start the research which can be anything from looking for news articles and I think that's very important to do. There is a website on the internet Medicare.gov Nursing Home Care which rates nursing homes and then a lot of talking. There are a lot of people to talk with; I think we all know people who have known somebody who's been in nursing home. Get that information. Talk to social workers. Talk to senior centers. And from there kind of determine which nursing homes might be good to look at.

And once that's decided the next step is to go look at it; and that in itself if a whole chapter of practically what to look for, what questions to ask, how to evaluate. But those are the three main criteria for determining what kind of nursing home.

**Kathy:** Right. I always suggest that they actually, they physically have to go there and be there and more than one time to really get a good feel.

**Joanna:** Absolutely! And what I tell people to do is after they're finished if they think doesn't matter what they think; just sit in the lobby, just sit in the lobby and look around see what's going on. See if there's activities going on, sometimes just talking to the people in the lobby; find out what the people there think--the children of the residents. Another thing I find out sometimes you can find out a lot just by who you speak to. I once sat in the lobby, thought I was talking to a family member and realized I was talking to a paid aid rather than; so this is somebody who was not so happy with the nursing home system. They hired somebody to go and sit with their loved one in the nursing home. And I realized when I spoke to her that this is important to know that if you have to pay somebody to stay in the nursing home to make sure your loved one gets the best care, maybe you better look further.

**Kathy:** Right, right.

**Joanna:** You never know what you're going to find out just sitting there. And yes absolutely go back a second time and look. Or even a third time.

**Kathy:** Right I think that's a good point too, look around. What if you're a long distance from your senior and you know, you can't necessarily visit daily or even weekly; how do you suggest that they kind of locate some—a place that be fitting for their senior?



**Joanna:** Well that's a good point too. Because, and it doesn't even have to somebody far away. There's no law saying that you have to love your parents. Or that you get along with them so many times you don't want to visit them but you should find somebody who will check up on them either a friend or a relative; pay somebody to do it, there's senior—there are all kinds of geriatric care people; advocates like myself but if you really want your loved one to get care-good care, you really have to have somebody. So it doesn't, it can be a formal or informal situation but it's important that somebody look in there. Just everybody has gone into a nursing home and just seen that one person who's sitting alone with little going on and little help being given to them. But, and those are the ones that are just neglected because there's no indication that there is anybody who is thinking of them.

**Kathy:** Right, they definitely need someone in their corner with some eyes on them, yeah.

**Joanna:** Absolutely.

**Kathy:** Well now if they're, if they don't need a nursing home right now, how far in advance should we start looking around and start considering our options?

**Joanna:** I really tell people they should start early. And when I'm saying early I'm saying really five years prior. A lot of people are not aware of the regulations governing nursing homes and people should understand that a nursing home can be very expensive. That means you are going to be spending a lot of your money paying for a nursing home. And until you get down to a point where you're eligible for Medicaid, now most people don't want to spend all their money down. They want to give money to their children, to a cause. So if you think five years prior, there are ways of transferring a lot of your assets and income and savings into another resource, it could be a child, it could be a trust, it could be any--a friend but unless you do that five years prior to going into a nursing home, you're going to be losing all your money before Medicaid will pick up the cost.

So I would say definitely find that part of the financial part of it should be done early. After that I think it's just a matter of making it a point of interest to keep—to find on top of what's going on in the nursing home industry. If you happen to be around a nursing home, you know take a look at it because the more you look at the more you have an understanding of how nursing homes work.

I compare it to buying a car. Most people don't just say "I'm going to buy a car" and buy the first car they look at. They want to look around and see different models and how they run. And that's just a, it takes time. Nursing home; looking at nursing homes take time so I say start early; a year...

**Kathy:** Right.

**Joanna:** beforehand.

**Kathy:** Right, I...you never know when you're five years is going to be up. So I suggest go ahead and start now. If you think you have an aging parent who might need this, go ahead and do



it now. I've seen so many people who get stuck in that five year look back and actually end up owing money to the government.

**Joanna:** Right, exactly. Exactly. And they're stunned; totally stunned.

**Kathy:** Right, yeah. They had no idea, that's good information. Thank you.

Can you tell us what we should look for if we're in a nursing home or while we're looking, what's a GOOD nursing home environment? What should we be on the lookout for?

**Joanna:** Okay, when you're in a nursing home you should always look at; I think number one the resident/staff relationship. I think that's number one priority because this is an indication of how the staff feels about its residents. I'm not going to say it's the only thing. Cleanliness is important. I think the way people look; that their hair is combed. That they're sitting, that they're dressed nicely. But I think almost more than that is to see that there's a respectful relationship between the residents and the staff members. Because that indicates how they're going to be cared for; these they indicate that they respect them and they're a person and they're going to make sure they're okay. So that's number one.

And I have to say there is something—something that people aren't always aware of, particularly when they take a tour of a nursing home. Many times you'll have somebody take you around to a nursing home and they'll walk into somebody's room without knocking on the door and to me right there that is a signal of lack of respect. No one should ever walk into a resident's room without first asking permission, if I see that I know that right away I'm dealing with a staff that does not feel as though their residents deserve any kind of respect. So I would definitely put that almost number one before anything else.

**Kathy:** Right.

**Joanna:** But there things. The other thing—another thing is to use your senses, your eyes, your ears. If you don't want to hear screaming but you also don't want to hear too much silence if everybody is drugged. And finally your nose! If it doesn't smell clean there; there's a problem. Either they're leaving these residents without ever changing them or bathing them or taking any kind of care of them. Do definitely notice what your senses are telling you.

**Kathy:** I think those are good points. We all—we all really want our loved ones to be treated with firstly respect and dignity but we want them to be loved!

**Joanna:** Mm-hmm. Exactly, exactly and acknowledged as human beings.

**Kathy:** Mm-hmm. Right. There are a lot of—a lot of really kind of sensory type things that we can examine, you know. We can see it! And we can know it's either right or wrong. And really once we're there, no nursing home is going to be perfect. If you do have a concern about how the type of care your loved one is getting; what's the best way, would you suggest, to advocate for your senior to make sure that their preferences are going to be respected?

**Joanna:** Well first of all, I want to step back just one moment Kathy and say that the really even before how to is that you SHOULD advocate. A lot of people who put a loved one in a nursing





home seem to think that's it. You know, you got them in a place which is supposed to take care of them and they're going to do it. They don't understand that you really have to keep on top of the care to make sure that it's being done properly and that they acknowledge that your loved one really needs personalized care. So a lot of places really just assume that you don't have to do anything.

Once that's acknowledged it always it good to notice just how your loved one is behaving if there's any big changes in behavior. The big things I always like to say to look for is changes in weight and changes in activity level. If somebody goes in heavy and loses 10 pounds in a month or so, there's something wrong. They're not getting their nourishment somehow. And that's a signal that the staff is not, is not aware or is not helping them either with eating or is not giving them the right food. Finding out why they're not eating, of course this could be vice versa if they were very slender and suddenly they're very overweight too. There's something else going on too. Retaining water perhaps? Perhaps they're not getting nourishing food.

**Kathy:** Not being active enough.

**Joanna:** Exactly! Exactly; the other part is how aware a person is. If you put your mom in a nursing home and she's still walking around and active, and all of a sudden every time you see her she's slumped over and looks very drowsy; there's something wrong there too. And I would say right away it's probably too much medication or they're too sedated.

So those are really important signs. That doesn't mean that just happened because you go into a nursing home, that's because something is wrong. Somebody is giving them the wrong medications or too many medications. So those are two big signs.

Another really important point you should do is check your mom or your dad to see that they don't have any sores on their body. A lot of people are not aware that older people tend towards bedsores, or I guess they call them pressure sores now. And sometimes they're not in a place you would notice them right away like if they're wearing a long nightgown, you might not notice it on their legs or buttocks.

So I always say hang around a little bit, if you're the family caregiver stay around if your mom is being bathed or being changed. Just to make sure there's no sores that are being missed by the aid who's taking care of her because nothing is more deadly than a pressure sore.

So yeah, you have to be very involved. Anytime you think there's something wrong, write it down. I always believe in documenting everything because it doesn't really work if you go up to somebody and say "I'm not happy with how my mom's being cared for." It's better to go in and say "My mom wasn't bathed on this day, or this day, or this day" and you actually have the date and the time. And just see all the information. Be factual. You don't have to be too angry. You just have to point it out and let people know that you're aware that something is not right.

**Kathy:** Right. I think letting them know that you expect a certain level of care and being involved. And letting them know that you don't stew in your anger, go ahead and let them know right away and get it corrected as quickly as possible. Attend your care plan meetings. Would you agree? People need to continue to be involved.



**Joanna:** Absolutely! That is probably the most important thing to do. Is to go to these care plan meetings and go to there with your own thoughts. But sometimes---nobody knows your mother better than you; or your father better than you.

**Kathy:** Absolutely.

**Joanna:** They just might be aware of some of the facts that you know. “Oh my mother never eats applesauce. You know, don’t give her anymore applesauce. It’s just going to sit there.”

**Kathy:** Right.

**Joanna:** Give her something else. You know Jell-O, whatever. But yes because you’re the one who knows best. These are just people who are caring professionally but they are not as aware as your mom—as much as you are.

**Kathy:** Absolutely. Don’t be afraid to let your voice be heard. So let’s talk a little bit briefly about, we touched a little bit about paying for nursing home care. What’s the difference between a nursing home and a senior center or an assisted living home facility with regards to payment and who accepts Medicaid and all of that long-term insurance, et cetera?

**Joanna:** Okay, this is- this is a good question. A lot of people are not aware of the difference between an assisted living and a nursing home.

An assisted living, almost all assisted living’s are privately owned. And they are privately paid for. They’re a business. And you pay for them. You pay for them and you pay for all the different services. Food, the aides, and I think laundry and housekeeping are included in the fee. Some of them you pay for meals. And as soon as you run out of money, you’re no longer there. They can tell you how much they love you to death, but if you can no longer pay an assisted living will let you know that you can’t stay there.

So that’s the main difference between them. An assisted living is a paid facility and fees can go up not just for room and board but the amount of care a person needs. A nursing home on the other hand is a skilled medical facility that is meant for 24 hour care—medical care. And you can pay privately or you can pay through Medicaid. Or you can use some long-term care insurance while you’re paying privately. But basically a nursing home accepts government finances; Medicaid. Assisted livings do not.

Also nursing homes like I said 24 hour care. That means night and day care; it means meals; it means recreation; it means housekeeping—all paid through Medicaid. Assisted livings it’s all privately paid for.

Now if you are—if you don’t need Medicaid and some people don’t need Medicaid for nursing homes yet, a lot of people go into a nursing home starting by paying privately. But nursing homes I guess depending in the state can cost between \$15,000 a month, some places I know in New York City; there are some places that cost \$25,000 a month.

Now a lot of people can’t afford that too long. I mean, that’s over \$100,000 a year! So most people are not going to be able to afford that and they do go on Medicaid, where the government





picks up the fee. So if you're not going to be able to pay for yourself, a nursing home is really the place you're going to have to be.

But if you have plenty of money, definitely go into assisted living. They are often more comfortable. You can bring your own furniture in. It's more of a lifestyle living while a nursing home is a—more of a medical model.

**Kathy:** Right. Assisted living is a good place to start.

**Joanna:** Absolutely.

**Kathy:** Until you need more care and then kind of move along in the continuum. I agree.

**Joanna:** Absolutely, mm-hmm. Yes.

**Kathy:** So in terms of nursing home care then are there new things coming down the path that we might want to know about, especially if you're thinking about long term care?

**Joanna:** Yes, this is why I think a lot of this is very exciting because the baby boomer generation is becoming old. And we baby boomers and I'll put myself in that as well, we were used to being activists. We were all involved in some demonstrations somewhere along the line, women's rights, equal rights, Vietnam, civil rights (if I didn't say that); so we're not going to stand for bad care. And a lot of nursing homes are sensitive to that.

There's a new trend that's beginning to take place throughout the country called *Culture Change*. That's a very broad category of conceptive care which shifts the emphasis away from the institution to the residents. And I'll explain.

Currently most nursing homes are institutional run. That means the staff decides on the schedule. Everybody is up at 7 in the morning, dressed and then the staff comes in and makes the beds while everybody is herded into the dining room and has breakfast by 7:30 in the morning. And then they go about their scheduled activities throughout the day and everybody's in bed by 8PM.

In *Culture Change*, the emphasis shifts to the resident. The resident can say to the staff "I'm not a morning person, please don't wake me until 10 in the morning. And then I want to get dressed but I don't want breakfast until 11". And the staff will go and help them get dressed and help them with breakfast.

So instead of having the whole day scheduled around the staff's activities, they're scheduling around the resident's activities. And this is a big change. It makes the resident feel more in control of their life.

**Kathy:** Mm-hmm.

**Joanna:** And I think this is going to be the way of the future, going forward.

**Kathy:** Right. It's very hard for facilities to do that but they really need to and we hope that our loved ones will be in one of those types of facilities, for sure.



**Joanna:** Exactly. That's what we really have to do. Encourage people to look for facilities like that and let the other facilities just be for people who are not going to questions their care. But I think the boomers are going to make a difference in this.

**Kathy:** Yeah, I think we want something different for sure. Well, Joanna we appreciate your time and sharing your vast knowledge with us today and we'll be sure to have links in our show notes to your website so people can find you and learn more about you and contact you; as well as your book. So we appreciate it and thank you very much.

**Joanna:** It has been nice talking to you Kathy.

*End Recording*

**Barry:** Well thank you Kathy for doing that. That was a great interview and really appreciate the time Joanna took to speak with you.

I'd like to wrap up today's episode with our standard quick tip.

We suggest you clean smartphones and tablets regularly with germicidal wipes. Why? Well, think about where you and your loved ones go with mobile devices and all the things the surface of your device might pick up. Well I'm not going to go into graphic detail about it, so let's just say that this falls in the category of "better safe than sorry".

With that we'll wrap up this episode of the Senior Care Corner Show. Once again, you'll find us online at SeniorCareCorner dot com. And we look forward to any questions, comments or even suggestions you might have on topics we could cover in the future. Or subject areas for which we might interview experts to provide you some more information. And until we see you again, thanks for joining us and we hope you have a great day!