The Northland Caregiver: Episode 2 - Ways to Help a Person with Cognitive Limitations be Independent in Everyday Activities

**Transcript**

**Leeza:** Welcome to the Northland caregiver, a podcast that's all about providing support to family and unpaid caregivers looking for helpful information and advice on how to safely and effectively care for aging loved ones, family members, friends and themselves along the way. I'm your co-host, Leeza Ochsner, from Duluth Aging Support, a nonprofit behind this podcast on a mission to help enhance the lives of older adults and caregivers in the Northland through outreach, awareness, advocacy, and collaborative partnerships.

And here with me is your host, educator, and Occupational Therapist, Dr. Mary Lou Donovan.

**Mary Lou:** Hello, everyone, and welcome back. Last month, we discussed the critical role safety and wellness plays in caregiving. This month, we're focusing on how to help you determine the level of function for the person who has cognitive limitations, and how to present activities in a way that best promotes success.

**Leeza:** Honestly, this is such an important topic and one that we could easily do several episodes on. But we'll try to share as much as we can during this episode.

To start things off Mary Lou, can you describe what you mean by one's ability to “function” quote unquote?

**Mary Lou:** Absolutely. When I'm referring to function, I'm talking about what people do. We use our brains to take in information through our sensory systems like seeing, smelling, hearing, etc. And once we take that information in, our brains work to make sense of everything that's been taken in. And finally, we have a response to the information shown by what we say or what we do, which is an indication of one's functional abilities.

People with cognitive limitations are sometimes identified as being at an early or mild, middle, or moderate, or late or severe stages. How we interact as caregivers with a person who has cognitive limitations will or should vary according to that person's ability levels throughout each of those stages.

And it's important to understand that these three stages don't have clearly defined boundaries. In fact, sometimes a person might display abilities in more than one stage at a time. The goal of today's episode is to help you identify the general level of ability for a person with a cognitive limitation and how to best modify an activity based on that ability.

**Leeza:** So, you mentioned part of the focus will be identifying cognitive limitations. But what, you know are, some of those physical limitations you know, something we should be thinking about as well, such as mobility, vision, and hearing issues.

**Mary Lou:** Yes, I'm glad you brought that up Leeza. Because we have so much to cover in this episode, we'll definitely be circling back to talk more about how you can promote safety and independence with daily tasks related to physical impairments in future episodes.

**Leeza:** Great. So, before we dive in further, can you please explain, you know, the why, you know, the why is it so important to first figure out the general level of ability for someone with cognitive limitations.

**Mary Lou:** Of course, the why is really twofold because it benefits the person receiving the care and also you as the caregiver. For example, it allows the person with a limitation to do as many things for themselves as possible, while remaining independent and safe, get help when they're stuck, and can't get a task done, increase their self confidence by reinforcing their sense of purpose and dignity, and get some exercise. Yes, bending down, down to put on your socks and shoes is a form of exercise.

On the flip side, it also benefits the caregiver by allowing them to save time, by being able to focus on doing things that a person cannot do for themselves. Get realistic expectations about what the person can do for themselves, give appropriate types of cues so the person can understand and react in a positive way to successfully finish the task, and to set up the environment in a way that will be best for the person with a limitation. When caring for a person with a cognitive limitation, it's important to match the task and the environment to that person's highest ability level. You don't want to give them something too hard or too easy to do. Occupational Therapists refer to this as the quote “just right challenge” unquote. If a caregiver knows how to modify cues and the environment for the person's ability level, then there's a higher likelihood of successful completion of that activity.

Remember, we all need to feel purposeful, independent and safe throughout our whole lives.

**Leeza:** I know we'll be covering this topic in more detail in another episode. But can you share an example of how to modify cues and the environment so that it matches the person's ability that you're caring for.

**Mary Lou:** Certainly, I love using the mac and cheese example. A person with no cognitive limitations or experiencing the early stages of cognitive limitation will be able to follow, well we'll say, a 10-step recipe and even modify it and understand how those changes will enhance the recipe. They will get the recipe, gather all the ingredients and measuring tools, preheat the oven and ultimately complete the task with no additional help.

However, as the person's cognitive abilities decline, they may need to ask questions or have a checklist they follow to ensure they have all the ingredients and steps done in the right sequence. They can find everything themselves, follow safety precautions, clean up the kitchen and enjoy serving the dish.

As a person moves into the middle stages of cognitive loss, they may need a more simple recipe, say three steps, or use a microwavable item. They may also not be able to read the directions, or they goof up the sequence or even walk away and forget their cooking anything. Even though they have their ingredients and tools out in plain sight, they may need reminders to turn on the oven or stove to use oven mitts to avoid burning themselves, turn on a timer or clean up the kitchen. Ingredients may also be missed, and the dish may or may not be edible once it's all said and done. In other words, someone in the middle stages of cognitive loss is going to need more supervision and help to safely complete the dish.

Lastly, someone in the early part of the late stages of cognitive loss may be able to help stir ingredients while seated but would not be safe around a hot stove. Or they won't know how to do any of the actual cooking or be able to assist with other steps.

In contrast, a person in the later stages of cognitive loss most likely won't be able to help at all.

So that was an example of a cooking task, and what kind of abilities we might see that would be different from an early, middle or late stage of a person who has cognitive impairment.

And before I move on to talk to you more about those three stages and a person's abilities, I want to give you some background to help you better understand the process of identifying and modifying tasks and the environment to help the person successfully perform their activities of daily living or ADLs as they're often referred to by occupational therapists.

**Leeza:** So, what are some of those examples of activities of daily living or ADLs?

**Mary Lou:** ADLs are basic tasks that all of us do on a daily basis like, dressing, bathing, toileting, grooming, which means brushing your teeth, combing your hair, things like that, or moving from one surface to another. Oftentimes, ADL tasks are things that we learned from the age of two on up. They are often what occupational therapists consider over learned activities because we don't really have to think much about doing them every day until something big changes, like your break your dominant hand, and you're required to do things with your left hand, which means that we have to think more about how to do things with that non-dominant hand.

The other category of activities are called instrumental activities of daily living or IADLs. And these tasks vary from ADLs in that they require more thinking to complete.

**Leeza:** Can you share some examples of the IADLs?

Mary Lou: Of course! This includes things like shopping, preparing a meal, doing laundry, driving, managing your medications or finances or taking care of your home. Or maybe caring for other people or pets or your communication. Things like using the phone, or computers, or writing letters.

**Leeza:** What are some tips to improve ADLs for your care partners and how do ADLs vary in the different stages of cognitive loss?

**Mary Lou:** During the early stages of cognitive loss, the person may easily complete their ADLs but may begin to have difficulty with their IADLs. Oftentimes, people will retain their abilities to do ADLs into the late stages of cognitive loss. But that makes it challenging for caregivers to understand when the person actually needs more help and supervision with those tasks.

For example, for a person with early stage, cognitive loss, they might still be able to hold their job for a construction company, but they may start to have difficulties with things like you know, for example, they're digging a hole in the wrong place, but they can still do their ADLs just fine.

Some other red flags that a caregiver might notice is when a person has multiple car accidents or even several dings on their car, good thing to check, or their checking account has been depleted or their kitchen catches on fire while warming up some soup on the stove.

When something goes wrong, a person in the early stage of cognitive loss may not know how to fix it, or they may start to show trouble with words or not be sure how to perform a new task. The person might not understand the implications of gathering too many charges on their credit cards, or they might not be able to follow their medication schedules or even they might forget to reorder medications before they run out. An important key for caregivers when you're working with a person at any stage of cognitive loss is to identify and be grateful for the things that the person can do, while also being mindful of the things they truly cannot do.

**Leeza:** So, once you've identified the various things a person you're caring for can and can't do, what are some helpful tips for successfully completing tasks, especially during the early stages of cognitive loss?

**Mary Lou:** I can't stress this enough: simplify, simplify, simplify. Everything from your sentences to your schedule and things in your house. Do your best to keep it simple.

**Leeza:** Honestly with how hectic most people's schedules are, my own, these days, I am pretty sure we could all benefit from a little more simplicity in our lives these days.

**Mary Lou:** Isn’t that the truth! Another thing caregivers can do is to start to clear things out of the house that aren't needed. For example, one of my participants in my dissertation study once shared that his wife had 25 pairs of black pants and shoes. I mean, who needs that?

**Leeza:** Sounds like we have a theme! So, simplification is definitely the key. What are some ways that a caregiver can simplify some of these things?

**Mary Lou:** Well, there are so many great tools that caregivers can take advantage of for keeping things simple, you know, something, like just having a calendar, a wall calendar, might keep a person on track, or they could use a digital calendar, or pill boxes. They could have timers for when they need to take their medication, things like that can really add to, just again, some simple ways to address those issues.

**Leeza:**I heard you say digital calendar. And I'm really glad you brought that up Mary Lou, because Duluth Aging Support actually recently launched a blog post about senior friendly tech options available on the market. And while it's not quite a calendar, the Amazon Echo came up in some of our research, and it's a really great device that's not just for listening, you know, to music and news. It can also be used to set some of those digital reminders. So, think about medical appointments, your medication, it even offers a variety of safety features. And we have this post available if you visit www dot Duluth Aging Support dot org forward slash blog. There's all kinds of blog content on there. But that's a really relevant one for using, you know, digital technology to help you simplify.

**Mary Lou:** Oh, that's a great call out Leeza, thank you! That’s good info. So, another thing that can really help family and friends, is a caregiver instructing or not instructing, but just teaching people what a cognitive loss looks like. It's important to keep social activities going for a person as long as possible. It’s equally important to start talking about things like driving retirement, transportation alternatives, or maybe even consider getting that person in for driving evaluation early on, for sure, you want to get any financial and legal issues taken care of as soon as you can.

**Leeza:** What about the middle stage of cognitive impairment? What are some changes caregivers should watch for in terms of ADLs or IADLs?

Mary Lou: Well, Leeza. In my experience, people in this stage often talk the talk but can’t walk the walk. It’s not uncommon for them to deny having any problems or they might make up false information. And that can get to be very problematic for you as the caregiver.

While people in the early stages of cognitive decline or dementia can usually do their own ADLs, you’ll start to see difficulties with some of those ADL tasks for people in the middle stages. For example, you know that the person can still dress themselves but their clothes might be dirty or their buttoning might be aligned incorrectly. So, they won’t pick on those things but you’ll see those things. Or another example, they might be able to go to the bathroom but they won’t know what to do if they run out of toilet paper, which is stored in the cupboard next to them. But that additional step often requires them to use a higher level of thinking.

**Leeza:** What are some ways caregivers can support a person who’s in the middle stage of cognitive decline, but you know, still want to live on their own?

**Mary Lou:** Oh, that’s a great question, Leeza! Because maintaining independence is very important for all of us as we age. But we also have to remember to keep safety and health as a top priority.

So, a person who’s at the early part of the middle stage may still be able to live on their own with a very set routine and additional support. Caregivers will have to help with the finances, give them needed supplies, and help with the transportation to appointments. Not only to appointments but to outings with friends and fun things to do in the community.

**Leeza:** Are there other things that caregivers can do to help during this stage?

**Mary Lou:** Yes, a person at the beginning of that middle stage will often pay attention best to items that are within their viewing range like being able to see the whole room or the whole street. But as the disease progresses, their attention is going to shift to things within a smaller visual area and eventually their field of vision, that’s what we call, will be things that are within arms reach. This is important for caregivers to know because you can place the things you want them to use or pay attention to within that viewing space. This decreasing viewing space makes people at higher risk for falls due to their inability to do a visual scanning of the environment as they move about or you might not pay attention to traffic when crossing the street.

**Leeza:** And what are some other changes that caregivers should pay attention to in the middle stage?

**Mary Lou:** The speed of information processing will slow down and the person you’re caring for may take two to three times longer to complete a task or they may become more impulsive or refuse to do things. The key thing here is patience. You want to wait longer for a response to your question. And you might have to wait two to three times longer than what you would for a person that has normal cognition. And you want to be realistic about your expectations too.

Remember that just because a person can do an activity the previous day, it doesn’t necessarily guarantee that they’ll be able to do it the next day or even that same afternoon. Fatigue may play a role in their completion of successful activities. So, you have to kind of roll with the punches on those things.

Similar to the early stages of impairment, simplicity plays a big role during this stage as well. From routines to choices, remember to keep things simple.

**Leeza:** What changes can caregivers expect once the person is in the late stages of cognitive impairment?

**Mary Lou:** People in the late stages of cognitive loss need twenty-four-hour supervision and care due to the difficulty of maintaining a person in their health and safety. This care is oftentimes done outside of the home, it's tough, it's tough to do it in the home.

So, in other words, the person who is entering the late stage will need full time help with parts of all of their ADLs, for example, they initially might be able to feed themselves using their fingers. But as, again, their cognition decreases and abilities decrease, holding utensils can become difficult. So, they'll need to be fed.

A person who’s entering this late stage will still usually be able to move their body parts so they can assist for care for some of those ADLs but as the person's disease process proceeds, they might be unable to move their body parts and they’ll need full assistance with all of those pieces.

But they can still respond to sensory information like seeing bright things, or hearing music that they like or smelling a warm brownie. They still have feelings and emotions like sadness or frustration and happiness. So, it's important to know what likes and dislikes a person with advanced cognitive loss has so that the most effective sensory information can be used to help them become more alert or in other cases, to try to calm them down.

**Leeza:** I imagine it would be helpful for families to tell staff at a facility where their person is being cared for about some of these sensory likes and dislikes, you know, ahead of time.

Can you talk a little bit about what happens to the field of vision and speed of processing information during this late stage?

**Mary Lou:** Yeah, the field of vision will decrease even more than it did during the middle stage. And the speed of processing information also slows down more too. So, it'll be important for you to place items even closer to the person in order to get their attention. And you want to wait at least 30 seconds to get a response to your question.

**Leeza:** And what types of memory issues should caregivers be aware of at this stage?

**Mary Lou:** Well, a person in the late stage of cognitive loss may recognize family and friends, and staff, but not recall that person's name. So, it's really helpful to them, for people to reintroduce themselves when approaching and really be mindful not to startle that person. Because again, their field of vision is going to be fairly close.

So, no matter what challenges you face on your caregiver journey, it can be very helpful to remember these three points. Always love the person and not be frustrated with their behaviors. It's the person who matters. The behaviors are caused by the disease versus the person. And you can always choose to be at peace over being right, or you can pick your battles. So, prioritize what you really want to become frustrated about.

**Leeza:** Such a great perspective, Mary Lou, thank you!

If you didn't catch her first episode, we always wrap it up by answering a question that was submitted by a local caregiver. And the question is, you know, my wife gets really agitated in the late afternoons, she stands by the front door, waiting for the kids to get off the bus even though our kids have their own kids now. However, when I tell her this, she doesn't seem to understand and only gets more irritated and sometimes even a little bit angry. What should I do?

**Mary Lou:** Well, occupational therapists don't give diagnoses. That's not really our job. But from my experience, and from the reading and research I've done it sounds like your wife might have a condition referred to as sundowning.

This can occur in the late afternoon or evening. And oftentimes, you'll see it continue into the night when the person won't sleep, or sometimes they get out of bed. The causes may come from the person being thirsty or hungry or overly tired. They might have pain that they can't describe, or they might not have had enough activity during the day that makes them feel bored or depressed. So, a few suggestions to try with the person who's showing signs of sundowning are to make sure the person's up and busy during the day as much as possible, without overloading their schedule so they aren't overly tired. Have them get some form of exercise every day and try to discourage them from taking any long naps, especially late in the day. Help the person establish their cycle of day and night differences by getting them outside or near a window with some nice bright light during the day. And keep to a schedule and do the same routine daily. Aim for quiet evenings. Get a person involved in a quiet activity, like listening to calming music or playing a simple game if they can do that. Maybe offer them a favorite snack but try to avoid caffeine or sugar.

If it continues to be a problem, you want to talk to your doctor so they can rule out any medical reason that your loved one may be showing signs of sundowning.

Always remember to check our show notes out for additional helpful resources, like the National Institutes of Health, Alzheimer's disease and related Dementias Education and Referral Center or a DEER or the Mayo Clinic's website or the Family Caregiver Alliance.

**Leeza:** If you're interested in even more resources about dementia, head to www Duluth Aging Support that org forward slash resources, where you'll find a whole section dedicated to dementia information featuring Age Well Arrowhead, Alzheimer's Association, Dementia Friendly Duluth, Mary Lou's business, Positive Dementia Paths and many more resources that can be of help. Once again, that's www Duluth Aging Support that org forward slash resources. And as always, a friendly reminder that if you have a question related to aging issues, we'd love to answer your questions on our podcast, send them in when you email podcast at Duluth Aging support dot org or give us a call at 218-576-7123 once again that's podcast at Duluth Aging Support dot org or 218-576-7123 and simply leave your question on our voicemail. And don't forget to subscribe to our podcast, The Northland Caregiver on Spotify or on www dot Duluth Aging Support dot org forward slash podcast.

**Mary Lou:** Thanks for tuning in! And we hope you'll join us next month as we discuss how you can modify cues and the environment to best fit the needs of the person you're caring for. We’ll give more details and as always, hope to answer questions that you call in about aging issues. So please do, feel free to call those in to the address and website that Leeza just mentioned.

**Leeza:** Until next time, take care!

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