Speaker 1: Hi everyone. And welcome to doula givers, ask a death doula. I am your host, Susan O'Brien. Thank you so much for being here today. We are talking about dementia at the end of life. So the dementia patient at the end of life, and as you probably are well aware of dementia and Alzheimer's, and I'm gonna explain the definition of that is a [00:00:30] huge problem in the disease and the number of people we have affected by this disease. And it's a very different way that the dementia and or Alzheimer's patient, which by the way, Alzheimer's is a type of dementia presents at the end of life. And so how do we know when our loved one with dementia is actually headed towards the end of life and how do we support them? So we're gonna cover all of that today because I find that [00:01:00] this is very missed in end of life care.

Speaker 1: For those of you who may not know my background, my name is Susan O'Brien. I'm a registered nurse. I've worked most of my nursing career in hospice care, which is end of life care and or oncology, which is cancer care. And I am the proud founder of the international doula givers Institute with the end of life, doula trainings, death, doula trainings, and again, the dually giver practitioner training. So I have a lot of experience in this area, and that's why I wanna share the knowledge that I have in the hopes to help you and [00:01:30] your family have a better end of life experience. So today dementia and end of life. First, let's start off with sharing what the definition of dementia and Alzheimer's disease. What is this? What does it mean? So dementia is a general term known for, or a decline in mental ability, severe enough to interfere with functions of daily living Alzheimer's disease accounts for 60 to 80% of dementia cases.

Speaker 1: And [00:02:00] it is the most common form of dementia among older people. Okay. So you might have heard Alzheimer's, that is a type of dementia and it counts for 60 to 80% of all dementia patients, uh, patients, approximately 4.5 million Americans suffer from the disease, which usually begins after age 60. Here's a problem. We have an aging demographic, like we have never seen before in our world with that is going to come chronic [00:02:30] disease issues, dementia, cognitive ones, physical ones, financial ones, which is another issue. So the average age of life is 81. Right now they are now projecting because of medical tweaks and advances and stem cell research and all of that, that we're gonna be living well into the nineties, even a hundred. So planning on longevity is critically important. So the downside of [00:03:00] aging is that, you know, you have this beautiful vehicle, right?

Speaker 1: That we've been gifted to have this experience with like a car. It has miles on it, it wears out. Um, and so we have to be just aware in the sense that the longer we live, the probab of having issues, chronic issues of all different types is very high. And dementia is one of the most challenging on so many [00:03:30] fronts, emotionally, physically, and financially for families. And it can go on for 14 years, 24, 7 and care. So the sensitivity around this area, we need to share this. And we need to know that when we are showing up as practitioners or we know people, especially those who now have an end of life with their loved one who has suffered from the dimension Alzheimer's they have most likely been through years [00:04:00] of 24, 7 heavy duty care. So we wanna know what we can do to show up, to support them, not only in the space at end of life, but even prior to that.

Speaker 1: So the definition, again, it's a cognitive, which means mental decline usually starts with forgetful short term memory. So it's very interesting when you are trying to diagnose this because there's no real definitive diagnosis. Um, but it's really marked by short-term memory loss. So, [00:04:30] you know, where did I park my car, or where are my keys, or what did I have for lunch today? Long-term memory tends to stay intact, which is again, a fascinating act around this. So if you see somebody who you love that is having short term memory, and again, safety is always the most important thing with anything that we do. So for me, if there's an indication that somebody may be having, um, shortness of memory, or even heading down into a dementia type [00:05:00] of disease, but process it's to be on top of that, to be ahead of that. So God forbid they are not caught in an accident or any of that.

Speaker 1: So again, really being honest with what's happening and kind of going deeper so that you can help to prevent, um, and put safety measures in place before anything happens. That could be really something that can't be reversed. So Alzheimer's disease is a mental decline that shows up first as loss of memory function, next to be [00:05:30] affected next to that are be affected are the emotions and inhibitions. So this is where we start getting really layered first it's forgetful, but then it's emotions and being laid by meaning that there is going to be, and usually is a reversed presentation of what the person was like in their life. So let me give you an example. I have a family that we are working with, whose father got, and there's many different types of dementia. So he had [00:06:00] an early onset, um, dementia that he got at a younger age in the fifties, and he could be in the forties even.

Speaker 1: And he was a very, um, regimented man, very organized, very, um, proud. And he became, um, you know, trying to use gentle words, just very flamboyant and, um, his, you know, uh, kind of vulgar with his language and he would go out and make these big purchases [00:06:30] of like cars and came home with a huge dog one day. And his family was very upset cuz they said he'd be and embarrassed that people saw him like this. So again, it's usually people who start, um, having the more in depth disease processes start actually switching from what they were like for the most part in life. So let's say somebody was the sweetest, loving, gentle, they might become verbally abusive of and even combative. [00:07:00] So this is a very, very important thing. What I say to families is it's not your mom, it's the disease. Okay. Because we want really to bring as much comfort into this space.

Speaker 1: That being said, you always have to then, okay, what are safety issues and what are the practical parts? But the emotional toll that this plays on people is really heavy. And I just had a, a family say that their mother was really abusive at the end of life, with dementia, with her staff, you know, the nurse and everyone. And they were so embarrassed. [00:07:30] So don't be embarrassed. It's the disease and, and staff know that. So is it comforting? I think it is, but this is still again, a very hard topic to discuss. So let me just share with you again that then after mental decline, forgetfulness can come Layle can come. Emotional can even become physical, um, acting out. They talk about obviously the brain being affected and the neurotransmitters not being able to you connect. [00:08:00] So that is just a little bit of behind the scenes.

Speaker 1: Alzheimer's disease cannot be cured. Dementia cannot be cured and is a tremendous burden on caregivers. It is 24 7 care psychologically, physically and economically. All right. So we really wanna start with the prevalence that we have up a crisis with dementia and Alzheimer's right now, we need to do everything we can to share information show up today on this podcast. I wanna really address end of [00:08:30] life and the dementia patient because when we do our doula givers training for family caregivers, and we talk about the three phases of end of life there section in the last phase that talks about the indications that someone is heading into their transition phase. And this is fascinating. Now not everyone will go through every step every time, but many of those are, uh, mark. And then we can tell that somebody's headed into their transition phase. [00:09:00] The thing here with dementia patients is that many of the indications that somebody is headed towards their end of life, transition phase are things that they experience within years of their disease process.

Speaker 1: So my families are like, wait a minute. Like for instance, one of them is that my mom is sleeping. Most of the time. My mom is talking to people. She seems to be talking to people that are not that there that I can't see. So these are even becoming incon. These are all indications again [00:09:30] for a person that's not suffering from dementia, indicate that they're headed toward is that end of life moment for the dementia patient. These are things that can happen for years in that journey. So then how do we know families say to me, Suzanne, how do I know my mom is suffering for dementia? How do I know when she is headed towards that end of life? How do I know when we should be calling hospice? I'm gonna share with you how, you know, as a former nurse, I know how people qualify to be admitted to hospice and [00:10:00] for dementia patients and Alzheimer's patients, it's actually quite challenging.

Speaker 1: Okay. Because they present with so many things early on in their journey. That don't mean that they're getting ready to have their end of life, but this is the one indicator that we go by a rapid decline in weight loss and food intake. So rapid decline in food intake that is now leading to a measurable weight loss. That's letting us know that [00:10:30] yes, that person is most likely headed into the end of life phase. Okay. Cuz it's very difficult. Otherwise, to be able to identify that with dementia patients, here's something really important that I want you to hear. If you get your mom on hospice services, based on she hasn't been eating a lot, there's there's weight loss. We can tell that for her to stay on hospice. Okay. Is that, that has [00:11:00] to be a steady decline. So again, we've had patients and this has been a real problem in hospice is that that person kind of bounced back a little bit, started eating a little more or didn't continue to lose weight and hospice could not them on hospice services because there wasn't anything measurable that was saying for the dementia patient that they were, they were in a steady decline.

Speaker 1: So I just want you to be aware of that, that it really, again, will be an admission based [00:11:30] on a weight loss reduction in a short period of time, based on again, lack of intake and then needs to be consistent with that. And it usually is. It usually is. So that is something really important that you wanna know. And you also wanna know that if for whatever reason, if your mom woke up and tends to come back and is eating more, that she will, what I call graduate from hospice, they, they call it getting kicked off, which is terrible. Cause families really do need the support. [00:12:00] So we wanna not be aware of that because when somebody does not re qualify to stay on the services, families can be really dependent on the service. It can really hit them for. So we wanna be aware of that.

Speaker 1: So just like the indications again, that somebody is in a healthy person without dementia, um, in their cognitive way, the indications could be sleeping most of the time, TA you know, talking to people that you dont see or there incontinence, [00:12:30] um, those kind of in, uh, you know, again, not eating a lot, those, those are similar, but it's gotta be for the dementia patient, that there is a marked weight loss that can be quantified. Now, how, if your mom is bed bound, how do you measure weight loss is she's not gonna be able to get on a scale. Maybe not. Well, what they do is they measure circumference. So they'll take an R measurement or a thigh measurement with a Tate measure and they wanna see that that continues to get less over the time [00:13:00] period. So that's how they would market. Um, so that is a, again, a very, very important thing to know about the qualifications to get on hospice.

Speaker 1: Now, this is what I want you to know as end of life practitioners, people who are gonna show up to help a family with a dementia or Alzheimer's patient as an end of life doula as a doula giver, that kind of thing. This is going to be a completely different space than the active disease process, [00:13:30] because we started this podcast talking about when people it's 24 7 people can be laid Bial. They can be safety, risk, all of it, all of it. It's the heaviest care I've ever seen, um, or one up there up and at, at the very top, um, you know, people getting up and wandering and safety and all of that nonstop. And so when you come in at the end of life, they now have been admitted to hospice services end of life diagnosis [00:14:00] because of the weight loss due to not eating, you have a whole different presentation.

Speaker 1: The person is most likely going to be in bed very weak now. And now it's that, you know, watching that process of actively dying and keeping people dignified and clean and helping with the family, you're not gonna be having that person who's, you know, getting out of bed and trying to get out the door. Uh, for the most part, you might have some terminal restlessness, which you could have with everybody. So we'd use our tools with that. [00:14:30] But when you come in, don't think that you have to know everything about how to care for an Alzheimer's of disease patient, because this is an end of life scenario. So it's marked by the weight loss due to not eating, which is gonna make that person incredibly weak and bedbound for the most part. So now you are watching for skin breakdown, you're watching for, you know, uh, keeping dignified pain, free, all of that and helping the family.

Speaker 1: So it's a very, very different way [00:15:00] that you're caring for that dementia patient as an end of life patient. Okay. So I just wanted to share that, cuz that is needing to be very clear as well. Um, yeah. So by the time the person is hospice appropriate. Okay. So let's talk about what you can do ahead of time. We're gonna go into a space here with new information and new ideas that are coming out about how [00:15:30] we can do our advanced directives or plan for my own care right now ahead of time in the chance that I ever down the road got dementia or Alzheimer's. So you, I hope, and if you don't, we're going to thoroughly cover that. And these podcast series, advanced directives and advanced directive is two dot a healthcare proxy. Somebody you would name to speak your wishes for you. If you cannot speak for yourself and a living will, which [00:16:00] would state what you would want or not want for end of life care.

Speaker 1: If you cannot speak for yourself for anticipating dementia and or Alzheimer's, you can do an advanced directive with specific instructions that if it, the situation comes where one day I have advanced directive, I have dementia advanced that I can't speak for myself. This is what I want. This is what I don't want. [00:16:30] And one of the things that's coming up now is something called. I call it no food for thought, this is what I named it a long time ago, the no food for thought theory, philosophy option. And now it's known as V said, so voluntarily stopping, eating and drinking. And it is a process we're gonna have a whole podcast just on V said and how it works and what you need to know. Um, all of the components that [00:17:00] go along with that. But I want you to know that organically at the end of life, the swallowing reflux turns off turns off.

Speaker 1: So there comes a day with my end of life patients, inevitably one day they are not gonna be able to swallow. And this is a first telltale sign that they are headed into their end of life. And of course it's a huge safety issue, but the body is weak and the body knows what to do. And the body is saying, I'm not needing [00:17:30] nutrients. I don't need fuel. I'm gonna turn this off. So none goes in and it starts to quietly shut down. Brilliant. Right? The body's brilliant animals do this all the time. People with advanced disease process can actually choose consciously to take this earlier. This measure earlier, this organic way that the body by stopping deciding I'm gonna stop eating [00:18:00] or drinking. And the V said, voluntarily stop eating or drinking is just that. So it's saying I'm disease process. I don't wanna continue this.

Speaker 1: So I'm going to, uh, not put nutrients in. So it's not that my swallowing reflux is gone. It's that I'm choosing to do this a bit earlier. However, with that being said, there's many things to it. Um, people get parched. There's a lot to it. We'll do a full V, said podcast for you to go over all of it. Um, but, and I have resources below in [00:18:30] this one, but this is a option to do in an advanced directive to say, if one day my journey takes me on where I have advanced dementia and I cannot speak and I cannot make choices. I don't want a spoon put to my mouth. I wanted to make t-shirts. That said that. It's how I feel personally. I, if I can't recognize you, [00:19:00] if I can't do anything for myself, if I'm sitting there 24 7 care, no enjoyment of life, the way people are kept alive is by being <affirmative>.

Speaker 1: Okay. And I don't, I don't personally want that. And I know a lot of people don't want that, but it needs to be clearly shared with your family, why you don't want that and what you would want instead. So again, of course being kept comfortable on my don't feed me, but make sure that I'm comfortable and, and, you know, [00:19:30] very minimal pain if at all, dignified and helped me on this journey out of this world. So that is what V said is, and that is an option that you can put into your advanced directive. In fact, there's a link below with an actual advanced directive with that option within it. So I want you to take a look at that resource as well. I know this is new to a lot of people, and I know this can be, um, heavy discussion, but it's a very necessary discussion because [00:20:00] we have a crisis, an elder care crisis that is only projected to increase for decades to come.

Speaker 1: We don't nearly have a setup to care for them at all. In the medical profession, housing financially, people are not prepared. And of course with the longevity of aging becomes a problem with chronic illnesses, cognitively, physically, and financially. So we can add [00:20:30] that in. Um, okay. So I just wanted to share with you some tips that you can do for the caregiver of dementia patients. We wanna show up for people. We know this is hard. So if you have somebody in your family and, and what I have typically seen is that it usually falls on one family member to do the care, usually falls on a female and it's 24 7. And so I understand from that people are good, but I understand there's many [00:21:00] dynamics at play. But when I come into support families as a doula giver with dementia, many times, it's this one family giver who's been doing this 24, 7 for years, and they are burnt out.

Speaker 1: They are physically ill. They are sometimes again, angry and resentful at other family members for not helping out. Here's what we wanna do. We wanna make sure that we are giving respite care to our family members that, you know, there might be one beautiful family member who wants to [00:21:30] live with mom and dad help care for them pitch in show up, let them know that you have the weekend off rotate with other family members, say to your other siblings. Hey, we know that Sarah is living with mom and dad. We all need to take at least one weekend a month to let her have a vacation or respite or whatever we need to show up. We know it's not comfortable. We know it's not easy to interrupt our lives, but this is, this is what we can do. And this is our moment to do it.

Speaker 1: So we need to do that when you're coming into care for [00:22:00] people, make sure that at the end of life, that you are giving that caregiver, respite care that people are coming in, that you're taking tasking and all of the doing off of them so that they can be present in this last moment of time with their loved one. Because if we are actively doing all of the time, we're missing it. And this is the last time we have. So when you come in to support somebody who now has an end of life, loved one with dementia at the end of of life, [00:22:30] they have again be aware that they've probably been through years, 24, 7 care. We wanna really swoop in there. We wanna have meals being delivered. We wanna have people rotating coming in and spending the night so that mom can get rest.

Speaker 1: We wanna make sure that they are eating and drinking and, and moving their body a bit, taking a walk around the neighborhood, making sure that they're caring for themselves. Cause I will tell you that this has not been done, that they are going down just like [00:23:00] the loved one. And it's just the most intense care. So really creating that loving, supportive space, rotating the care you can ask people to bring in meals, um, making sure that that person's getting rest. That is so super important. So if somebody can, each person can take a night in that home where mom can be in bed. And if something is, you know, going on with dad, we'll wake you up and call you. You don't have to have that ear up all the time. I know that it's really, I know that it's really hard care, but it's something that is [00:23:30] so prevalent right now that we have got to get resource and, and tools to know how to approach this area in the healthiest way possible.

Speaker 1: So to wrap up today, the dementia patient at the end of life will present in a very different way than other end of life patients. The same indicators that we use for people who have disease processes that we know are end of life, and that are headed into their transition phase, are gonna mirror the dementia patient [00:24:00] in their active phase. So it gets confusing, right? So how do we know that that end of life dementia patient is now at the end of life, it's gonna be marked by weight loss. So it's gonna be marked. Mom is not eating, she's refusing her meals or she's just not eating. And we can see that there's weight loss, call hospice, call hospice, call hospice, call hospice, get them on there again. If this is going to be an extended period of time to be re-certified on [00:24:30] hospice, there has to be an shown decrease in weight loss consistently.

Speaker 1: So just be aware of that now. Um, again, when we come in, we wanna make sure that we are supporting the caregiver, the, that you're not gonna be. If even if the diagnosis is dementia, you're not gonna be coming into a home or caring for somebody that's going to present like that active disease process. Not gonna be walking out the door, not gonna be [00:25:00] hopefully really combative or laid BI. Like some dementia patients can be or many can be, it'll be marked I weight loss, which will be then that weakness. And that person will probably be in bed by the time you get there or for that whole end of life period of, of, uh, care. How can you and I share in being proactive with our wishes now today in the chance that dementia would be a part of our journey in the [00:25:30] future.

Speaker 1: Well, in your advanced directive, you can write what you would want or not want in that scenario. And you can also, if you chose to put in no food for thought V said, voluntarily stop eating and drinking. Because if I can't recognize you, if I can't speak, if I am just sitting in a diaper, if I have no quality of life, I do not wanna be kept alive by being spoonfed. [00:26:00] These are individual choices. There is no right or wrong, but it's, if we don't choose for ourselves, it will go into default. And it's usually what we do not want. So again, this is just food for thought and really important food for thought. There are some great resources below I ask you to please review this podcast, leave a review and also drop a comment. I would love to hear your feedback. And if you have any questions, let me know we are going to move, move into the future together in [00:26:30] the most positive way for everyone in this world. So again, thank you so much. This was the doula givers ask a death doula podcast. My name is Susan O'. Brian. I will see you in the next episode.