

# Home and Institutional Care

The program provides insight into the process of evaluating the most appropriate environment for care giving (home, daycare, institutional) as well as daily survival tips on care giving.

**JON MERRIL:** So the first question on the list is: What are the unique challenges of home versus institutional care?

**BETH GALIK:** Well they are slightly different. In terms of home, really what you're trying to balance with older adults with dementia who are living at home or in their relative's home is balancing their independence and their autonomy versus their safety, especially in kind of earlier stages of the illness because you want to maximize the things that they are able to do for themselves but by the same token, you don't want put individuals in jeopardy or have them get frustrated because they're trying to do tasks that may be too difficult or challenging for them like paying bills or managing the checkbook or, in some cases, cooking even or driving or administering their own medications. And so things change over time and so you have to kind of always be on alert for this. And what maybe worked six months ago in terms of their level of supervision may need to adapted and changed. And that's one thing that is challenging for family care givers; I think recognizing some of the changes, because they are kind of in the midst of it every day and they may not see things that people who are removed from the situation might have any easier time trying to see. And plus family care givers have that whole history and relationship with the older adult with dementia and sometimes respond more on an emotional basis. And it may be harder for them to recognize some of the impairments that their family member may have. As the disease progresses and moves more into middle or late staged illness, the physical care demands become greater for care givers. And many family care givers are really hesitant even to ask from help from other people. And even if help is offered, sometimes they're hesitant to accept it. Many times family care givers have long ago made commitments to one another that if anything were to happen, especially with children, would you take care of me? Would you have me come into your home? And often time these type of commitments are made based on things that used to be, when individuals with dementia long ago often died from other medical problems because our treatments weren't as effective. And so a family care giver maybe in the sixties or seventies may have cared for someone for a few years, maybe two or three. Whereas now we know that with the advances in health care, people living longer, this can be a longer term proposition. And so it's sometimes challenging for care giver to really accept when it's become too difficult for them to manage by themselves any more. In terms of, the other thing that we see is it becomes more challenging, especially as the disease progresses, to try to structure activities for people so they get kind of an appropriate level of stimulation. Because of a clinical apathy that happens with probably up to sixty-seven percent of individuals with dementia, they're very challenging to motivate and they don't have a lot of self-initiation and this is kind of part of the disease. And so often what I hear family members telling me is, well he will just sit there in front of the TV and kind of watch it and may dose off or I can't get her to do things and participate like she used to or she'll put things in the wrong place and it may just be easier for me to do it myself so I don't have to go and redo it. Now day programs, if you're going to try to keep a family member in the home setting, medical adult day programs can be quite helpful in trying to provide not only structure and appropriate levels of stimulation for the older adult with dementia but also respite for their care giver. And many of them run five days a week and often they'll have transportation so they can come pick someone up at their home, take them to the program, and then they'll return home around three, between three and five in the afternoon. And



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those things can be helpful. In terms of institutional care, when a family's made a decision, and all these decisions are very individual, to move their relative into an institution, it's often challenging for the family care givers even more so than the new residence to the nursing home or to the living facility because the families are having really a change in their roles. From being kind of direct, hands on care givers to transitioning to now to where they're still caring for that individual, but they're functioning now more as their advocate and they're kind of having to turn over the care to someone else. And that can be a challenging thing to deal with because that person has invest a lot of time and maybe a lot of love and has come to know maybe the idiosyncratic likes and dislike of that person and all the small things. And they may try to tell the other care givers that, you know the staff in the nursing home or the assisted living facility may not kind of give proper due to that and say you know kind of, "Oh, we'll be okay. We don't have to worry about that." And you know sometimes that's a challenge. Also with institutional care giving there is a problem, you know I think and we're very fortunate that Copper Ridge because this has not been as much as an issue for us, but recently in terms of staff turnover, nursing assistances provide, whether it's in assisted living facilities or homes, provide the major direct handle and care for residents with dementia. And often times there's a large turnover and so what is so important I think in an institutional setting is having regular assignments so that there's not a rotation because that allows individuals with dementia and their caregivers to really develop a relationship. And it may not be kind of what we think of as a relationship; there may not be a lot of talking or communication. That way especially if the individuals are more progressive into their dementia but people learn, the care givers can learn their patterns, things that motivate them, foods they like to eat. And all that information really can be lost if assignments or rooms switched frequently or if a facility is unable to maintain the number of nursing assistants that they need. The other challenge is I think that sometimes institution face in when you're, I think it's kind of a double edged sword. In facilities that are dedicated maybe to the care of dementia as Copper Ridge is, we don't run into a whole lot of problems that other facilities have in terms of where there's a mixed population of people who are cognitively intact but have a lot of medical needs versus individuals who have dementia. Because what may happen, wandering and kind of hoarding and picking things up or laying down in somebody else's bed happen quite commonly with individuals with dementia. And for residents who re cognitively intact, this can be upsetting and sometimes they can escalate even a catastrophic reaction in the individual with dementia if they're trying to redirect them and the individual with dementia doesn't understand that. So that can be a challenge. By the same token if you do have a homogeneous population, so you do have everyone with dementia kind of in a prescribed area, there are their own unique challenges in the sense that we know that up to seventy, eighty percent of individuals with dementia at some point during the course of their illness will likely have neuropsychiatric symptoms or these kind of non-cognitive symptoms; things like depression or delusions, hallucinations or agitation, sleep disturbance. And when you have several people in a small area and individuals that are highly sensitive to the environment, sometimes kind of balancing this can be a challenge. So I think there's not a right or wrong. You just kind of have to look at your relative, what you think your relative may need. The thing that an institution can provide is a routine and a structure similar to that what the day program was able to provide. And in most cases this is very helpful. However there has been issues, especially around bedtime and I can give you an example of one of my former patients. He's a gentleman who worked evening shift. He was a house keeper and maintenance person for the federal government and he was used to working the four to twelve shift. And so he often didn't go to bed until two o'clock in the morning when he would get home. And when he was admitted to a small assisted living facility, they were encouraging him to go to bed around eight p.m. But this was never his life pattern, and but this was the structure of the facility though. In order to stay there he really needed to fit into their structure because they didn't have staff available to kind of be up and monitor him because he was quite active in the evening. And so that can be a challenge. Sometimes when people have unique patterns, you need an environment that can provide a structure but also you know provide a certain sense of flexibility so that you can try to meet the needs of residences so that you don't have to use medication to sedate people to get them to sleep when this may just be their normal pattern. Another example would be people who are not early risers. I know that for these individuals living in an institution where breakfast may be served at one time can be somewhat challenging because they may not want to get up at six a.m. or seven a.m. and have breakfast at seven thirty. They may want to do it a little bit later and could there be an option for you know having meal brought up later or a continental breakfast? So those are things that I think institutions really struggle with, is trying to have some type of regular routine but also trying to meet some of the individual needs of people with dementia because those individual needs can often times decrease the incidence of behavioral problems as well.

JON MERRIL: I have a couple of things just to follow up on what you said.

BETH GALIK: Sure.

JON MERRIL: If you could give a real small snapshot of if someone's staying at home, and you've brought all these points up and I just want to consolidate them into a little bit more of bulletised points, if someone's being cared for at home by a care giver you had mentioned that they might not be able to do the books and their might be sort of expectation management on the part of the caregiver as to what's reasonable or not reasonable for this person to continue doing. Is there issues with you know people accepting that loss of cognitive function? Or what sort of, to kind of get in the head of the head of the care giver a little bit, you know what

goes through their head when trying to care for a loved one you know as their going through the process of dementia?

BETH GALIK: I think one of the challenging things really is that one of the hallmarks of a dementia is that the individuals who have it often times don't recognize their own deficits. Or if they do recognize their deficits, they kind of minimize them. So therein lies the disconnect. Because what we're basically asking care givers to do then, family care givers, is to function as that person's good judgment and insight for them. And so care givers and families I think are constantly faced with trying to talk people into doing things or trying to get them to do things that they may resist or not want to do or don't think that they need to do. So in other words, someone may have had an accident while driving the car or gone shopping and parked the car and gone in to purchase something and come out and not been able to find it. But yet if you try to talk with that individual's dementia about it's now time to stop driving because of these problems, they may deny that the things ever happened because they don't recall them or they'll minimize them or come up with a reason why: well, I was feeling sick that day and it won't happen again or they may just say that it's not and a problem and you're trying to take away my independence. I think it's challenging for families to try to really manage that balance between safety and maintaining independence. By the same token I think sometimes what can happen, happen to some family members is that they will kind of take over and do things for the individual that they may be able to do for them self. And often this centers around hygiene issues. So rather than maybe providing cues for the individual to wash the person may be able to, if you soap up their wash cloth for them and hand it to them, they may be able to do that them self rather having you kind of just go in and just do it. And we know that individuals with dementia often don't recognize for what they are they often misperceive things. And so if you can have them through cueing and kind of role modeling do as much of their care as is feasible or possible, often times you can cut down on the incidence of catastrophic reactions or individuals resisting care.

JON MERRIL: That's great. Those are some very very good examples and issues. If we can switch gears a little bit, no that much, it seems like it might be a hard thing for a care giver to evaluate appropriate placement. One of the things that you mentioned was the day programs and I would imagine that people may not be aware of these programs. Do they exist, are they marketed much to hospitals and social workers and nursing staff and facilities or is this something that people generally find out just by the marketing programs of these organizations?

BETH GALIK: They program, they exist throughout the country, they've become more popular especially within the past decade and individuals may find out about them from a hospital setting. If a loved one's had a recent hospitalization that might be something that's recommended as a time of discharge. I think primary care providers whether they're physicians or nurse practitioners also can be good referral sources for day programs. And if individuals are interested in locating a day program near to them, there often are several different day programs in the county. And if they contact their county's office on aging or in states that have townships, their township's office on aging, those organizations will often be able to provide referrals or a list of places that are near to them. In looking at day programs you want to also look as you would for a facility, a place that has some experience or some track record in working with patients with dementia. Because you want to find out if their staff has any special training regarding caring individuals with dementia or what's their philosophy of care. Those things can often be helpful in selecting a program.

JON MERRIL: And do you know about reimbursement? Are these programs typically reimbursable by Medicare or insurance policies or is it mostly out of pocket?

BETH GALIK: Unfortunately day program mostly are paid for through people's private funds. And here in the Baltimore-Washington area day programs on average cost somewhere between seventy to eighty dollars a day. And that includes a main meal, two you know main hot meals, two snacks, and often the transportation as well as supervision in activities. They can also provide referrals to outside resources such as physical therapy or occupational therapy. And there's medical supervision provided by a registered nurse who's at the day program. So private funds really are the majority of, main source of what pays for a day program. Individuals who have medical assistance are eligible for day programs and for them the pay may be nothing at all or a minimal charge. I think actually medical assistance patients, they are able to get that service without any additional funding. Depending on what state or county you're in will depend on whether or not counties offer any services or subsidies. And often this is highly dependent upon the state's budget until recently there's been a cut back on the amount of funding available for day programs for individuals. And basically though if you, when I talk with families about day programs, a family's very motivated to try to keep an individual at home or in their home kind of as long as possible. The day program really helps with that and it's significantly less expensive than having a person admitted to an assisted living facility or a nursing home. So even though it's not inexpensive, in comparison to the other option if they're needing more supervision and care it is another resource.

JON MERRIL: Okay. And so we've talked a little bit about home versus institutional care. Are there any gems or words of wisdom for someone that's taking care of a loved one in their home in terms of when they can't handle it any more and when to transition to institutional care?

BETH GALIK: What we know from research in working with individuals with dementia and their care givers is the two most common reasons for individuals with dementia to transition to institutional care from a home setting is incontinence actually and the onset of behavioral disturbance or one of these neuropsychiatric symptoms that I was talking about earlier. At often times either one or both of these things and they tend to happen in middle stages of the illness and so they may happen kind of around the same time. And this is really when I think the majority of people make a transition to you know a structured institutional setting. But everyone's different and so what one family care giver is able to tolerate and what they want to do may differ from someone else. So I often tell family care givers that the decision is up to them and that I can give them guidance and I can give them recommendations, but ultimately you know unless there are major safety issues that are not being addressed in the home setting, the decision really is up to them. And there are, a handful of them, but there are families that do keep their relatives in a home setting until the time that they die. It's very unusual because the care needs become so great and the only times I've ever seen it work successfully is when they're with extended family kind of living in the home. So it wasn't just one person, it wasn't a child or a spouse. It was kind of several people who were kind of all pitching in and doing that. So it varies but I'd most often transition to kind of a more structured situation happens kind of in the middle stages of the illness and when physical care needs become greater and when these problematic neuropsychiatric symptoms may kind of raise their heads.

JON MERRIL: And just in case someone got into the program right when you're speaking about neuropsychiatric symptoms, can you just run off a list of what types of things people might encounter?

BETH GALIK: Sure, some of the things are delusions which are fixed false beliefs are common in individuals with dementia. And often times they take on a persecutory flare so that the patient may believe that their spouse is having an affair or that there's a plot to do something to them or that someone's trying to poison their food or poison their medications. And we know that in patients with Alzheimer's disease which is a common cause of dementia that delusions happen to about thirty to forty percent of individuals with dementia. Hallucinations also, are a little less common but they often times can happen in combination with delusion. And it's when you have a sensory experience without a stimulation or a stimuli there so that you may see voices or you may see things that aren't there. Visual hallucinations tend to be the most common hallucination in older adults with dementia, especially older adults who have a concurrent eye disease such as macular degeneration or glaucoma. Those individuals for some reason seem to be more at risk. Sleep disturbance is common. So the gentleman that I was talking about earlier so it was his routine to kind of stay up a little later and then wake up a little bit later in the morning. For some individuals they've had a very routine pattern of sleep and then suddenly that really gets changed around and they're sleeping during the day and they're up all night. And that can be quite exhausting for family care givers. And probably the most common neuropsychiatric symptom that we see in dementia is depression. And it happens in probably somewhere between twenty-five to forty percent of individuals with dementia. And the depression in dementia looks a little different than you might expect depression to look like in a young population. Often times if you ask a patient if they feel sad or if they're depressed they'll tell you no. But they may have a lot of physical complaints, vague physical complaints which we call somatic complaints. They may have what we describe as anodynia which is if they don't react to pleasurable experiences any longer, they don't get joy from things they usually enjoyed. They can also develop appetite and sleep changes. And often times individuals with dementia have an irritability to them rather than so much of a sadness. Although they can also experience sadness and feelings both of decreased self attitude or decreased self esteem. So these are some of the things that are examples of some of the more common neuropsychiatric symptoms. And for most individuals with dementia they happen in middle stages of the illness although they can happen at any time throughout the course of it. There are some people who may go through their whole progression through dementia and never experience any of this. They probably are in, well we know that they are in the minority. And somewhere between seventy and eighty percent of people at some point in the course of their illness may experience one or more of these.

JON MERRIL: Okay, and this leads to another issue. In looking through your resume and you've done a lot of you know studies on different aspects of dementia and different coping. But you mentioned the lack of, despite the fact that people might be exposed to things that they used to enjoy that they no longer enjoy them. What about sexuality and dementia? I guess on both the care giver and the patient's perspectives?

BETH GALIK: Well, in terms of sexuality and dementia and dementia, there are a lot of different kind of areas. One is when you may have a patient with dementia who because of Alzheimer's disease in particular being an illness that effects our frontal and

temporal lobes, that's where the damage is, that's where most of our social controls and basically our breaks are. The way I like to put it, so if we see someone walking down the street and they have an unusual outfit on our frontal lobes tell us don't make a comment out loud so people can hear. We might think, ooh that's an ugly outfit, but we don't say anything. So individuals with Alzheimer's disease, that area of the brain is affected and so they're more likely to be more disinhibited. And sometimes that can come out in terms of sexual disinhibition. You may have an individual who was maybe not very sexually active or interested in things and then suddenly there's a change in the context of the dementia. And they are pressuring the well spouse to have more relations with them than the well spouse is used to. So that's one challenge. Then you may by the same token also have a well spouse who is always, you know the couple's always had a sexual relationship with one another and now they may want to pursue that whereas the patient may not be as interested. Or you may have a spouse who says, you know well this is not the same person I married and I don't have the same type of feelings anymore. So I think there's all kinds of challenges when you're dealing with issues of sexuality. I think the most important thing for providers to remember is to talk about this and to let them know that these things are normal feelings and that they're not alone, family care givers or patients are not alone. And to kind of talk these individual issues you know out with their health care provider if they can you know facilitate that. Also when you're in an institutional setting the sexual feelings may result in some problems in the institutional setting. For example individuals with dementia have often displayed symptoms of what we call agnosia. It's a perceptual problem where people don't recognize situations or people for what they actually are. And they may see someone who might resemble their spouse on some sense and they may misidentify that person as their spouse and may pursue them. And the other individual may like the attention, the other person may not like the attention, the other resident, or both residents seem to have pleasure by maybe walking or holding hands or kissing. That other individual may have a spouse or may say you know, hey I don't approve of this. And so I think there's all types of challenges that really can be faced in terms of sexuality and dementia. And then kind of on the extreme and you know I think these cases are not as common but they do happen, one of the other neuropsychiatric symptoms we can see is kind of an acute mania where people where people develop this intense hyper sexuality and pursue kind of to the point that it is dangerous for other people and if you're in an institutional population that people may or may not be able to consent. And so these individuals may need to be treated either with certain behavioral approaches or limit setting or changing their room versus in some instances you need to try courses of medication to curb that. So the issues with sexuality and dementia really are very broad, broader than you might think. And it's something that I think providers should ask their family care givers about and try to find out where they are in that spectrum or if there's a problem there or not.

JON MERRIL: That's great. And you've done work in other areas too with regard to dementia. Do you have some other observations that, I mean that was tremendous, with regard to cognitive impairment or other I don't know, are there other gems that you have to share from your research?

BETH GALIK: Sure. In terms of my other area of research interest is really in what we call restorative care. And this is trying to have people with dementia either maintain or if possible improve their levels of physical activity as well as their functional abilities. We know that when individuals, especially who are admitted to institutional settings such as nursing homes or assisted living, often times the care givers, the nursing assistants may perceive it's just easier, they're giving better care to someone by just doing things for that person. So rather than having them feed themselves they may just feed the resident rather than having them participate in some things in terms of using a spoon or special adaptive fork to eat. Or you know again you were talking about a family care giver who may be concerned, well if I let him wash his face he might miss a part so I'm just going to do it all myself. And then what can sometimes happen is the functional decline we see in dementia can kind of out pace what we might expect it to be if the changes were just due to the dementia. And instead we're having kind of a forced dependency. And it's not that people are trying to do anything to do anything wrong. They're actually kind of a lot of times doing this out of a sense of caring for the individual and they want to make sure that the person's having their needs met. But one of the things that we're trying to do here at Copper Ridge, and we're in the process right now of doing a pilot program, is testing the impact of physical restorative care programs for individuals with moderate to severe cognitive impairment. Because these programs have been tested in individuals who don't have impairment or have only mild deficits but it's never really been worked out with people who are more progressed. One of the things that I know our nursing staff and our nursing assistants and our rehab staff have noticed over the years is that when an individual with dementia becomes acutely medically ill for whatever reason, they have a bladder infection or they get a pneumonia or they fall and maybe they have a fracture. And then after that the residents who are able to get, who have care givers who are kind of trying to get them back to where they were before tend to do better in comparison to people who say, okay they've had this decline and now this is just where they are now, and that folks tend to have, from what we can perceive, and we're trying to test this to research a better quality of life. If they're able to be more physically active and walk or help feed themselves. And it could be that they may be able to self feed with set up and cuing for ten minutes and maybe they get tired and then they need assistance and that's okay. So you're really just trying to balance again that same thing that we talked about earlier in terms of the resident's independence versus their safety. But the goal really is not to prolong life necessarily but to try to, the life that someone has with this chronic illness of dementia, you're trying to provide good quality of life because individuals with dementia can have good quality of life.

JON MERRIL: And that leads to the next question which is: Is that your motivator? What motivates you personally to contribute?

BETH GALIK: I think that that probably is one of my main motivators. So that until there's a cure or more effective treatments out there for the underlying cognitive symptoms, I'm very motivated to try to maximize patients' as well as family and staff care givers', their quality of life and their experiencing their experiences in terms of caring for individuals with dementia. Often times by the time individuals with dementia are admitted to a long term care facility, they may be very progressive in their illness and may not be able to communicate a whole lot verbally. But they do experience things in the moment and they can experience joy and you can get a wonderful smile or a hug or you know a whole host of things that are you know very personally and professionally rewarding. You can feel good about yourself if you see a resident who may be having an escalation in their behavioral problems. And by going in and trying to diffuse the situation and use certain behavioral approaches or by teaching a nursing assistance or a family member to do that on their own, that can give you great satisfaction in having made a difference in that person. So I think that often times we view dementia, particularly Alzheimer's disease really as, the general public views it as a death sentence. But really individuals live with this illness nowadays on average from eight to fifteen years. And so really what they're living with is a chronic illness and we wouldn't say to someone with diabetes or with multiple sclerosis or Parkinson's disease, well you have a progressive illness and now we're going to not treat you or now your life is over. Of course we're going to try to treat individuals, we're going to try to maintain and preserve the parts of them that are special so that they can have a good quality of life. There's one story that I always think of when I talk about this. One of the nursing assistants was describing to me one of the residents she cared for who's very very sedentary and had problems with depression, very difficult to motivate pretty much of anything. But they found out from her family that she loved Frank Sinatra so if they could play Sinatra music that would kind of, then they might be able to get her moving more. And then we were fortunate for a period of time to have a gentleman entertainer who came to the facility who sang Sinatra songs. And to her, he was the real Sinatra. So all had to do to get her moving when one of his shows would come would be to go in and say you know, "Come on! Sinatra's here!" And she could be out there and singing some of the songs surprisingly and smiling and those things really make a difference I think for our care givers here at Copper Ridge, with the families as well as for me.

JON MERRIL: So the, one other question is: How do you stay motivated you know with the decline that's inevitable? And sounds like it's almost like a carpe diem type philosophy of just seize the moment and you know enjoy every moment of life you know independent of what the overall pattern is.

BETH GALIK: Right, I mean I think that you have to try to take that perspective a little more. And I think it's certainly more challenging when as a family member you've had a whole other relationship with this person and you know it's someone you love and you care about and you're seeing them decline. But knowing that there's things that you can do in terms of the way that you communicate with that person, the way you interact with them that can make a difference in their day. The other thing that I think keeps professional care givers involved in this field is you have to be a certain, you have to be a bit of a detective because our patients aren't often, very rarely are they able to tell us what is wrong. And so we have to take clues that we get from the family, from the history that we take as well observing the patient's behavior, talking with other individuals that may be working with them, doing mental status exams, physical exams, and trying to take all that information and kind of put it together and come up with kind of, okay these are the things that I think that are affecting this problem and this is what we might be able to do to help it. And I think that individuals who like a little bit of a mystery and don't necessarily need everything kind of handed right out to them in terms of the patient can just come in and tell you all these things are wrong, it attracts to the field of dementia. And I enjoy that to this day.

JON MERRIL: That's great. And just in summary to kind of end this, do you have any closing remarks that you'd like to sort of instill in people, gems that have made a big difference?

BETH GALIK: Sure, I think one of the most important ones is to remember that individuals with dementia are highly sensitive to the emotions of others around them. They may not be able to put words to it but if you are anxious and nervous, they will mimic those behaviors and they will in turn become anxious and nervous. And so one of the main things I try to communicate with families as well as professional care givers are how you want them to be is how you have to behave. And so one family member said to me one day is, "You know you're so up beat and you're so positive. It's like you're Doris Day." And I said, "Well that's just my Doris Day imitation." I'm being an actress because if I'm upbeat and positive and if I go to that individual and I smile and I approach them, they're going to mimic those behaviors back to me and generally, not always, but generally be more cooperative. So you have to kind of be constantly aware of what body language and what emotions you're displaying because they're going to come out in the other person. That's one thing. The other is to be flexible and creative with your care approaches. Don't always ask an individual with dementia, do you want to? because they'll tell you most often the time, no. But instead suggest things or, come on let's go over here I think this will be really fun. And just kind of go with them rather than asking them if they want to. And you also need to be alert to

what's going on in the environment and the impact that the environment may be having on the individual. On the weekends at Copper Ridge we would have a lot of visitors come in on a Saturday or Sunday or in the afternoon. And there was one lady in particular where this was very distressing to her and that she perceived where Copper Ridge really was her home and that all these people she didn't recognize 'cause they hadn't been there throughout the week, many of them, were suddenly coming in. And she started to display some behavioral problems because of this. So trying to be creative and looking at the impact of the environment. And what we did was changed kind of where she was located and the nursing assistants had other activities for her in a quieter section of the unit at those times, especially on the weekends. Just doing something that simple by being alert to the environment could make a huge difference for this individual. And then in closing one comment to care givers, whether they're family care givers or are nursing assistants or nurses or other health care providers who care for individuals with dementia, always remember to be kind to yourself and know that there are going to be days that are good and there's going to be days that are more challenging. And as a care giver those things are going to happen and you can't kind of fault yourself or blame yourself and that you just need to get back up the next day and keep trying.

JON MERRIL: And let me just throw sort of an observation in listening to a lot of the descriptions. A lot of the things that you're describing with people with dementia, you know it's the cycle of life. There are very similar issues with child care. You don't have, you know for the adult that's going through the latter part of life they're disinhibited. For a child, they're just getting those inhibitions, the social strictures put into place. And in addition you know when you mention day care there's of course the analogy to child day care. It would seem that there's more literature, you know for your know there's Dr. Spock and the lay literature and so forth but there's a lot of child care literature out there. Is that literature applicable or have there been insights that have been gleaned from that in caring for people. I mean even when you say Doris Day or you know being a good teacher you know it's just, it seems like there's an interesting parallel there. And I'm just wondering, is there meat there or is it just- ?

BETH GALIK: I think that there are, in many ways that analogy can carry over but we have to be careful not to kind of take it too far. And the main difference being, with children they're constantly able to do more and to do better and they're improving. And so their trajectory is very different. And so with parenting eventually you're seeing them move to an independent, functioning, you know hopefully contributing member of society. Whereas when you're working with someone with dementia, you're going through really a reverse pattern that may not follow things exactly like this. I think that in terms of the motor, the loss of motor skills is probably that we see with dementia holds up the truest for, as children kind of gain ability. So first they're able to kind of support their trunk weight and hold their heads up and they can you know sit and they may be able to crawl and then walk. And then they may be able to use finger foods and then on to then you know utensils. We see those things decline in a similar pattern with older adults with dementia. But what we don't want to do is infantilize this group. While we can be positive and use humor and play to kind of motivate individuals, we have to also remember that these people are adults and so we can't kind of treat them as children in adult bodies. So yes I think there's an analogy but I think we have to be cautious on how that gets played out. There are some good books that are available in terms of guides for care givers. Two of my favorites, one is called Creating Moments of Joy. It's by an author named Joline Brackie. And this one's kind of, it's inexpensive, it's in paper back. It really is a guide, really mostly for families who are living with someone with this illness, on how to get through the day and how to be in the moment with their relative and how to make experiences more positive and how to communicate with these individuals. And a lot of it centers around not constantly reorienting people to reality and instead kind of meeting them halfway where they are in some circumstances. It's a very, I've read it, it tends to be a more uplifting book than many of the books out there about dealing with dementia because it gives you practical strategies and things you can do which I think in turn makes care givers feel more confident in their abilities. Now as a reference manual I recommend The 36-Hour Day. And I, it was interesting that you used the Dr. Spock analogy because I say this is the Dr. Spock of dementia. So that when I was young I remember my mom taking her well-thumbed Dr. Spock book out whenever I had a bump or a rash or if I was giving her particular trouble with something and she would look it up in the book. But she didn't sit down and read Dr. Spock from cover to cover, otherwise she would kind of probably be overwhelmed. And it's the same thing I think with The 36-Hour Day and that's by Nancy Mason and Peter Rabins. It's a wonderful book and it really kind of I think it's a wonderful reference guide but I don't recommend families sit down and read it kind of cover to cover because I think often times they can be overwhelmed by the amount of information that it presents. They read it in, I tell people to read it in small spurts. There's also another good resource that's free through our federal government. It's the Alzheimer's Disease Education and Referral Center. It's called the ADEAR Center. And they have a website that you can go to, it's [www.alzheimers.org/adear](http://www.alzheimers.org/adear). And they also have a 1-800 number, it's 1-800-438-4380. And they provide wonderful educational materials. You can either download or if you call the number and say, "Can you mail me the care giver packet?" They'll send that out. They also keep an up to date list of research that's going on in terms of dementia and can provide that to families. And all that's supported through our tax dollars. It's something that's free of charge.

JON MERRIL: That's great, I'm really glad that you mentioned those resources. That makes a big difference to people. In

conclusion could you just state your name and institutional affiliations, we'll splice that into the piece too. But I've really enjoyed speaking with you and I think you've offered tremendous insights. So I think it's really going to help us quite a bit move the course along and put together a great product.

BETH GALIK: Great, well it's been a pleasure talking with you as well. My name is Elizabeth Galik, I go by Beth. I'm a nurse practitioner and my affiliation is I'm a nurse practitioner with Copper Ridge. I'm a senior faculty member with the Copper Ridge Institute. I have an appointment as a lecturer at the Johns Hopkins School of Medicine in the Department of Psychiatry. And I'm also a clerical instructor at the University of Maryland School of Nursing.

JON MERRIL: Fantastic. Well thanks so much, this has been great.