Episode 103: Best Practices & Guidance: Navigating Assisted Living and Skilled Nursing Facilities

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Dan Keller: Welcome to this episode of *Substantial Matters: Life and Science of Parkinson's*. I'm your host, Dan Keller. At the Parkinson's Foundation, we want all people with Parkinson's and their families to get the care and support they need. Better care starts with better research and leads to better lives. In this podcast series, we highlight the fruits of that research, the treatments and techniques that can help you live a better life now, as well as research that can bring a better tomorrow. At some point in the course of Parkinson's disease, it may be necessary to consider admission to an assisted living facility or a skilled nursing facility.

As this is most likely a long-term prospect, making the right choice of a facility is critical, raising many questions, including location, physical layout, services, experience of the staff and caring for people with Parkinson's, costs and more. Nurse clinician Joan Gardner, and physical therapist Rose Wichmann of the Struthers Parkinson's Center with locations in the Minneapolis area, explore some of the issues in choosing a facility and offer some questions to get answered in making the choice. Today's podcast is sponsored by Kyowa Kirin. To kick off our conversation, I asked Joan what people should think about first.

Joan Gardner: It's important to think about location - is the future facility in a location that's accessible for families and friends or in an area of town that's difficult to get to or unsafe to get to? Are you thinking about, are you comfortable coming and going is one key point, but not always achievable. Level of care is something also for people to think about. Will there need to be a move to another facility if symptoms increase? What is the capability of staffing to manage symptoms as Parkinson's symptoms progress? What is the staffing? Can they meet staffing needs with increased symptoms? What kind of activities are offered? Are there exercise classes, are there activity classes, what's the opportunity for making social connections?

Oftentimes, people with Parkinson's throughout their journey with PD need rehab care. Are their rehab therapies on site or do they contract with another company? If so, what is the level of understanding of Parkinson's disease from those rehab staff? What about transportation? Are there outings to grocery stores or to other things like museums or other kinds of field trips?

Of course, what is the knowledge of staff around Parkinson's manageability of symptoms and things like that? That speaks to Parkinson's awareness. Do staff understand that symptoms are really variable from person to person? That Parkinson's will progress over time? The very important question of the understanding of the needs for pills on time for Parkinson's, which we'll talk about later.

Rose Wichmann: I think there's a few other important things to consider as well. One is just the reality of cost. There may be a place that someone thinks is perfect, but if it is not an affordable place, there are questions that need to be asked-answered. Is there a flat rate for the services that are provided or are cost based on the cares that are provided? Do they accept what are called State Waiver Programs or do they accept medical assistance if that financial need is available?

Then there are also just practical concerns. Where would the apartment or the room be located within the site? Considering things like distance walking from dining room or activities, is there an elevator that the person with Parkinson's needs to get on and off, which can sometimes be very difficult for someone with freezing and then there's just approachability and the willingness to partner and listen to the unique needs of the individual with Parkinson's disease.

Dan: Is it a mistake to assume that staff at most places know about dealing with Parkinson's disease? I guess that includes staff, not only the professional staff, but all the way down to aids and people who would be doing hands-on care at various times.

Joan: I think that Parkinson's disease education for staff is not mandated as education for dementia is. Most staff members have not had formal education. However, there are some short training programs through some of the online programs, but we find that these programs don't really address practical strategies in managing symptoms of Parkinson's disease. Usually, they give a much higher level overview of Parkinson's symptoms, and that obviously isn't helpful information to providing day-to-day care, especially from the direct care providers, the nursing assistants. Most staff are not educated in Parkinson's care.

Dan: Do they often misunderstand or misinterpret Parkinson's symptoms?

Rose: There are several symptoms that are widely misunderstood that people with Parkinson's may have. Probably one of the most common misinterpretations is the lack of facial expression or facial masking that's caused by Parkinson's disease. Because people with Parkinson's don't usually have a lot of facial expression, they can sometimes be labeled as depressed or disinterested or even confused or not understanding what's being said when that's not the case, it's simply the loss of facial expression that can happen in Parkinson's.

Another misunderstanding is what are referred to as motor fluctuations, the ons and offs of Parkinson's. A care assistant might see someone walking down the hall at 10:00 AM, only to have that same person asked for assistance around noon, and sometimes that's misinterpreted as attention seeking or manipulative behavior. When in fact it just has to do with where the person is in their medication cycle and how their symptoms are doing.

I think the third main one that I can think of is freezing, freezing of gait, where that person gets stuck, literally unable to move. Sometimes people misinterpret that as someone who, again, is being abstinent or resistant when indeed their feet are really just kind of stuck at that moment due to that freezing of gait that can happen in Parkinson's disease.

Dan: Some of these symptoms may be related to off times. What is the importance of delivering medication on time and how realistic is that?

Rose: I think pills on time is an extremely important part. As we all know in Parkinson's disease, usually the federal and state laws provide flexibility in that if a pill is scheduled at a certain time of the day, the person administering that pill may have an hour before or an hour after to give that pill and have it be considered on time, that just doesn't work for people with Parkinson's. Staff really need to understand the importance of pills on time, every time.

Dan: Have you ever been able to study or have there been studies of how often that happens and it's adhered to?

Joan: Yes, we have. A couple of things, projects that we've been involved with here at the Struthers Parkinson's Center. One actually involved our affiliated hospital setting, Methodist hospital in St. Louis Park, Minnesota, where we worked with nursing leadership, the pharmacy nursing departments to really drill in the importance of pills on time. We actually use the electronic medical record in providing cues to nurses to signal the need for timeliness and administration of carbidopa-levodopa for Parkinson's disease.

Another project Rose and I are involved with is the Struthers Parkinson's Care Network, where we use an acronym called TULIPS to describe the care needs of those living with Parkinson's. One of the letters in that acronym is P for pills on time. We conduct medication audits are actually the sites in the care network conduct medication audit several times a year, where we study the scheduled time and the administrated times of carbidopa levodopa. We do find that with education nurses and other levels of staff who distribute medications, the med techs in most assisted livings are able to change their habits once they understand the importance of pills on time and we see changes in those numbers.

Dan: You define the P in TULIPS as pills, but the whole thing is T- U -L- I- P -S, so what are the other letters stand for and how do they inform the staff about the needs of people with Parkinson's?

Rose: A red tulip is the international symbol of Parkinson's awareness, which is why Joan and I chose that word to develop the acronym TULIPS. The T and the TULIPS acronym stands for time. We know that with the slowness of movement that is caused by Parkinson's disease, is very difficult for someone with Parkinson's to try and hurry or rush. If they're feeling stressed like they feel like they must hurry, they generally get even slower because stress makes all the symptoms worse. The T in the acronym stands for time.

The U in the acronym stands for understanding, and that's the need for understanding these ons and offs that can happen in Parkinson's, or the freezing of gait, or some of the other kind of mobility issues that we see in people with Parkinson's, and in understanding the cues that people might benefit from in helping them to move.

The L in the TULIPS acronym stands for life, quality of life, and we all need good quality of life, but people with Parkinson's sometimes need modifications in order to achieve good quality of life. The importance of exercise in Parkinson's is well-known, and so incorporating exercise into the daily routine is very, very important. Modifications of leisure interests.

People may garden in a raised bed from a seated position rather than being able to stand in garden because of balance issues if gardening is something that someone would be interested in doing. Or someone might need an adaptive equipment piece in order to eat more easily or get dressed more easily. There's a variety of things that can offer good quality of life.

Joan: Then the I in the TULIPS acronym stands for increased awareness. This goes back to the thinking about symptoms of Parkinson's disease. Most people equate symptoms with motor symptoms, the tremor, the slowness of movement, the stiffness that somebody might have, the changes in balance, but the non-motor symptoms in Parkinson's disease are just as important as motor symptoms. There's a very large lack of awareness of non-motor symptoms such as mood changes, depression or anxiety, low blood pressure, constipation, changes in skin, sleep changes, cognitive changes.

There's a great opportunity for awareness of non-motor symptoms with staff who work in residential care communities. We talked about the pills on time, the P in the TULIPS acronym, but I'd like to add that one of the things we like to really teach our patients and families along with healthcare providers, when you're translating a medication schedule for a resident living with Parkinson's, it's important to enter specific times. Carbidopa-levodopa, 25 over 100 at 8, 12, 4 and 8, not the QID which is medical language for four times a day, because QID is different in every computer program out there. It's really important for staff to enter in specific times, and that will hopefully translate into that resident receiving pills on time.

Then lastly, the S in the TULIPS acronym stands for support, and obviously we all need support in order to live well, but in particular symptoms for Parkinson's a low voice volume is a very key characteristics in way of speaking for individuals with Parkinson's. Oftentimes, it's difficult to hear what they're saying, and just teaching staff to ask that resident with Parkinson's to sit up tall and take a deep breath and say it again with a loud voice because we want to hear what they have to say. Also, mood changes, supporting that depression or anxiety are common in Parkinson's disease and how can we support that individual as they live and work through those symptoms. The last thing is supporting family caregivers and including them in the care plan and in communication

Dan: They have a role as an advocate also overseeing the care?

Rose: I think family caregivers need to understand that even if their loved one may be transitioning to a different living situation, they'll always be the family caregiver, and they're a really important member of the team. They do have a role as an advocate to ensure that their loved one is receiving the care in the best possible manner. It may be a family caregiver who's raising awareness of those important things like pills on time or understanding Parkinson's symptoms.

They also maybe the person who catches a misunderstanding or an error as people transition from hospital to senior living or from home to another community, sometimes there are errors inadvertently made as to how medication schedules are transcribed or how other things may have been changed within a hospitalization.

A family caregiver could recognize that error and inform the staff, and then they know the individual with Parkinson's best. They knew that person likely before Parkinson's and they know them now, and they have great awareness of their personal preferences and choices and what kinds of things would be their likes and dislikes, and all those things are extremely important in the plan of care.

Dan: What have we missed or that might be interesting to add?

Joan: I think one thing that we could add here is one of the early questions about our site's familiar with Parkinson's disease? I think sometime that depends on who the staff is and the experience of the staff, but what we have found over the years is that you don't know what you don't know. A health professional may have think, "Well, I've worked with 5 or 10 people with Parkinson's, and I certainly know everything there is to know about Parkinson's disease," but really then, when they start learning, they open their mouth and are aghast because of what they didn't know.

Invariably, people will say, "Oh, I wish I would have known that for Mr. Such and Thus," and, "Oh, Mrs. Smith, I could have done so much better if I would have known this. Knowledge is power and really gives staff confidence if they understand symptoms and again understand practical strategies on how best to manage those symptoms person to person, because again, Parkinson's is really a variable disease and has variable symptoms person to person.

Dan: The care partner probably is a good educator for the staff in a non-threatening gentle manner say, "Well, actually everybody's different, and my partner often exhibits this or that."

Joan: Most definitely. We all know that Parkinson's disease is unique to each person. Everyone's symptoms are just a bit different. If an individual has worked with a person with Parkinson's, they know one person with Parkinson's. The next person that they meet or care for may exhibit completely different symptoms and have completely different preferences. I think we have to be attuned to that and know that Parkinson's looks a bit different in each and every individual.

You've made an insightful comment about caregiver education and their role in educating staff about their loved one's particular care needs. However, it can become a burden to caregivers because staff changes so often at residential care communities, the staff attrition rate is usually around 50% and more in some geographical areas of the United States. Caregivers often tell stories of, "At every shift change, I'd have to say it all again. Then I'd finally get staff to work with my loved one and they would leave, and then I had to start all over again."

Some kind of process for education that is ongoing to meet the needs of staff coming and going within a facility is important. We have to say that the Struthers Parkinson's Care Network can serve that purpose. It has a way to keep education up and manage staff attrition.

Rose: A point of clarification though that I would like to say is, it's very appropriate to say that there are online training programs or some online education about Parkinson's. They tend to be very brief and they don't tend to offer, as Joan mentioned earlier, the practical strategies of care for Parkinson's disease. I'm a little uncomfortable saying one is not good, but I think we need to say that they can be rather brief and that people don't get a lot of background information or a lot of hands-on suggestions on what may be the most helpful.

Dan: It sounds like they can be useful, but they're not the end-all and be all.

Rose: Exactly.

Joan: I agree.

Dan: Well, very good. I appreciate this. I'm sure that people considering moving to an assisted living facility or the like will take away quite a bit from it. Of course, there's quite a bit on the Parkinson's Foundation website too. Thanks.

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For more information on choosing an assisted living or skilled nursing facility, you can search for assisted living and skilled nursing in our library at parkinson.org/library. There you can see fact sheets with tips on finding the right facility of each kind, along with detailed worksheets, with questions and room for answers that you can use to evaluate each facility that you may be considering.

While the task may seem overwhelming at first, these worksheets should help you keep each facility's attributes better organized to be able to make a good choice. To learn more about the importance of receiving medications on time through our aware in care hospitalization kit and resources, please visit parkinson.org/awareincare.

You can also download or order our publication on medications by visiting parkinson.org/store. If you have questions about today's topic or anything else having to do with Parkinson's, our information specialists can provide answers in English or Spanish.

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