



## INTERDISCIPLINARY TEAMS

### Functional Decline and Psychosocial Changes With Parkinson's Disease

Barbara Resnick, PhD, CRNP, and Paige Hector, LMSW

Mr. R is a 79-year-old white male with a history of Parkinson's disease, hypothyroidism, depression, benign prostatic hypertrophy, degenerative joint disease, and hypertension. He transitioned into the nursing home 3 years ago when his care needs, especially for transfers and ambulation, increased. At the time of admission, he was no longer able to transfer independently or ambulate the short distance to the bathroom.

Parkinson's disease treatment is optimized with 25 mg of carbidopa/100 mg of levodopa, three tablets twice daily and two tablets three times daily, respectively. Other medications include 25 µg of levothyroxine daily, acetaminophen 1000 mg three times daily for pain, 240 mg of diltiazem CD daily for hypertension; 75 mg of sertraline daily for anxiety, 5 mg of finasteride daily for benign prostatic hypertrophy, 0.4 mg of tamsulosin ER at bedtime for benign prostatic hypertrophy, and 3 mg of melatonin at bedtime for insomnia.

Before his transition into the nursing home, he used a motorized wheelchair for moving long distances and enjoyed his independence with this mode of transportation. However, while using the chair in the facility, he ran into the walls and had difficulty steering safely. He was referred to physical and occupational therapy (PT and OT) with the goal of optimizing his function and independence. PT and OT evaluated his ability to drive the motorized wheelchair multiple times and consistently concluded that he had decreased spatial awareness, increased reach time (indicative of poor reflexes), and poor safety awareness. Their recommendation was to remove the motorized wheelchair and use a regular wheelchair for transport.

Mr. R began having increased difficulty with swallowing and lost 15 pounds over 6 months. Speech therapy was ordered, and a bedside swallowing evaluation completed. The recommendation was to change from a regular texture diet to a pureed diet with thickened liquids. He declined this diet as he felt that the modified texture and liquid negatively impacted his quality of life. Both he and his daughter acknowledged the risk of aspiration, and he has continued to eat a regular diet and drink thin liquids. He insists on eating in an independent dining room setting and often chokes and coughs while dining.

Mr. R repeatedly brings up the loss of his ability to use the motorized wheelchair with staff, including the administrator, as well with his daughter, other friends, and relatives. When talking about the chair, he becomes angry. He also expects to be transported immediately to his desired destinations and becomes upset when staff cannot

accommodate his time frame. His perseverance with this issue is disruptive as it consumes a large amount of time for staff, family, and friends.

The director of nursing, the administrator, the medical director, the attending practitioner, the geriatric nursing assistant, the behavioral health specialist, and the social worker share their insights into possible strategies for managing this situation as an interdisciplinary team (IDT).

#### Attending Practitioner

Michele Bellantoni, MD, CMD

Dr. Bellantoni is an associate professor in the Department of Medicine at the Johns Hopkins University School of Medicine. She is also the clinical director of the Division of Geriatric Medicine and Gerontology, and medical director of the Specialty Hospital Programs at Johns Hopkins Bayview Medical Center.

As the attending physician, I would meet with the patient and his daughter to express empathy with his loss of independence in mobility and changes in swallowing abilities. I would help them understand that the contributing factors include his progressive neurologic deficits, which are common with Parkinson's disease. I would discuss how difficult the adjustment can be and offer counseling by a trained social worker or psychologist. I would consider increasing the dose of sertraline to more effectively help his mood and coping with his disease. If we increase the dose, it is important to monitor for delirium or any side effects. In addition, for his safety I recommend that his meals be supervised. Together, our team will strive to find a way to maximize his independence through a schedule of activities that will bring him pleasure and still be doable for staff.

#### Geriatric Nursing Assistant

Robin Ingram, GNA

Ms. Ingram is a geriatric nursing assistant at Roland Park Place in Baltimore, MD.

I find that the most successful approach to working with Mr. R is to orient him to the schedule of the day. Even though he often doesn't remember what is said, I write it down for him to reference.

Sometimes he can be redirected if I provide him with activities that I know he might enjoy, like listening to some music or going to the café. He particularly enjoys going to the social cocktail hour on Fridays as well as musical activities. When he talks about the loss of the motorized chair, I reassure him that I will get him where he needs to go on time.

#### Director of Nursing (DON)

Judi Kulus, MSN, MAT, RN, NHA, RAC-MT, DNS-CT

Ms. Kulus has been a certified AANAC RAC-CT Master Teacher since 2004 and currently serves as the vice president of curriculum development for AANAC and AADNS where she oversees and coordinates the associations' certification and educational content.

As a DON, I would like to share several key considerations. Assessment of Mr. R's decision-making capacity is essential. Decision-making capacity is the ability of the resident to make personal choices, weigh the risks, and make informed decisions. Mr. R's situation poses risks (choking and expressions of anger). As part of a decision-making capacity assessment, the IDT can assess how to offer alternatives to minimize risks. Perhaps creative programming ideas like an Xbox gaming system with a virtual reality option for driving can be offered. If his desire to use his motorized chair is for independence, perhaps identifying a schedule of alternative activities and support for his meaningful engagement can be offered.

Handling resident frustration over their declining limitations and life losses can be challenging. It is important to empower staff to support residents with their needs and preferences. Supporting Mr. R in his physical limitations is essential, but also supporting him emotionally with handling and mitigating the loss he feels is equally important.

Recommended team activities include:

- Conduct a formal decision-making capacity assessment to assess Mr. R's needs, wants, vulnerabilities, and alternatives. Because decision-making capacity is unique to each resident and each situation, repeat it frequently to continue to assess the resident's capacity to make informed decisions.
- Document in detail the education provided to the resident about his choices and risks, including any handouts or patient education material that are used.
- When allowing resident choice that includes risk, make sure the resident (and family) understands the risks, and document that there was understanding.
- Understand that even cognitively impaired residents can make decisions, but the risks must be assessed and mitigated.
- Encourage staff to respond to residents' needs in creative and flexible ways. Provide positive reinforcement when they, for example,



The journey might continue to be challenging for Mr. R, but an interdisciplinary approach will help the staff to achieve the best possible quality of life for him while easing their own workload.

help Mr. R enjoy an activity by helping him get there in a timely fashion.

- Ensure policies and procedures (P&P) that allow for residents' informed choice and that staff are following the P&P.
- Offer alternatives to driving the motorized chair, such as virtual driving programs.
- Ensure ongoing discussions regarding choking risk and safety to eat in the independent dining room. A choice that involves risk is never "one and done," as frequent reevaluation is needed.
- Encourage staff to anticipate his needs to reduce frustration with wait times for assistance. For example, if we know Mr. R likes to go to cocktail hour at 4:00 on Friday afternoon, we can anticipate that and build it into an evening staff member's assignment.

#### Administrator

Nigel Santiago, MBA

Mr. Santiago is the executive director of Haven of Phoenix in Arizona with 12 years' experience in long-term care. He holds an MBA from the University of Arizona.

As an administrator, I view situations from a person-centered care approach as well as from a risk management perspective. I would ask staff to schedule a care plan meeting with Mr. R and his daughter. The members of the IDT to attend the meeting include the DON, Mr. R's charge nurse, a nursing assistant that knows Mr. R very well, the registered dietitian, the dietary manager,

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the attending physician, the director of social services, speech and physical therapists, and the activities director. The IDT should review Mr. R's treatment goals and advance directives to confirm his wishes for future care. The team can also discuss a referral to restorative dining to determine whether Mr. R. can use adaptive strategies to increase safe dining practices.

At least weekly during the stand-up meeting, I would get an update on Mr. R's situation to ensure that staff are operationalizing the care plan and keeping the documentation up-to-date, and that Mr. R's daughter is being kept apprised of progress. I would ask the staff development coordinator to collaborate with the social worker to organize staff training on working with residents when they decline care or make choices that may not be in their best interest. Coordinating such training also anticipates Phase 3 implementation of the revisions to the Requirements of Participation around residents' rights and facility responsibility, and compliance and ethics.

*Encourage staff to demonstrate flexibility, compassion, and patience, but also focus on what is realistic.*

#### Behavioral Health Specialist

Lori Nisson, MSW, LCSW

*Ms. Nisson is Family & Community Services Director at Banner Alzheimer's Institute/Banner Sun Health Research Institute. She has spent more than 20 years specializing in clinical and leadership positions, serving the needs of patients and families coping with emotional, neurological, and behavioral problems.*

Mr. R appears to be struggling with loss of abilities and possibly loss of control. This anger may be tied to loss and/or depression. I would recommend that the social worker listen to his perspective and that a current screening for depression, the Patient Health Questionnaire (PHQ-9), be completed. Based on results of this screening, it may be helpful to ask his attending practitioner to consider increasing the dosage of a medication, adding another medication or augmenting the sertraline. Alternatively, a psychiatric consultation may be helpful to comprehensively assess his depression and adjust his medication management for depression or possibly suggest a counseling intervention. It might also be helpful to have staff develop a schedule of times they will be available to assist him with transport. This schedule should be posted in Mr. R's room. If he becomes demanding, staff should firmly but gently redirect him to the schedule.

#### Social Worker

Paige Hector, LMSW

*Ms. Hector has over 25 years' experience in post-acute and long-term care settings as a social worker and clinical educator.*

From a social work perspective, I would provide active listening to help Mr. R express his feelings regarding the changes in his health and abilities. I would avoid trying to problem-solve while listening but rather engage in resident-guided discussion using statements like, "It must be so frustrating to not

have the freedom of your electric wheelchair. You're really angry about that." Or, "I hear that this is so difficult. What has been the hardest change for you?" I would try to look beyond the anger to identify other emotions beneath the surface — such as grief, anxiety, or feeling offended, hurt, disrespected, or distrustful. I would acknowledge the losses and helplessness (using whatever emotions that he identifies).

Although Mr. R expresses his anger toward the staff, there may be other

targets of his anger: the Parkinson's disease, his loss of control, his disbelief at where his life is now, or even the medical team who can't "fix" the illness. I would encourage staff to allow him to vent his feelings and frustrations and understand that it is probably not about them. I would make sure that staff feel comfortable maintaining boundaries in the event Mr. R's anger toward them becomes offensive (e.g., foul language). If that

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occurs, I would say, “I can listen and talk with you, but not if you choose to use that language.” Or, “We need to take a break. Can we meet again at [time]?” and then honor that commitment.

I concur with the recommendation from my behavioral health colleague to develop a transport schedule. This

should be done with Mr. R, the staff, and his daughter. By developing the schedule together, the likelihood of his following it may increase. If he chooses to not follow the schedule and insists that staff transport him, follow through with the behavioral health recommendation to gently and firmly redirect him to the schedule. Consider saying, “Mr. R, I will be available to transport you at

[time]. See you soon!” Try to keep this exchange positive, light, and respectful, and do not get engaged in a discussion. It is imperative that the staff be consistent with the schedule every day, on all shifts. The social worker can help coach and mentor staff on having successful conversations with Mr. R. And, when he follows the schedule, praise him! “Mr. R, thanks for sticking to the schedule. I’m here to take you wherever you’d like to go!”

Ask Mr. R and his daughter what would make the loss of the electric wheelchair less difficult for him, that would make living in the nursing home easier and that would bring him more joy.

### Medical Director

Melvin Hector, MD, FAAFP, CAQ

Geriatrics, CMD

*Dr. Hector is a Tucson-based physician with over 30 years of medical director experience.*

As the facility medical director, it is important for me to know that the complexities of Mr. R’s situation (from grief and loss, to medical issues) are being recognized and addressed by the patient’s attending provider and the IDT. There are great opportunities to train staff on how to be successful with residents who make choices that seem unwise, how to communicate with people who are angry or in disagreement, and how to carry out treatment plans that require setting boundaries and instituting consequences. Documentation should ensure that care is being provided in a person-centered way, and at the same time that it demonstrates good principles of risk management. It is important that existing policies on resisting, refusing, or declining care and the right of a resident to self-determination are both consistent with the care documented and honored.

As medical director, I would want to know that his medication regimens are optimized (that Mr. R’s high dose of carbidopa/levodopa is essential and not part of the problem, and that his sertraline — a selective serotonin reuptake inhibitor — is the best choice for depression associated with the Parkinson’s disease). I also want to know that his behavioral expressions are recognized and that a care plan has been developed and carried out. It is also important that the IDT address the issues of his decision-making capacity and depression and recognize the possibility of dementia. Discussion regarding feeding tubes should be approached and documented — if only to discourage it. Given the resident’s medical condition and his expected decline, the topic seems inevitable. Given the patient’s desire to continue eating a regular textured diet and his potential for pneumonia, this topic must be addressed proactively. Mr R’s advance directives must continue to be well-defined, documented, and current.

### Summary

The IDT identified a useful approach for how to move forward in the care of Mr. R. Further assessments were completed regarding depression, and a care plan meeting was established as recommended to discuss options for treatment to improve Mr. R’s quality of life. He did not screen positive for depression on the PHQ-9, and Mr. R did not want to increase his antidepressant medication. Two nursing assistants who know Mr. R very well contributed to developing a schedule based on his daily routine and desires. The staff was more successful in meeting Mr. R’s needs and preferences, and the family and friends contributed as their schedules allowed. The transportation schedule was posted in a place he could easily see it. His advance directives were reviewed, and no changes were made in his decisions around end-of-life care, which included a palliative approach to care that included decisions to forgo hospitalizations or any life-extending measures. He and his daughter were willing to try a mechanical soft diet in lieu of regular textures, and he agreed to move to the supervised dining room. The staff discussed the best seating arrangement for him and introduced him to a fellow resident who was able to engage him in conversation during mealtimes. The social worker mentored the staff to help improve successful communication with Mr. R, ensure consistency with the established schedule, and provide positive feedback.

As with most resident situations in the post-acute and long-term care setting, employing an interdisciplinary approach can yield valuable insights from each discipline that contribute to a comprehensive care plan. Each individual brings his or her unique perspective, which ultimately helps create a resident-centered plan of care that upholds the regulations and helps manage risk. The journey for Mr. R might continue to be challenging, but with an interdisciplinary approach the staff will be more likely to be successful in achieving the best possible quality of life for him while easing their own workload. 

Dr. Resnick is the Sonya Ziporkin Gershowitz Chair in Gerontology at the University of Maryland School of Nursing in Baltimore. She is also a member of the Editorial Advisory Board for *Caring for the Ages*. Ms. Hector is a clinical educator and public speaker specializing in clinical operations for the interdisciplinary team, process improvement and statistical theory, risk management and end-of-life care, and palliative care, among other topics. She is a member of the Editorial Advisory Board for *Caring for the Ages*. She is passionate about nursing homes and supporting staff to care for the most vulnerable people in their communities.

### KEY POINTS

The interdisciplinary approach was important in combining each discipline’s unique perspective in a balanced set of recommendations:

- Allow Mr. R to vent his frustration about his current life situation.
- Encourage staff to demonstrate flexibility, compassion, and patience but also focus on what is realistic.
- Conduct a detailed capacity assessment around decision-making for safety.
- Bolster the daughter’s roles as her father’s supporter and the staff’s care partner.
- Ensure that staff are attuned to Mr. R’s daily routines, likes, and dislikes.
- Encourage creative interventions such as the Xbox gaming system.
- Continue to discuss treatment decisions and goals of care.
- Talk with the daughter about the progression of Mr. R’s Parkinson’s disease to ensure she has realistic expectations of the future.
- Instruct all staff to firmly and gently redirect Mr. R to the transportation schedule.
- Update and operationalize the care plan consistently.
- Ensure thorough documentation by all discipline representatives.
- Conduct staff training on resident rights and facility responsibilities.

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