CASE IN POINT: What Happens Next: Experiences of Caregivers Following a Family Member’s Move to Long-Term Care for Dementia

It’s all too easy to imagine that the stress of caregiving is over once a family member with dementia moves to long-term care. New research shows that while caregiving changes, it doesn’t end, and professionals need to continue their support of the family as they navigate a new reality.

By Robyn Birkeland, Ph.D. and Tamara Statz, MA, LMFT
CASE IN POINT

It's all too easy to imagine that the stress of caregiving is over once a family member with dementia moves to long-term care. New research shows that while caregiving changes, it doesn't end, and professionals need to continue their support of the family as they navigate a new reality. BY ROBYN BIRKELAND, PH.D. AND TAMARA STATZ, MA, LMFT

New Caregiver Roles

Often after a move to managed care, a family caregiver is no longer primarily responsible for medications, daily grooming, chores, and laundry. This decrease in logistical responsibility allows caregivers to enjoy spending time with their family member without the distraction of a to-do list. In fact, numerous caregivers in the RCTM study shared that their relationships strengthened as a result of being free to focus their attention solely on their family member while visiting. One caregiver shared, “I love that I can just go and sit with my mom. I don't have to rush around...
What Happens Next:
Experiences of Caregivers
Following a Family Member’s
Move to Long-Term Care
for Dementia

doing things for her. Now, I can just sit with her and
hold her hand.” That said, caregivers are not without
responsibility. On the contrary, they assume new roles
once their family member has moved into long-term
care. Three roles to be examined today are: consultant,
monitor, and advocate.

Consultant
The role of consultant centers on the caregiver’s expert
knowledge of their family member’s medical history,
life history, personality, and preferences. Oftentimes
the primary caregiver is the most familiar with the
family member and might be the only remaining
person who knows this information. Caregivers are
responsible for communicating this knowledge to the
long-term care staff from casual conversations to the
more formal care conferences. Some families even
create memory books or biographies with pictures
and stories about the family member and display it
in his or her room for all who enter to see. Armed
with personal information, the staff can individualize
the family member’s care and make stronger connec-
tions with the family member (Davies & Nolan, 2006;
Gaugler, Reese, & Sault, 2015).

The more the staff know about the family mem-
er, the more they can individualize their care. For
instance, caregivers often relate how difficult it is to
going their family member to take a shower. If the staff
knew that the family member always showered in the
morning, liked to use lavender scented soap, or only
took baths, it could help staff to accommodate those
preferences. Staff could adjust the schedule to offer
morning showers, or ask the family member to bring
lavender soap from home, or even offer baths, instead
of showers, if possible. These changes could promote
cooperation and provide a much more enjoyable bath-
ing experience for the family member. Other practi-
cal preferences can include whether or not the family
member is a “morning person” or prefers to sleep in,
is a vegetarian, has had previous trauma such as post-
traumatic stress disorder (PTSD) from military ser-
vice or other causes, or has a particular affinity to dogs
and would enjoy a therapy dog visit.

Monitor
The monitor role is often considered the “eyes and
ears” of the residents in long-term care. In this role,
the caregiver holds the staff responsible for providing
adept and compassionate care based on a Care Plan,
which may include doctor’s orders (Davies & Nolan,
2006). This may very well be the least appealing role
that caregivers assume. Caregivers evaluate the care
being provided by staff in many ways. What is the
quality of care? Are residents treated fairly and with
warmth and dignity? How effective are the staff’s
interactions with residents? Do they offer enough,
and varied, activities? Is there flexibility in residents’
schedules? For instance, does the staff get everyone
up early in the morning, even the residents who like
to sleep late? If a resident sleeps in, is breakfast pro-
vided when they awaken or does the staff simply give
a small snack until lunchtime? Additionally, caregivers
frequently scrutinize their family member’s bill
each month and confer with staff, such as a nurse care
Advocate

There are a variety of ways a caregiver can engage in advocacy, including working in the community to raise awareness, championing individual care, and working with long-term care providers to improve care for all of the residents (Davies & Nolan, 2006). Participating in a walk to raise awareness about dementia or fundraising for a community dementia organization are two common ways to advocate in the community. Becoming a mentor, attending a support group, and/or sharing a caregiving journey with others also help fulfill the advocacy role in the community.

Advocating for improved individual care in long-term care centers often takes the form of promoting a family member’s best interests with staff. Caregivers are responsible for expressing concerns that their family members cannot express for themselves. Whether this advocacy occurs in passing or by scheduling and/or participating in care conferences, it is a critical role caregivers assume. When a caregiver notices that something is amiss with their family member’s care, advocating means bringing the issue to the attention of the staff and working collaboratively to brainstorm solutions and implement a plan to improve the situation. Caregivers may also take on the responsibility of measuring the success of the solution and meeting with the staff to implement a new solution, if the first option proved ineffective. However, family members may resent this role. Frequently, caregivers state, “I should not have to do this, they should just be doing their jobs.” While this is true, there is also an element of human error, miscommunication, and context that can be challenging to avoid entirely.

In addition, caregivers can advocate for all long-term care residents by simply visiting the long-term care center. The presence of a visitor (pets and children often are a highlight) can bring energy and excitement to all the residents. Visitor presence keeps the staff on their toes as well, showing them that families are present and paying attention to the care their family members and other residents receive.

Caregivers can also advocate more directly for the residents. For example, one caregiver in the RCTM study was compelled to write a letter to her husband’s long-term care center asking for increased activities in the memory care unit as few were offered. She was concerned that the residents were not adequately engaged during the day. Due to the paucity of activities offered, she regularly had to take her husband out of the memory care wing to enjoy activities in another residential area. Her letter resulted in a significant increase in activities offered for residents in the memory care unit.

Emotional Distress

Along with these new roles caregivers assume after moving their family member to long-term care, they frequently experience a new kind of emotional unease. It is often believed that the move of a family member to long-term care alleviates the caregiver’s feelings of stress and burden from caregiving. However, this belief is not entirely accurate. In fact, there is a considerable emotional toll on the caregiver in making the decision to move a family member (Sury, Burns, & Brodaty, 2013). Caregivers can experience significant emotions related to the placement decision, including feelings of depression, sadness, loneliness, anger, resentment, and yes, some relief (Gaugler et al., 2015; Gaugler, Reese, Mittelman, 2016; Müller, Lauteenschläger, Meyer & Stephan, 2017). Two of the most common emotions caregivers may experience are guilt and stress.

Guilt

Whether related to the move, family dynamics, pressure from themselves or others to be a “perfect” caregiver, challenges in their relationship with the family member who has moved, decision-making, or another cause entirely, guilt is often the resulting emotion. As a caregiver in the study sarcastically expressed, “Guilt is the gift that keeps on giving.”

Caregivers often express concern over moving their family member either “too early” or “too late.” As a counselor, it is useful to support caregivers in the knowledge that there is no perfect time to move. There are numerous factors that go into the timing of a move as well as the location. Helping the caregiver to accept that “there is no place like home” can also be useful, as a room in a long-term care center will never be quite as cozy as mom’s home of fifty years. Reminding caregivers that they are doing their best, that their family member needs time to adjust, and that they need to work closely to build relationships with staff can help to alleviate this experience of guilt.

Caregivers may also experience guilt over feeling some relief that their family member has moved to long-term care. Caregivers, regardless of whether their family member was living with them or independently, no longer need to provide continual supervision. They can go to the store without worrying about the safety of their family member at home. They can begin to engage in their previous daily activities without wondering if mom is trying to use her stove. This freedom
brings a sense of relief to many caregivers. On the other hand, it also can elicit feelings of guilt. Caregivers wonder if it is okay for them to get back to doing their normal activities while their family member is in long-term care. They question if they should be having fun when their family member may not be happy. Caregivers, particularly spouses, express concern about what other people will think of them and their decision to place their family member while the caregiver is seemingly now carefree and out enjoying life. In addition, they may feel guilty about not using their free time to visit their family member more often.

**Stress**

As mentioned previously, stress levels often do not decrease when a family member moves to long-term care (Gaugler et al., 2015). On top of new caregiving responsibilities and lingering guilt, adult children in particular may feel torn between responsibilities toward their job, their own family, and their parent. They are stressed about making time to visit their family member and how they perceive their family member is adjusting to living in long-term care. A common experience is a stress reaction when the care center calls unexpectedly or on a regular basis. One caregiver in the study remarked, "I always wonder is this the call? (that mom has died)."

There are many effective ways to help reduce feelings of stress. Encourage caregivers to take time for themselves and to engage in activities that make them happy. Relaxation exercises, such as deep breathing and progressive muscle relaxation, can be valuable methods of stress management. Caregivers often find peace in meditating or practicing yoga. Writing in a journal can help alleviate feelings of tension.

**Support**

Considering the possible emotional distress and the new responsibilities of a long-term care move, it is important to support caregivers who have moved their spouse or parent to long-term care (Afram, Verbeek, Bleijlevens, & Hamers, 2015). Often, there is a lack of support from friends and family once the family member has moved to long-term care. Whether it is because well-intentioned friends and family do not want to risk asking potentially upsetting questions, or because they do not know what to say or do, caregivers frequently feel alone and unsupported after the move. In addition, peers and family may feel that everything is fine now that the responsibilities that existed before their loved one lived in long term care have concluded, and they may perceive that the caregiver no longer needs extra support.

For example, one caregiver in the study related that neighbors, who used to deliver meals regularly, come over significantly less often now that her husband is living in long-term care. Another caregiver in a similar situation stated, “I don’t need their help any less, but they think I do. But if anything I need it more, or in a different way.”

Some caregivers expressed dissatisfaction with the kind of assistance they were receiving. For instance, one caregiver lamented that the type of support she received was not what she wanted: “I need help, not advice.” Offering advice, but not any kind of help along with it, can be a well-intentioned but ineffectual attempt at support. Offering personal opinions about how you would handle a situation may come across as judgmental, and may even be perceived as attempting to find fault in their caregiving decisions.

Caregivers should be encouraged to engage in social activities with caregiving peers, as well as with friends and family. Caregivers can gain support from those in similar caregiving situations, and may benefit from attending a support group. Other caregivers find that they just want to get away from thinking and talking about caregiving. Some note that they do not mind sharing with support groups, but it just adds to their stress to hear about other caregiving situations. In fact, one caregiver related that he liked to travel out of his small town to socialize with strangers who did not know him. He valued being able to talk to people without having to share that his wife has dementia and lives in long-term care. He thought those conversations went really well, until he would have to mention his wife and “the conversation just kind of ends.” He questioned, “Where do you go from that?”

For caregivers who would like to engage in support groups, information can be found at https://www.alz.org/apps/we_can_help/support_groups.asp. Local libraries, churches, and long-term care centers often host support groups. Moreover, families of long-term care center residents can meet informally as well. In fact, some long-term care centers host opportunities for the families to get together. Online message boards like the boards found at https://www.alzconnected.org/ are another a good source of social support.

It is also important for caregivers to spend time enjoying social opportunities with friends and family. Caregivers often describe feeling lonely and uncomfortable initiating social activities with friends. Caregiver spouses, in particular, may feel uncomfortable about joining in social activities without their spouse. Caregivers have shared a variety of reasons...
for avoiding social activities, from feeling conspicuous without their spouse to simply not knowing what to do without him or her. One caregiver spoke of the pain of going from “we” to “I” as she participated in activities and made new memories without her husband. Caregivers may view themselves as a burden to their friends and believe that asking to spend time with them would be infringing on their friends would need or prefer to spend with their spouses or families. As a counselor, it is often effective to ask the caregiver how she or he would feel if the situation were reversed. Caregivers recognize quite quickly they would want to spend time with their friend and would not see it as an intrusion into their life at all. Scheduling weekly outings with a friend or alternating friends can be very beneficial, particularly on the weekends. Many spousal caregivers wistfully describe their weekends as long and drawn out. As noted in the section on guilt, taking time to engage in fun activities may be hard for caregivers to allow themselves to do, which makes it that much more critical that professionals in aging strongly encourage caregivers to do so.

Conclusion
Moving a family member to long-term care can be a stressful process that starts with making the decision to move. After the move, caregiver stress persists as family members assume new roles in an attempt to ensure the well-being of their loved one in a new environment. Whether it be communicating their family member’s medical history, life history, and preferences, advocating for their family member, raising public awareness, or evaluating the care provided by the staff, caregivers have several new responsibilities. They can also experience challenging emotions, including significant guilt and stress. Caregivers may feel socially isolated, particularly spousal caregivers, in addition to receiving less support from friends and family. At the same time, the transition to a long-term care experience can build stronger connections between the caregiver and their family member. Once their family member has moved to long-term care, the caregiver’s daily caregiving responsibilities typically decrease, providing greater opportunity to be present and focused on their family member when visiting. This time and undivided attention can enhance relationships and strengthen bonds. Oftentimes the experience of relief and stress are felt simultaneously, which can be a confusing experience for caregivers. Given this, it is critically important for aging professionals and society, as a whole, to be aware of these concerns and to support caregivers after a move to long-term care.)

REFERENCES

Tamara L. Statz, MA, LMFT, is a licensed marriage and family therapist with over fifteen years of experience working with older adults and their families. At the University of Minnesota - School of Public Health, she works on the Residential Care Transition Module Study, providing psychoeducation and counseling to relatives who have recently moved their family member to long-term care due to memory impairment. Contact her at stat0057@umn.edu, 612-625-8159, or visit www.sph.umn.edu.

Robyn Birkeland, Ph.D., is a study counselor for the Residential Care Transition Module Study (RCTM) in the School of Public Health at the University of Minnesota. She provides psychoeducation and counseling to relatives who have recently moved their family member to long-term care due to memory impairment. Contact her at birke015@umn.edu, 612-626-8872, or visit www.sph.umn.edu.
Scenario:
After working with more than fifty caregivers on a research project funded by the National Institutes of Health (NIH), it is clear that caregivers often do not feel comfortable sharing some private thoughts with friends or family that, conversely, they will reveal to a trusted neutral party such as a counselor. These conversations with caregivers who have moved a loved one to long-term care support previous research that suggests caregivers feel guilty or even ambivalent about the move itself, the timing of the move, and their role as a caregiver. What follows is an amalgam of stories and emotional responses reported by caregivers in study sessions.

Discussion:
Miriam Sprouse is a retired 73-year-old teacher. She has been married to her husband, John, for almost fifty years. John has moderate to severe Alzheimer’s. He was first diagnosed with dementia seven years ago. Miriam noticed nine years ago that she needed to help him more with little things, like remembering what to buy at the grocery store and reminding him to take out the trash. As time went by, she needed to take over the household finances as John forgot to pay some bills and paid others more than once. As John had been an accountant and was always very organized, this realization was very startling.

After John was diagnosed with Alzheimer’s, Miriam began to assume all of his caregiving responsibilities. She drove him to doctor’s appointments, cooked all his meals, made sure he took his medicine, and reminded him to bathe. Years passed, and John experienced increased cognitive decline, greatly affecting his functional living skills. He often refused to take his medicine or shower. He did not change his clothes, and could go all day without eating if she didn’t encourage him.

John also began to wander. He would leave the house during the day and later at night as well. Miriam was always able to catch him before he wandered too far from home, but she grew increasingly concerned that he would leave their, or their neighbor’s, yard. She realized she needed to watch him all the time during the day. She could not leave him home alone while she went out for groceries or to play mahjong in the afternoon as she had for the past twenty years.

She looked into adult day care centers and found one that was relatively close to home. She would drop John off and run errands for the afternoon. John grew to dislike the day care center. He did not want her to leave him there. He would wander out of the building and staff had to find him. Miriam was worried that he was looking for her. She tried to explain to John that she would be back, but every time she dropped him off, he became agitated and would wander. The staff at the day care center ultimately told her that they didn’t have the staffing to look for him and that if he left again, he would not be allowed back. Miriam did not bring him back after that warning. She figured he would walk away again, so what was the point?

At home, John began to wander out of the house more frequently and at all hours of the day and night. Once, Miriam was unable to find him for 30 minutes and when she did, he was eating flowers on the side of the road. Miriam worried what she would have done had she not found him or had the flowers been poisonous. She worried that he would freeze outside or be hit by a car in the middle of the night.

Miriam often was not able to sleep through the night due to John’s frequent and long awakenings and her concern for his safety. She installed alarms on her doors so that she would hear if John was leaving the house. He would open the door, the alarm would sound, and she was able to stop him before he wandered out of the house…until he realized he could leave while
she was in the bathroom. There was nothing that she was able to do to stop him during that time.

Miriam was exhausted, emotionally and physically. Her health was suffering. She had friends and family who came by to visit and bring meals a few times a week. Her children called almost nightly to check in on how she was doing. Their pastor came by fairly often to see how they were doing and offer support. She was grateful, but still overwhelmed with responsibility and worry. Miriam knew that she could not take good care of both John and herself. She knew she could not provide the supervision and care that he needed. She worried about his safety and her health. After much consideration, Miriam decided to move John to a nearby long-term memory care center.

Miriam felt a tremendous amount of guilt while making the decision to move. She felt even more guilt after the move, when John would ask her if he could go home. Despite over time coming to accept that the move was inevitable, Miriam struggled, wondering if she moved John too soon. Thankfully her friends and family assured her that she did the right thing.

Miriam heard of a caregiver support group at John’s care center. She decided to give it a chance, and eventually made friends with another woman who was caring for her spouse who lived there. Both women were able to swap stories and encourage each other on their journeys as spousal caregivers. They shared the experience of wistfully thinking that “This is not how our retirement was supposed to be.” Eventually her friend’s husband died. Miriam experienced grief, arising from the way their friendship changed as a result.

During her time in the support group, Miriam learned about different roles that she assumed as she cared for her husband. She connected strongly with this content. The first role she was told about, being a Consultant, was very empowering for Miriam. After several decades of being married to John, she knew myriad details about his life history and preferences. She found this conversation about being a Consultant especially helpful as she was scheduled to have a conference regarding John’s care plan later that week. She had a few ideas about things that could be changed in his care to improve his quality of life, and she had a newfound desire to share these ideas with the director of nursing at the facility.

For Miriam, the role of Monitor was less enticing. Her first thought upon hearing about the role was “Why should I have to do that? Shouldn’t the staff be doing what they say they are doing? What am I paying for?” As the support group leader explained, this is a role that caregivers commonly resent assuming. The leader also explained the differences between being the “eyes and ears” of a family member’s care versus feeling the need to oversee all the details of care. After hearing more about the Monitor role, Miriam realized that she was engaging in this role each time she visited John already. For instance, she was sure to take notice if his laundry was done and put away, and if he ate lunch and was taken to the bathroom afterward. In addition, her positive rapport with staff helped Miriam see that this role might be more taxing for other caregivers in more tenuous situations, but in her situation, she was confident trusting the staff.

Finally, when the support group leader explained the idea of caregivers being Advocates, Miriam lit up. This is what she had been doing all along! Her desire to see John have the best care possible and to speak up if she thought something could be improved were responsibilities she was passionate about performing. She also realized that her weekly visits to John were a form of advocacy not only for him, but also for the other residents in the facility, especially those who might not have family or friends visit often or at all. She came to embrace the idea that her presence made a difference not only in the facility culture, but among the staff who cared for the residents. She also decided she would participate in the Alzheimer’s walk in her community for the first time.

As the support group leader explained, all three of these roles often occur simultaneously. Miriam saw how this resonated with her situation and felt a new sense of empowerment throughout the discussion at the support group. She left with a heightened awareness of the importance of her role and how she was making a difference not only in John’s life, but in the lives of other residents in the facility, other caregivers, and all who are going through the experience of Alzheimer’s and caregiving. •CSA

Robyn Birkeland, Ph.D., is a study counselor for the Residential Care Transition Module Study (RCTM) in the School of Public Health at the University of Minnesota. She provides psychoeducation and counseling to relatives who have recently moved their family member to long-term care due to memory impairment. Contact her at birke015@umn.edu, 612-626-8872, or visit www.sph.umn.edu.

Tamara L. Statz, MA, LMFT, is a licensed marriage and family therapist with over fifteen years of experience working with older adults and their families. At the University of Minnesota - School of Public Health, she works on the Residential Care Transition Module study, providing psychoeducation and counseling to relatives who have recently moved their family member to long-term care due to memory impairment. Contact her at stat0057@umn.edu, 612-625-8159, or visit www.sph.umn.edu.