

# Program Update



## Person-Centered Program Design & Family Caregivers

### Background and Program Design

One in five South Carolinians will be over 65 by 2029<sup>1</sup>, and the U.S. Department of Health and Human Services anticipates 70% of all older adults will need long-term services and support.<sup>2</sup> In an effort to be more responsive to South Carolina's demographic shift and the growing demand for long-term care, the South Carolina Department of Health and Human Services (SCDHHS) implemented Healthy Connections Prime, a program for older adults over age 65 receiving both Medicare and Medicaid benefits. In this Fall 2018 Program Update we will explore the program design and how family caregivers factor into this design.

Person-centeredness is a key element of Healthy Connections Prime's program design. Person-centeredness supports the balance between what matters to the member ("important to") and what helps the member be safe and healthy in a way that works for him/her ("important for").<sup>3</sup> This approach recognizes the support provided by family caregivers and includes four program design domains: **assessment and care planning**, **benefit design**, **training**, and **quality improvement**. The Medicare-Medicaid Plan (MMP) care coordinators play an integral role in all aspects of this approach as the individuals with the most contact with a member and their caregiver(s). Care coordinators see the caregiver as a vital participant in the multi-disciplinary team.

#### Who Are Family Caregivers?

A family caregiver provides unpaid, informal care to another adult in need of assistance due to a chronic medical condition. A recent study by the AARP<sup>4</sup> found that 38% of family caregivers were adult children caring for their parents, 27% cared for other relatives, and 20% were spouses or partners. The remaining 15% of caregivers identified as friends or neighbors. Nearly half of family caregivers reported performing medical/nursing tasks including but not limited to medication management.

## Assessment & Care Planning

As part of the overall annual member assessment conducted by the MMP care coordinator, both members and identified caregivers are assessed. Each annual assessment identifies member strengths and areas where assistance is needed. For example, does the member have a cognitive impairment or need help with activities of daily living? To what degree does the member self-manage, co-manage, or delegate health care decisions?

Often identifying members with cognitive impairment is the beginning of linking members with high-needs and their caregivers to appropriate services. Thus, the first step of a member assessment is always cognitive assessment. Cognitive impairment can range from mild to severe and can be impacted by a variety of factors

<sup>1</sup> Stein, E., Waldrep, S. & Pearson, J.L. (2015). Creating Direction: A Guide for Improving Long-Term Care in South Carolina. South Carolina Institute of Medicine and Public Health

<sup>2</sup> U.S. Department of Health and Human Services. (2017, October 10). Who Needs Care? Retrieved November 9, 2017, from <https://longtermcare.acl.gov/the-basics/who-needs-care.html>

<sup>3</sup> The Learning Community for Person Centered Practices. (2012). Person Centered Thinking Workbook. Retrieved November 13, 2017, from <http://www.learningcommunity.us/documents/Workbook.pdf>

<sup>4</sup> Reinhard, S., Levine, C., Samis, S. (2012). Home Alone: Family Caregivers Providing Complex Chronic Care.

including disease processes, medications, and lifestyle habits. Even a mild cognitive impairment can lessen the ability to meet one's own needs, thus, putting more reliance on caregivers. If an impairment is identified, the care coordinator can request a complete clinical assessment by the member's physician and also recommend additional services. Care coordinators also consider non-medication interventions when appropriate.

One MMP reported that 28% of their members had an involved caregiver. Over an 18-month period, the MMP conducted 1,544 caregiver assessments and also educated all identified caregivers about caregiver-related stress.

If a caregiver has been identified as part of the comprehensive assessment, the MMPs use a uniform, validated caregiver assessment tool (the American Medical Association's *Caring for the Caregiver Self-Assessment*). The tool primarily focuses on caregiver well-being and assesses depression, stress, and overall

quality of life. By assessing caregivers, MMPs promote early intervention that may prevent "burnout" by integrating caregiver needs into the overall member care plan and thus help members remain at home. Caregivers are also invited to participate in the multidisciplinary team, at the member's request.

## Benefit Design

Engaging members in "what matters most to you" discussions is especially important for members who may be battling multiple chronic conditions or a serious illness. Recognizing the need for these conversations as well as the importance of ensuring care supports member wishes, South Carolina integrated a palliative care benefit into its program design. Palliative care can help relieve the treatment burden for both members and caregivers. Research shows palliative care can decrease hospitalizations, promote more effective management of distressing symptoms, and increase overall quality of life/satisfaction for both the member and his/her caregiver. Nationally, 1 in 5 caregivers report a decrease in this physical, emotional, or social health as a result of caregiving activities.<sup>4</sup> A randomized clinical trial published in 2016 showed early palliative care intervention, although designed for patients, reduced caregiver depression and improved vitality and social functioning when compared with palliative care provided later in the disease process.<sup>5</sup> As such, palliative care providers play an important role for our member's caregivers. These providers inform and educate, and this approach to care can also facilitate advance care planning discussions which avoids planning under pressure.

In 2016, 49% of Healthy Connections Prime members eligible for palliative care accessed this benefit.

## Training

In tandem with member and caregiver assessment, education and training of care coordinators, members, and caregivers is an essential design feature. The Alzheimer's Association of South Carolina estimates 1 in 8 South Carolinians over age 45 suffer from cognitive decline, and over 304,000 South Carolinians act as unpaid

<sup>4</sup> Center to Advance Palliative Care. (2018). Caregiver Corner. Retrieved January 19, 2018 from [www.getpalliativecare.org/resources/caregivers/](http://www.getpalliativecare.org/resources/caregivers/)

<sup>5</sup> Baldwin, Kelly. (2016). Press Release: Early Palliative Care Provides Important Benefits for Family Caregivers of Patients with Cancer. Retrieved from <https://www.asco.org/about-asco/press-center/news-releases/early-palliative-care-provides-important-benefits-family>

### MMPs Promote Dementia Capable Training

Additional trainings have been offered to MMP staff and/or caregivers:

- Lewy Bodies Dementia: The Importance of Comprehensive Care and Support
- Methods and Techniques for Early Screening for Dementia for People with ID/DD
- Providing Safe and Effective Nutrition for People with Dementia
- Dementia Workshops

caregivers to individuals with Alzheimer's or dementia.<sup>6</sup> In light of the prevalence of cognitive impairment in the older adult population, dementia-capable training was incorporated into the design to supporting members and caregivers in Healthy Connections Prime. Care coordinators undergo dementia-capable training, including a *Dementia Dialogues* certification program offered through the University of South Carolina Office for the Study of Aging. The certification program supports the person-centered dementia care framework while training staff and caregivers to “step into the world” of the person with dementia. This training ensures care coordinators are skilled in working with persons with dementia, knowledgeable of services that may help, and aware of the appropriate community resources and tools to support family caregivers. Further, care coordinators are equipped to coach caregivers regarding how to address disruptive behaviors that stem from Alzheimer's or dementia. Care coordinators have also completed Advanced Dementia training through the Alzheimer's Association of South Carolina Chapter. The Advanced Dementia training has been so successful, one MMP also offers this training to its members' caregivers as a means of providing support, relieving stress, and helping members to avoid transfer to a long-term care facility.

## Quality Improvement

South Carolina MMPs are required to conduct Quality Improvement Projects (QIPs) and to engage caregivers in the QIPs. Through QIPs, the MMPs have worked to address common problems, whose resolution leads to better member outcomes and enhanced quality of life for members and their caregivers. Over the past two years, QIP focus areas have included working to reduce member falls, increasing respite care utilization, and reducing caregiver burden. Examples of the education and support tools created as part of QIPs include a caregiver toolkit and a fall reduction kit. The fall reduction kit was targeted to address the problem that more than 1 in 4 older adults in American fall each year and that falls can contribute to injury, other illness, and loss of independence. The kit

The MMPs administered QIPs as follows:

- **Absolute Total Care:** Administered a fall prevention QIP with outcomes measured by a decrease in fall risk score among members who engaged in the QIP.
- **Molina Dual Options:** Developed a QIP aimed at a reduction in caregiver burden and increase in member quality of life measured by decrease in the rate of caregivers who report high stress levels
- **First Choice VIP Care Plus:** Developed a QIP that encouraged use of respite services to reduce caregiver burden measured by respite authorization volume and decrease in reported caregiver stress

The Carolinas Center for Medical Excellence reviewed each MMP's QIP and noted confidence in each QIP process and evaluation method as well as improvements for future QIPs.

<sup>6</sup> Alzheimer's Association of South Carolina. (n.d.). Alzheimer's in South Carolina. Retrieved January 19, 2018 from [https://www.alz.org/sc/in\\_my\\_community\\_105019.asp](https://www.alz.org/sc/in_my_community_105019.asp)

included information for members and their caregivers about how to reduce falls at home and in the community, as well as an exercise book, pedometer, exercise wall chart, motion sensor night light, water bottle, and medicine bottle opener. The caregiver toolkit addressed topics such self-care, safety, and support services.

## Results and Lessons Learned

A truly person-centered program is responsive to both member and caregiver needs. This is indicative in early outcomes and the experiences of MMPs such as:

- Caregiver stress is addressed via assessment and care planning
- Caregivers are able to keep loved ones safe at home through benefit design focused on relieving the burdens of symptoms and treatment
- Caregivers are coached to manage challenging behavioral through dementia capable training
- Caregivers are supported the education, respite, and other caregiver resources

Thoughtful person-centered design has allowed the MMPs to target caregiver supports to those most at-risk while also equipping care coordinators. MMPs have adopted new practices focused on caregiver training, and the MMPs see meaningful involvement of members and caregivers in Enrollee Advisory Committees.

South Carolina's experience has demonstrated the importance of promoting the State's priorities via contractual requirements with the MMPs while allowing for plan innovation. The State and MMPs have worked together to define and fine-tune the most effective ways to support members and their caregivers. Supporting caregivers can be challenging as it is sometimes difficult to identify and engage caregivers particularly when there are multiple caregivers involved. MMP staff have also noted that there are also opportunities to address other caregiver needs such as training and assessing the caregiver's desire/ability to provide care. MMPs continue to refine their approach to data collection, analysis of caregiver burden, and the interventions used to address it.

New priorities for both the state and MMPs have emerged. Based upon MMP experiences, health plans are adopting best practices more broadly within their organizations. These best practices can be leveraged now and in the future. As South Carolina prepares for the growing long-term care needs of older adults, it is important to continue to integrate person-centered design that promotes a cultural shift in how caregivers are recognized and supported by not only be health plans but by the health care system.

### Honoring Those Who Care for Others

*"My health plan has really made a difference in my life."*

One member stated he always wanted to join the Army like his brother who received several awards and honors, but he could never join because he had to care for his sick mother. The member often proudly told his care coordinator about when his health plan featured his support for his mother in their newsletter. When the member requested a copy of the newsletter, his care coordinator framed it and presented it to him at his next home visit. Upon receiving it, the member became emotional, expressed his gratitude, and stated, "I have never received any awards or honors before, and I'm going to carry it around to show all my friends."