



ALS ASSOCIATION ROUNDTABLE

DELIVERING THE BENEFIT OF
COMPREHENSIVE PALLIATIVE CARE
TO THE ALS COMMUNITY

October 8, 2024

EXECUTIVE SUMMARY



OVERVIEW

Since 2019, the [ALS Roundtable Program](#) has regularly assembled members of the ALS community for thoughtful, facilitated discussions about issues of priority for people living with the disease, helping shape the ALS Association’s strategic planning efforts and identifying actions to continuously improve ALS care, advocacy, and research. Roundtable meetings bring together a diverse group of individuals who reflect a range of ALS expertise and experiences, including people living with ALS, caregivers, clinicians, researchers, government officials, and industry partners.

On October 8, 2024, we convened our 12th multi-stakeholder Roundtable to discuss opportunities and challenges related to delivering comprehensive palliative care to the ALS community. The day-long meeting, which included a fireside chat, three expert panels, group discussions, and small group brainstorming, promoted candid conversations among participants about how to enhance a fuller understanding of palliative care and increase the ALS community’s access to, acceptance of, and utilization of it.

The agenda for the day was designed to define palliative care for ALS, with a specific focus on the psychosocial needs of people living with the disease and their caregivers, treating side effects and symptoms of ALS to make it more livable, and learning from the experiences of other patient communities.

BACKGROUND

DEFINITION OF PALLIATIVE CARE

Meeting participants were provided with the following definition of palliative care to lay a foundation for the day’s discussions.

“Palliative care is the focus on improving the quality of life [for individuals] by caring for their minds, bodies, and spirits while they live with serious illnesses. It supports not only the person with the disease, but also their loved ones, families, and care partners. Using expertise in symptom management and communication, palliative care helps people navigate difficult conversations and decisions, while focusing on maintaining their identity as a whole person, not by their disease, and providing comfort.”¹

SNAPSHOT OF THE CURRENT LANDSCAPE

The Association regularly surveys people living with ALS and current and past caregivers through the [ALS Focus™ Survey Program](#). Key findings related to palliative care that were derived from several different surveys are summarized on the following pages.

¹ Definition provided by Dr. Ambereen Mehta, director of the Johns Hopkins Bayview Palliative Care Program.



IMPACTS OF ALS ON DAILY LIFE AND CARE NEEDS

- A [2020 ALS Focus survey](#) found that the inability to do activities and limitations with mobility or walking mattered most to people with ALS in their daily lives, both from their own perspectives and from their caregivers' perspectives.
 - Nearly 90% of survey participants with ALS reported experiencing emotional issues. Notably fewer said these emotional issues had a big impact on their daily lives.
- In a [separate survey conducted in 2020](#), 56% of ALS Focus participants reported needing professional care for ALS at home, such as home health aides, nursing, physical therapy, or speech therapy. Over 40% said they paid for at least some of this care out of pocket.
 - According to 41% of these ALS Focus participants, allied health professional visits outside the home, like physical therapy and speech therapy, were needed for ALS.
- Based on surveys conducted in [2022](#) and [2023](#) about mobility equipment, 16% of participants with ALS and 26% of current caregivers said they should have started using a power wheelchair, portable ramp, or rollator sooner.
 - Sometimes participants didn't know about portable ramps.
 - Some participants weren't emotionally ready to accept they needed a wheelchair.
 - The data also suggested that having access to mobility equipment could help combat feelings of social isolation and contribute to quality of life.

IMPACTS OF INSURANCE DENIALS

- In [2022](#), nearly one in three ALS Focus participants reported that a prior authorization or claim for ALS health care had been denied by their insurance company.
 - In-home care services, including care delivered by physical therapists, occupational therapists, speech therapists, and certified nursing assistants, were the third most common denial.
 - Denials of prescriptions and medication supplies were most common followed by denials of power wheelchairs and wheelchair accessories.
- Insurance denials themselves take a toll on well-being. For survey participants who had a prior authorization or payment for a claim denied, 48% experienced worry or stress, and nearly a third said these denials led to challenges for caregivers.
- Qualitative results showed that anticipating insurance coverage of future needs like new treatments evoked anxiety and fear in both people with ALS and caregivers.



CAREGIVER PERSPECTIVES

- In [2021](#), ALS Focus asked current and past ALS caregivers about the programs they needed most. From a list of 24 services and supports, hospice care was ranked as the third most needed service. However, only 40% reported they currently had access to palliative or hospice care. In other words, caregivers highly need palliative or hospice care, but many aren't accessing it.
 - Home visits from nurses or occupational and physical therapists were most needed, and training in general caregiving was second most needed.
- Three out of five caregivers surveyed (61%) cited worrying about the emotional and physical wellbeing of their family and loved ones as their top concern. Forty-four percent were concerned about depression.

TELEHEALTH

- A year into the pandemic, ALS Focus conducted a [survey on telehealth](#). At that time, over three quarters of participants reported having a telehealth appointment for ALS.
- Nearly a quarter accessed a health care provider out of state through telehealth.
- More than 60% said telehealth saved them a lot of time and that it improved their quality of life somewhat or a lot.

KEY TAKEAWAYS

ALS is a progressive and debilitating disease with few treatment options and no cure. As a result, people living with the disease need a comprehensive approach to care that addresses their physical, emotional, and spiritual challenges. It is this patient-centered, wholistic approach that palliative care can bring.

Throughout the day-long Roundtable meeting, multiple overarching themes emerged as key takeaways for advancing comprehensive palliative care for the ALS community.

- **Introducing palliative care early in the disease journey.** It is critical to introduce palliative care as soon as possible, not just as people approach the end of life, to ensure the care they receive is in line with their values, priorities, and goals. A proactive approach that integrates palliative care from the time of diagnosis can improve quality of life and help people with ALS “stay ahead of the game.”
- **Widely integrating a palliative care approach into ALS care.** All people with ALS should have access to palliative care, even if they are not referred to a palliative care specialist. Incorporating palliative care into ALS clinical guidelines would help normalize both generalist and specialist palliative care.



- **Addressing mental health and psychosocial challenges.** Emotional and mental health needs must be addressed alongside management of physical symptoms, with regular check-ins and ongoing support for people with ALS, caregivers, and family members.
- **Providing additional support for families and caregivers.** Care models need to incorporate support for caregivers, who face their own unique challenges.
- **Overcoming stigma.** There is a need to remove the fear and misconceptions surrounding palliative care and differentiate it from hospice care.
- **Advancing clinical education and integration.** Ongoing education is necessary for both palliative care specialists and ALS care teams to ensure that each understands the other's role and can provide integrated care.
- **Providing information and facilitating communication.** People with ALS, families, and health care providers need to be empowered with tools and resources to navigate palliative care and guide decision-making throughout the ALS journey.
- **Promoting equity in care.** All people living with ALS, regardless of race, background, or socioeconomic status, must have access to the care and resources they need. Financial, institutional, cultural, and knowledge-based barriers prevent people from fully accessing palliative care.
- **Offering both telehealth and in-person care.** Telehealth has expanded access to palliative care but can lack the personal connection of in-person visits. Both methods are valuable and should be available so people with ALS and caregivers can opt for the modality that best meets their needs.
- **Recognizing spiritual care has a role to play for many.** While not everyone is religious or finds solace in faith-based interventions, spirituality and support delivered by chaplains within the health care setting can provide people with ALS and their families comfort and peace throughout their journey.
- **Pursuing data-driven improvements.** More research is needed to improve the delivery of palliative care in the ALS ecosystem and increase understanding of its value. Data on outcomes, such as reduced hospitalizations, improved quality of life, and delayed need for other medical interventions, can help drive public demand and advance changes in policies and reimbursement.
- **Planning for the future.** As new therapies emerge, palliative care will continue to play a crucial role in managing symptoms and improving quality of life, complementing clinical advancements.

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