

ADVOCATING FOR MS ADULT DAY TREATMENT PROGRAMS AS PART OF THE COMPREHENSIVE CARE MODEL

CMSC ADVOCACY STATEMENT

March 2024

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PANEL

Chairs

BRIAN HUTCHINSON, PT, MSCS

Director

John A. Schafer, MD Multiple Sclerosis Achievement Center Dignity Health Citrus Heights, CA

SARAH A. MORROW, MD, MS, FRCPC, FAAN

Director

Multiple Sclerosis Program Professor of Neurology Department of Clinical Neurosciences Hotchkiss Brain Institute University of Calgary Calgary, Alberta, Canada

RACHAEL STACOM, MSN, ANP-BC, MSCN

Senior Vice President

Population Health Independence Care System Brooklyn, NY Nurse Practitioner BronxCare MS Center Bronx, NY

Panelists

FREDERICK W. FOLEY, PhD

Psychologist, EAP Services, RWJ/Barnabas Health Professor Emeritus of Psychology Ferkauf Graduate School of Psychology Yeshiva University Bronx, NY

Director of Neuropsychology and Psychosocial Research Multiple Sclerosis Center Holy Name Medical Center Teaneck, NJ

DARCY HAGER-SLAVIN, OTR/L

Supervisor M Health Fairview Achievement Center Paul, MN

JESSICA HUTCHISON, MS, CCC-SLP

Manager

Multiple Sclerosis Day Program The League for People with Disabilities, Inc. Baltimore, MD

MICHELLE KING, MS, CTRS

Senior Director

King Adult Day Enrichment Program Rocky Mountain MS Center Westminster, CO

TIFFANY MALONE, MSW, MSCS

Program Manager

John A. Schafer, MD Multiple Sclerosis Achievement Center Dignity Health Citrus Heights, CA

RANDALL T. SCHAPIRO, MD, FAAN

Clinical Professor of Neurology (Retired) University of Minnesota Founder Fairview Multiple Sclerosis Achievement Center Paul, MN

CMSC

JUNE HALPER, MSN, APN-C, MSCN, FAAN

Chief Executive Officer Consortium of MS Centers Hackensack, NJ

Medical Writer

NANCY MONSON, BS

Certified Health Coach Southbury, CT

INTRODUCTION

Day treatment programs for adults with multiple sclerosis (MS) were created to improve the quality of life (QOL) for those affected by this disabling disease and their care partners. These programs offer nonmedical services to people with MS such as rehabilitation and nutrition therapies, cognitive training, physical activity programs, stress-reduction and recreational activities, disease education, peer support, and opportunities for social interaction.^{1,2} For care partners, day treatment programs offer respite from providing care for loved ones and the opportunity to spend time doing things they personally enjoy. The programs also allow caregivers to continue working to maintain income and health insurance coverage and to address their own healthcare needs and QOL.

Recognizing the importance of adult day treatment programs for both people with MS and their care partners, the Consortium of Multiple Sclerosis Centers (CMSC) convened a multidisciplinary virtual roundtable on October 23, 2023 to discuss issues affecting these programs. Participants included a physical therapist, a speech therapist, an occupational therapist, a recreation therapist, a social worker, a nurse practitioner, a psychologist, and a neurologist, all of whom work at or have knowledge of day programs around the country, and a retired neurologist who founded the first adult day program for people with MS in the United States.

The National Multiple Sclerosis Society (NMSS) has created guidelines and recommendations for day programs titled *Serving Individuals with Multiple Sclerosis in Adult Day Programs*, available at: https://secure.nationalmssociety.org/docs/HOM/ADC_guidelines.pdf.³ Although this publication is now almost a decade old, it provides an excellent roadmap for staff and administrators on medical,



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psychosocial, and other issues affecting people with MS and how to manage adult day programs. Rather than re-creating this document, the CMSC roundtable participants chose to develop an advocacy statement, the intent of which is to:

- » advocate for MS day treatment programs as essential components of MS comprehensive care and for relief of loneliness and isolation, which can contribute to the burden of disease;
- » emphasize the common goals, objectives, and content of effective programs;
- » highlight diversity, equity, and inclusion (DEI) considerations in delivering programs to all populations of people with MS who need them; and
- » advance understanding, acceptance, and utilization of day treatment programs for multiple stakeholders (people with MS, care partners, referral sources, individual and organizational partners, foundations, and funders).

EVOLUTION OF ADULT DAY PROGRAMS FOR PEOPLE WITH MS

The first comprehensive MS adult day program was established in the United States in December 1985 in St. Paul, Minnesota.⁴ The program was conceived by neurologist Randall Schapiro, MD, whose mother had relapsing MS that had progressed to secondary-progressive MS. Dr. Schapiro observed that his mother needed care during the day, but he was hesitant to place her in a nursing home, which was his only option at the time. He also recognized that many of his patients had similar needs. As director of an MS center, he was able to negotiate with Fairview Hospital Association to explore a day program for people with MS, which led to the establishment of the MS Achievement Center (MSAC) day program. To attend, individuals were required to be living at home (as opposed to in a care facility) and to have an Expanded Disability Status Scale (EDSS) score of 5 to 8, although people with lower disability status scores were allowed to participate if they also had a significant cerebral component to their disease.

MS management in the 1980s was difficult because there were not yet any disease-modifying therapies available. This program, therefore, focused on symptom management, aggressive maintenance rehabilitation for people who were expected to progress in disability, restorative rehabilitation for people who were expected to improve, and psychological assistance for all. Offered services included physical therapy (PT), occupational therapy (OT), spiritual guidance, therapeutic recreation, and psychological and vocational counseling. The MSAC was founded on the staunch belief that the answer to disability is mobility, and if individuals could keep active and mobile (with or without the use of assistive devices), they could function at the highest level possible for as long as possible. They could also remain in their home environment and potentially avoid being placed in a long-term care facility as

their disease progressed, which could represent a significant cost savings to families and society and improve QOL by reducing depression and loneliness.

Participant acceptance of the MSAC program was initially very low. Potential members, almost universally, had withdrawn from activities that involved leaving home (eg, going to church, restaurants, movies) and had experienced a loss of social skills. The thought of leaving the home for an entire day was stressful and elicited a negative response.

Care partner acceptance of the MSAC, on the other hand, was extremely high from the beginning, given the burden these individuals experience in caring for people with progressive MS. Eventually, of 3,000 patients with MS being treated by Fairview Hospital Association at the time, 25 people with significant disability were convinced to try the program two days per week. They soon became enthusiastic participants and their social skills improved. By two years, 23 of the original 25 participants were still attending the program.⁴ By 2008, when Dr. Schapiro retired, the program had grown to 200 participants and was offering PT, OT, swallowing rehabilitation, chaplain services, social services, counseling, cerebral stimulation, and therapeutic recreation activities.

The program was called the “Achievement Center” to highlight the philosophy of doing as well as one can with whatever abilities one has.

In a paper published in 1988 in the *Journal of Neurological Rehabilitation*, Schapiro and his colleagues reported that “participants of the center feel such attachment to the goals that they elected to call themselves ‘members of the Achievement Center’ rather than patients, MSers, clients, etc.”⁴

The MSAC was founded on the staunch belief that the answer to disability is mobility.

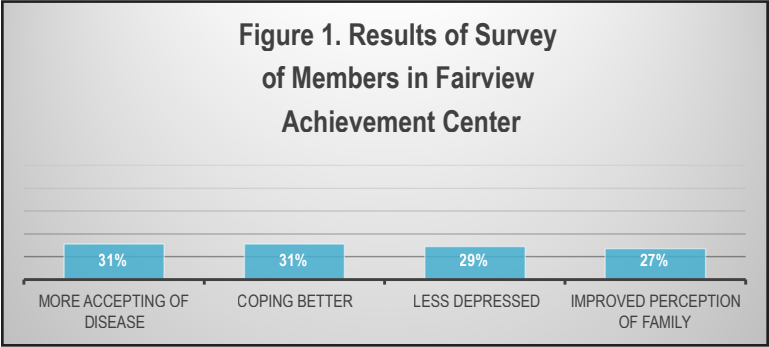
The program continues to this day to serve people living with MS in the community and is operated by M Health at Fairview.

IMPROVED HEALTH OUTCOMES

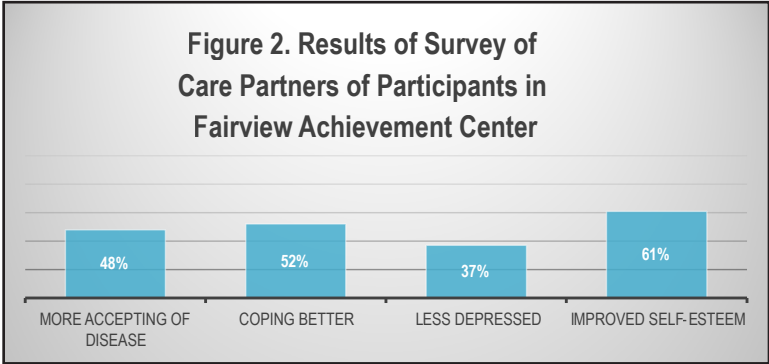
Anecdotal, it was clear to Dr. Schapiro and staff that members who attended the Achievement Center program were maintaining function despite progression, had better mental health, and were avoiding nursing home admission. In conjunction with the University of Minnesota, Dr. Schapiro conducted a prospective comparative trial in the hopes of (1) showing the program was of value to participants, and (2) obtaining reimbursement for services from insurance companies. The study, the results of which were published in 1998 in the *Archives of Physical Medicine and Rehabilitation*, compared 20 members receiving services at the Achievement Center one day a week for five hours to 26 patients in a nontreatment group.⁵ At the end of one year, the researchers were able to report that fatigue frequency as measured by the MS-Related Symptom Checklist and items from the Rehabilitation Institute of Chicago Functional Assessment Scale were significantly reduced in the treatment group but not in the comparison group. Although functional status was not statistically significant between groups, the researchers observed that there was less loss of function among people who attended the day treatment program.

Figure 1 presents data from surveys of members at the Achievement Center in its nascent stage, revealing that a third felt more accepting of their disease and were coping better as a result of involvement with the center. They were also less depressed and had an improved perception of their families. Similarly, family care partners observed that half of patients with MS appeared to be more accepting of their diagnosis and were coping better, a third appeared to be less depressed, and 61%

seemed to have improved self-esteem (**Figure 2**). These positive psychological results were achieved despite negligible changes in physical functioning. “It is clear that the members enjoy their association with the Achievement Center. It is equally clear that most had little enjoyment in their lives before the center opened,” Schapiro et al wrote.⁴



Source: Schapiro RT Soderberg J, Hooley M, et al. The Multiple Sclerosis Achievement Center: A maintenance rehabilitation approach toward a chronic progressive form of the disease. *J Neuro Rehab*. 1988;2:21-23.



Source: Schapiro RT Soderberg J, Hooley M, et al. The Multiple Sclerosis Achievement Center: A maintenance rehabilitation approach toward a chronic progressive form of the disease. *J Neuro Rehab*. 1988;2:21-23.

Since the formation of the first Achievement Center, other facilities across the country have successfully created programs and services for people living with MS. Some have adopted the name, ‘Achievement Center,’ while others have developed day programs custom-suited to the needs of their communities. **Table 1** presents case studies from two programs highlighting their benefits.

TABLE 1. DAY PROGRAM CASE STUDIES

CASE STUDY

1

The following case study illustrates the social, emotional, cognitive, and caregiving benefits of adult day programs.

A 55-year-old female who lives at home with her sister was diagnosed with MS in 1992 at the age of 24. She has been attending the adult day program for 20+ years. When she started attending the program, she was walking and needed stand-by assistance with activities of daily living. She now uses a power wheelchair and has minimal use of her bilateral upper extremities. She requires assistance with all aspects of her care.

The member attends the adult day program three days a week, during which time she engages in conversation, light upper extremity passive range of motion (UE PROM) exercises, cognitive stimulation, and a robust arts program. The day program is a respite for the family.

Due to the nature of the disease, the day program has not prevented physical or cognitive deterioration. Instead, it has acted as a resource and social outlet

for this member and her family. She has benefitted from seeing how others deal with complex medical conditions and has learned first-hand what she can do to help herself, such as using catheters and feeding tubes. Beyond the wealth of knowledge, she has gained a sense of belonging. She and her family have also become involved in social groups outside of the day program, and the day program has helped to educate the member and her family about other resources available to them in the community, including an MS camp. Finally, the day program has helped the member advocate for herself and has always welcomed her with open arms whenever she comes through the door.

Darcy Hager-Slavin, OTR/L
Supervisor
M Health Fairview Achievement Center
St. Paul, MN

CASE STUDY

2

A second case study highlights the benefits of adult day programs in detecting early changes in health due to consistent contact with participants between their medical visits.

A long-time member of the Achievement Center program who resides in a care facility recently arrived to the program, and staff instantly noticed that he did not look well. During his nine years participating in the program, he has shown a strong interest in maintaining his overall physical function, but on this day he presented with lethargy and minimal interest in exercise. After careful observation and assessment, his family was contacted with staff concerns, and his sister made an urgent appointment with the member's primary care physician.

His sister sent this message to staff members the following day: "I want to thank you for alerting me to my brother's condition yesterday. You may have helped save his life! He had a blocked catheter and UTI,

dehydration and sepsis. When the doctor saw him, he suspected early sepsis, and directed us to the ER where tests could be done ASAP."

This case demonstrates how day care staff may notice health issues and progression of disease at an earlier stage than if the individual remained at home, allowing for earlier intervention and perhaps fewer hospitalizations.

Tiffany Malone, MSW, MSCS
Program Manager
John A. Schafer, MD Multiple Sclerosis
Achievement Center at Dignity Health
Citrus Heights, CA


LITERATURE REVIEW ON ADULT DAY TREATMENT PROGRAMS

Beyond the previously cited research published in 1988 by Schapiro et al⁴ and in 1998 by DiFabio et al⁵, there is a dearth of literature exploring the benefits and challenges facing day treatment programs for adults with MS. Few large, high-quality, randomized, comparative trials have been conducted, and other types of studies have yielded mixed results. One of the latter studies, conducted by McGuire et al, found positive outcomes in regard to QOL, mental health, and well-being, but no significant changes in cognition or fatigue for a 10-week, 90-minute psychoeducational wellness program.⁶ The researchers enrolled 43 people with MS and 11 controls, and asked all of the study subjects to complete surveys at baseline and 10 weeks focusing on changes in self-reported levels of depression, anxiety, perceived stress, cognition, pain, social support, and fatigue. Improvements were found in depression, anxiety, overall mental health, perceived stress, and pain among individuals participating in the wellness program compared with nonparticipants.

Early study results of a pilot wellness program in 65 people with MS found benefits for functional status, fatigue, fear and avoidance of physical activities, depression, somatization, and pain.⁷ The program consisted of five hours of education focusing on physical, mental, social, and intellectual domains of wellness over the course of 12 weeks. Unfortunately, the study lacked a control group, making it difficult to draw conclusions about the findings.

An observational study by Gasper et al compared survey results from 220 people with MS who were enrolled in 10 different day treatment programs to 330 people with MS in a control group recruited from the North American Research Committee on MS (NARCOMS) Registry and the iConquerMS database.¹ The researchers also surveyed 104 care partners of

persons enrolled in a day treatment program and 149 care partners of persons in the control group. The objective of the study was to gain insight into whether attendance at adult day programs delays declines in health-related QOL and affects healthcare utilization in people with MS, as well as identify the effect on the well-being of informal care partners over one year. Measures included the 12-Item Short Form Health Survey (SF-12), the five-item Modified Fatigue Impact Scale, the six-item Medical Outcomes Study (MOS) Pain Effect Scale, the Center for Epidemiologic Studies Depression Scale 10, and the Emotional/Information Support subscale of the MOS Social Support Survey. Patients were also asked to report falls, fractures, urinary tract infections, bed sores, number of inpatient days at a hospital, and number of emergency department visits. Care partners were surveyed on the SF-12, a three-item role overload scale, a three-item captivity scale, and the Midlife Development in the United States Affect subscale. Analysis of changes from people with MS in the day program and those in the comparison group were conducted for 199 and 301 people, respectively, who completed both baseline and one-year surveys, and for 82 care partners in the day treatment group vs. 125 care partners in the comparison group. No clinically meaningful differences were detected between the two groups, although attendees of the day treatment program showed a significant positive effect on the physical component scores of the SF-12. While benefits to patients and care partners were not evident from analysis of the data, the researchers suggested that short-term benefits of use of these programs might not have been captured by the study because most of the participants were already attending day treatment programs at the time of the baseline survey. In addition, they noted that 44% of participants in the comparison group were not formally attending day treatment programs but were engaging in similar activities, such as exercise



and social support programs, and 12% of the care partners in the comparison group were receiving individual counseling or attending care partner support groups, which may have diluted the effect observed in the treatment groups.

A qualitative, in-depth interview and survey study of 95 people with MS attending 10 different US day treatment programs found that participants felt the programs had an important and positive impact on their psychosocial health, much of which they indicated was due to their being in a socially cohesive group where they could be their authentic selves.² Patients cited giving and receiving social support as the most powerful benefit, along with increased emotional well-being, better comprehension of MS and its effects on the body, greater acceptance of their MS diagnosis, improved mobility and motor functioning, and better awareness of strategies for performing everyday tasks.

One of the more rigorous investigations into adult treatment programs for people with MS was a two-year randomized controlled trial looking at a comprehensive care program for both patients and their care partners, which illustrated the value of day programs for care partners.⁸ Guagenti-Tax et al compared 30 patient-care partner units to 29 control units. The program consisted of caregiving workshops, day treatment offering rehabilitation and group therapy to patients, home visits by a psychotherapist or nurse, and case management and liaison support. The units and controls underwent three assessments during the trial—at entry, 12 months, and 24 months. Physical functioning declined for people with MS in the treatment group; those in the treatment group also reported more perceived cognitive deficits but less anxiety. Subjects with MS in the control group perceived their health declined more than did the treatment subjects over the two-year period. The researchers found that care partners who were not in the treatment group

reported significant declines in perceived health and more problems with physical health and caregiving duties that interfered with their social lives than did those in the treatment group. Care partners in both groups complained that their caregiving commitment increased over the study period.

Malone et al reported on a four-year analysis of individuals with MS participating in a day wellness program.⁹ The data analysis included comparisons of annual outcomes measures against the individual's baseline scores. Areas measured included self-efficacy using the Multiple Sclerosis Self-Efficacy Scale-10 item (MSSE-10), physical activity using the Godin Leisure Time Exercise Questionnaire (GLTEQ), disease impact using the Multiple Sclerosis Impact Scale-29 item (MSIS-29), and QOL using the Quality of Life in Neurological Disorders (NeuroQoL) scale. Specific areas of the NeuroQoL examined included Mental Health and Social Health domains of Anxiety, Depression, Positive Affect & Well Being, Emotional & Behavioral Dyscontrol, Cognitive Function, Ability to Participate in Social Roles & Activities, and Satisfaction with Social Roles & Activities. Statistically significant changes in improvement were seen in Social Health domains at two years and maintained through year 3. In addition, significant changes were noted in the MSSE-10 at year 3. Decreases in self-efficacy and Social Health domains of the NeuroQoL were seen in year 4, while significant increases were seen in the GLTEQ. This analysis incorporated the first full year of the COVID-19 pandemic, which would be consistent with a reduction in Social Health domains and self-efficacy. The increase in physical activity may be due to the availability of more physical activity options (including online) during the pandemic.

Other studies of adult day treatment programs for seniors without MS indicate positive benefits on QOL and functional, social, psychological, and behavioral outcomes that may be inferred to extend to the MS population.¹⁰⁻¹²

UNMET NEEDS OF PATIENTS WITH MS

Some investigations highlight gaps in care for people with MS, which may be alleviated by attendance at a day treatment program. McCabe et al conducted a survey of unmet educational, psychological, and peer support needs of 2,805 people ages 19 to 92 years with MS in Australia.¹³ The majority of the respondents were female (79%). Patients who reported higher symptom severity also indicated greater unmet needs for education and psychological support. Overall, the survey highlighted unmet needs for access to a variety of peer support groups and opportunities for relationship and family counseling. In Ireland, Lonergan and colleagues found that unmet needs, particularly for physiotherapy, were most common among older, single, rural residents with EDSS scores >6.5 and progressive MS in an observational study of 632 people with relapsing and

progressive MS living in urban and rural areas.¹⁴ And in a study of 151 people with MS compared to 89 control subjects, Eizaguirre et al found that patients perceived themselves as having less social support than controls, which was associated with lower functional scores and predicted poorer health-related QOL.¹⁵

To gain a perspective on the views of professionals working with people who were severely affected by MS, Golla et al conducted focus groups and expert interviews with physicians, nurses, and social workers and identified four main categories of unmet needs: (1) getting support from family and friends, (2) obtaining healthcare services, (3) managing everyday life, and (4) maintaining biographical continuity.¹⁶

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LONELINESS AND ISOLATION CONTRIBUTE TO MS DISEASE BURDEN

In 2023, the United States Surgeon General Vivek Murthy, MD, released a report titled *Our Epidemic of Loneliness and Isolation: The U.S. Surgeon General's Advisory on the Healing Effects of Social Connection and Community*, which is available at: <https://www.hhs.gov/sites/default/files/surgeon-general-social-connection-advisory.pdf>.¹⁷ The report was created in response to statistics suggesting that half of Americans experience feelings of loneliness.

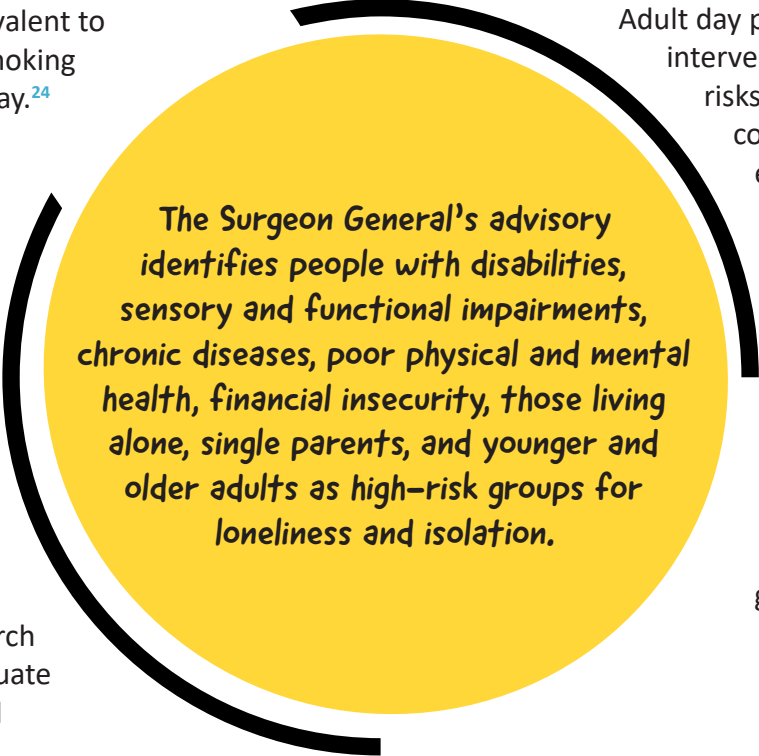
There are well-known physical and mental sequelae of loneliness and isolation, including depression, anxiety, dementia, suicide, cardiovascular disease (CVD), viral and other types of infections, and respiratory illnesses.¹⁸⁻²² Loneliness and isolation present a significant threat to longevity: Loneliness increases the risk for early death by 26% and social isolation increases it by 29%, while living alone increases the likelihood of premature death by 32%.^{17,23} One widely quoted statistic from a review by Holt-Lundstad et al that analyzed data from 148 studies with 308,849 participants indicated that the risk of premature death related to social isolation is equivalent to the risk incurred by smoking up to 15 cigarettes a day.²⁴ This group also found that loneliness and isolation conferred a greater risk of premature death than other well-established independent variables such as overconsumption of alcohol, physical inactivity, obesity, and exposure to air pollution. Other research has associated inadequate social connections and

isolation with a 29% greater risk of heart disease and a 32% increased risk of stroke.¹⁸

Loneliness and isolation are problems that predated the COVID-19 pandemic, and were exacerbated by the enforced isolation instituted to fight the global health threat. People with disabilities and those who are immunocompromised were disproportionately affected, and to this day must be careful about exposure to circulating viruses such as COVID variants, respiratory syncytial virus, and the flu virus that can cause significant morbidity and mortality. The Surgeon General's advisory identifies people with disabilities, sensory and functional impairments, chronic diseases, poor physical and mental health, financial insecurity, those living alone, single parents, and younger and older adults as high-risk groups for loneliness and isolation.¹⁷

The advisory not only recommends assessing all patients for loneliness and isolation, but also encourages providers to offer “social prescriptions” for patients who are lonely and isolated.¹⁷

Adult day programs can be an effective intervention to combat these risks—indeed, the meta-analysis conducted by Holt-Lundstad et al found that people with strong social connections had a 50% greater likelihood of survival over 7.5 years.²⁴ In keeping with that, a pilot study suggested that loneliness and depression may be reduced in persons with MS by a modest once-per-week telehealth support group.²⁵



The Surgeon General's advisory identifies people with disabilities, sensory and functional impairments, chronic diseases, poor physical and mental health, financial insecurity, those living alone, single parents, and younger and older adults as high-risk groups for loneliness and isolation.



ROLE OF PALLIATIVE CARE IN DAY TREATMENT PROGRAMS

The palliative care model—an approach or system of supportive care that can be delivered intermittently or continuously as needed—can include day treatment services. Rather than simply end-of-life care, as it is traditionally viewed, palliative care is a whole-person approach to the care and management of persons with serious illnesses. It is based on the needs of the patient, not on the patient’s prognosis, and focuses primarily on symptom management and improving QOL. Use of palliative care services does not prohibit treatment that can retard or cure disease progression, and it is typically reimbursed under Medicare Part B and by some private insurance plans.

Some day treatment programs receive referrals from palliative care services to offer patients with MS opportunities for relief from the symptoms and stress of the illness, boost social connectedness and reduce isolation, and improve QOL for both the patient and the family.

In a consensus statement released in 2018, the CMSC recommended early integration of palliative care for people with MS.²⁶ The statement and guidelines can be found here: https://www.mscares.org/resource/resmgr/2019_palliative_guide.pdf

CORE COMPONENTS OF EFFECTIVE DAY TREATMENT PROGRAMS

A number of day programs for adults with MS exist across the United States; **Table 2** highlights four such programs. The services provided and how they are provided vary from center to center. In general, the target clientele are individuals with MS who are not able to work and are isolated in their homes. Some programs are expanding their offerings to include part-time hours for younger individuals with MS who are employed and cannot

attend full-time. Participants may need assistance and supervision with various tasks and activities of daily living (ADLs) as a result of MS-related functional and cognitive impairments. Some programs require that participants be able to arrange transportation to and from the center and manage transferring and toileting on their own. Staff typically are not allowed to provide medical services, but may be able to refer participants for such care.¹

TABLE 2. EFFECTIVE ADULT DAY TREATMENT PROGRAMS FOR PEOPLE WITH MS

This table presents an overview of four adult day programs that have been in existence for over a decade and are successfully helping to improve the quality of life and function of patients with MS.

01

John A. Schafer, MD Multiple Sclerosis Achievement Center at Dignity Health

Location: Citrus Heights, CA (Greater Sacramento area)

Director: Brian Hutchinson, PT, MSCS

Program Manager: Tiffany Malone, MSW, MSCS

Age of Program: 10 years (opened February 20, 2014)

Hours of Operation: Monday to Friday 7:30 AM to 4 PM

Services Offered: Physical, cognitive, and emotional wellness activities and MS education. Services and education are primarily delivered in person in a 5-hour program format. The Achievement Center also offers two 2.5-hour programs a week for persons with MS who are still working and cannot attend a full-day session.

Daily Fee: Monthly fees are based on a sliding scale that considers household income.

Funding: Philanthropic donations plus monthly member fees.

Criteria for Enrollment: Members must have an MS diagnosis and be able to manage their transportation and toileting needs.

Reasons for Attending:

- » To improve physical function
- » To improve cognitive function
- » Socialization
- » To increase knowledge of symptom management

Reasons for Discontinuation:

- » Concerns about COVID-19
- » Returned to work
- » Distance to travel too far
- » Difficulty with transportation
- » Financial issues
- » Moved away from the area
- » Deceased

Challenges:

- » Funding
- » Small staff
- » Aging population
- » Transportation

M Health Fairview Achievement Center

Location: St. Paul, MN

Supervisor: Darcy Hager-Slavin, OTR/L

Age of Program: 30+ years

Hours of Operation: Monday to Thursday 9 AM to 3:30 PM

Services Offered: Recreation activities based on a member's interests, cognitive stimulation, nurse management, and physical maintenance program as prescribed. Occupational, speech, and physical therapy services can be accessed, but are not a formal part of the day program. Members attend one to three days a week.

Daily Fee: Varies based on staffing ratio; Medicaid waiver or private pay on a sliding scale that considers household income.

Funding: Medicaid waiver, private pay, and philanthropic donations.

Criteria for Enrollment: The program is open to patients with MS and other acquired neurological conditions that prevent them from engaging in full daily activities or full-time work. Disabilities range from mild to severe; clients must be able to manage toilet transfers with minimal to moderate assistance of one person. A small number of attendees live alone in the community, but most live in a group home due to extensive physical and cognitive impairments.

Reasons for Attending:

- » Socialization
- » To engage in activities that might prevent further physical and cognitive decline
- » Respite for caregivers

Reasons for Discontinuation:

- » Concerns about COVID-19
- » Distance to travel is too far
- » Difficulty with transportation
- » Financial issues
- » Medical complications
- » Deceased
- » Member relocation

Challenges:

- » Recent state changes restrict the center to only enrolling participants on Medicaid waiver programs who are >55 years of age
- » Funding issues related to taking participants into the community for outings; the center does not own a private bus and outings can cost \$200 to \$250 a trip for transportation plus expenses incurred on the outing (admission, food, etc)
- » An aging population that is increasing staffing needs
- » Finding the appropriate staffing model

King Adult Day Enrichment Program (KADEP) - Rocky Mountain MS Center

Location: Westminster, CO

Senior Director: Michelle King, MS, CTRS

Age of Program: 40+ years (opened January 1991)

Hours of Operation: Monday to Friday 7:30 AM to 4:30 PM

Services Offered: In-person services, education, exercise, and socialization.

The program runs on a college trimester system whereby the clients choose from 60 different groups (eg, physical therapy and exercise, cooking, crafts, discussions, cognitive training, and outings). Clients register to attend two groups a day and there is an add-drop period at the beginning of each semester that allows them to change groups. Individual goals are written up for all clients along with person-centered care plans focused on what the clients want to work on over the trimester. Staff members help clients formulate and address the goals for every 90-day period.

Daily Fee: \$100/day, with a sliding scale for individuals with MS who have limited incomes and are not on Medicaid or have Veterans Affairs (VA) benefits. Medicaid and VA both have contracted rates with KADEP.

Funding: Medicaid Home and Community Based Services (HCBS), the VA, and private pay partially cover program needs. Charitable contributions from individuals, foundations, and other private sources are also sought to cover costs.

Criteria for Enrollment: Clients must be transferrable with one person lifting and must be continent with or without use of a catheter. The program is open to patients with MS and other acquired neurological conditions that prohibit them from functioning independently and fully engaging in community life. Disabilities range from mild to severe.

Reasons for Attending:

- » Socialization
- » Cognitive stimulation
- » To maintain or increase physical functioning
- » To increase leisure participation

Reasons for Discontinuation:

- » Placement in nursing facilities
- » Deceased
- » Behavioral issues

Challenges:

- » An aging population
- » Replacing clients who have died over the past couple of years and helping the remaining participants grieve over these losses
- » Transportation
- » Maintaining and improving an aging building (carpet, roof)

The League for People with Disabilities

Location: Baltimore, MD

Manager: Jessica Hutchison, MS, CCC-SLP

Age of Program: 30+ years. Founded at Montebello Hospital; transitioned to Kernan Hospital in 1997 (now the University of Maryland Rehabilitation & Orthopaedic Institute). Moved to The League for People with Disabilities in 2018.

Hours of Operation: Monday to Thursday 10:00 AM to 2:00 PM

Services Offered: The MS Day Program runs 12 in-person and virtual group sessions per week. Services include physical exercise, stress management, communication strategies, cognitive stimulation, recreational activities, community projects, outings, opportunities for social interaction, physical and occupational therapy, and speech therapy.

Daily Fee: None.

Funding: United States Against MS provides the majority of funding, supplemented by grants.

Criteria for Enrollment: Clients must be able to independently toilet and feed themselves. Clients have different forms of MS, ranging from relapsing disease to secondary- and primary-progressive MS.

Reasons for Attending:

- » Community Involvement
- » Social interaction (camaraderie)
- » Resource sharing
- » To participate in therapeutic groups
- » To practice and maintain skills
- » To receive support of peers with MS

Reasons for Discontinuation:

- » Changing physical locations
- » Declining health
- » Deceased
- » Never returned following COVID pandemic

Challenges:

- » Balancing skilled staff support and cost
- » Funding
- » Transportation

Programs may be delivered short-term, for a few weeks, or may be ongoing, and may offer in-person services and activities one to five days a week during work hours, as well as virtual sessions. The focus of these programs is on a multidimensional wellness approach, including physical rehabilitation, cognitive wellness activities, health-related education, and

emotional wellness and social activities (**Table 3**). The programs strive to empower individuals to be as independent and mobile as possible, and to remain in the community in their own home if feasible. Attempts are made to customize the program for each individual client according to the level of impairment, needs, and personal interests and goals.

TABLE 3. 4 PILLARS OF EFFECTIVE DAY TREATMENT PROGRAMS

The CMSC Consensus Conference participants identified the following four components as essential to effective day treatment programs for adults with MS:

01. **PHYSICAL ACTIVITY**
02. **COGNITIVE WELLNESS ACTIVITIES**
03. **HEALTH AND WELLNESS EDUCATION RELATED TO MS**
04. **EMOTIONAL WELLNESS AND SOCIAL ACTIVITIES TO REDUCE ISOLATION AND LONELINESS**

Physical activity, which may include PT and OT rehabilitation services, are a key component of all programs and is geared toward maintaining or improving physical functioning, mobility, and fitness. Classes, discussions, activities, and counseling are offered to educate participants about their disease, nutrition, and general wellness topics, reduce stress, and improve their psychological outlook and mood. Activities to improve cognitive functioning are common elements, as well, and may include board games, puzzles, the use of technology, and discussions of current events and pop culture, along with recreational

activities such as crafts and creative arts therapies (music, dance, movement, and drama). Key social benefits include the opportunity for clients to form new relationships and interests, support and assist peers, and share their experiences, which in turn allows them to view themselves beyond the parameters of their disease and as more than their MS.¹⁷ Outings such as recreation or community events may also be included to supplement the core programs. Case management assistance is also typically included on the service roster.² Finally, in addition to providing temporary relief from caregiving duties, day treatment programs may also offer care partner-specific workshops and education to improve care partners' health, mood, and QOL.

Adult MS day treatment programs should be open and available to everyone, regardless of age, race, ethnicity, sexual orientation, socioeconomic status, and educational level, and most especially should be inclusive of those who have historically been excluded, unserved, and underserved.

DEI ISSUES

There is an urgent need to consider diversity, equity, and inclusion (DEI) issues—especially in the context of efforts to decrease loneliness and isolation among people with MS—in the context of adult day treatment centers. The 2003-2020 American Time Use Survey found that Black individuals and older adults were more likely to be socially isolated than Whites and Hispanics even before the COVID pandemic emerged.²⁷ Other research highlights the life-long discrimination and loneliness experienced by lesbian, gay, bisexual, transgender, queer, intersex, asexual, and other (LGBTQIA+) people.^{28,29} When an MS diagnosis is added to DEI issues, the risk for social isolation and loneliness undoubtedly increases.

Adult MS day treatment programs should be open and available to everyone, regardless of age, race,

ethnicity, sexual orientation, socioeconomic status, and educational level, and most especially should be inclusive of those who have historically been excluded, unserved, and underserved. Enrollment processes should be inclusive and mindful of racial and ethnic groups and LGBTQIA+ individuals. It is also important that the MS professional field encourage diversity in staffing and training to meet the needs of the current and future diversifying population of patients with MS and their care partners.²⁹

The CMSC has studied DEI issues as they relate to MS and a statement released in 2023 can be found here: <https://meridian.allenpress.com/ijmsc/article/25/5/199/493221/Diversity-Equity-and-Inclusion-in-the-Multiple?searchresult=1>.³⁰

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CHALLENGES AROUND DELIVERY OF ADULT DAY SERVICES

FUNDING ISSUES

The biggest challenge facing adult day treatment programs in the past and continuing today is that insurance is unlikely to reimburse for people with MS to attend the programs or pay for services provided, and individuals and care partners don't have the means to pay for them. Medicaid may pay for attendance, but has restrictions and requirements that individual centers may not be able to meet. In addition, Medicaid typically restricts people from receiving a home care aide and adult day treatment at the same time, which means that people who need help with ADLs must choose between the two services instead of getting their personal needs met. If they choose the home care aide, they also miss out on the social and other benefits that come with adult day treatment. The lack of strong research findings to support the benefits of day programs and related cost savings hampers reimbursement by insurance for services.

Today, most of the programs across the US are philanthropically funded; some receive government funding. At M Health at Fairview, decreased funding from outside referral sources like the MS Society have led to a reduced number of members. Diminished referrals to the program, changes in medical management and state licensure requirements, and the cost of staffing to adequately manage participants have also played roles in how many participants can be accommodated. In addition, the COVID pandemic resulted in deteriorating medical status among some members or a reduced desire to attend due to concerns about exposure to contagious illnesses. **Table 4** offers a glimpse into the funding challenges faced by the MS Day Program at The League for People with Disabilities.

TABLE 4. DIVERSIFYING FUNDING SOURCES

MS Day Program at The League for People with Disabilities

Current Funding: Program scholarships are foundation funded, so services are offered on a no-fee basis to participants. Of participants who currently access the in-person program, 15% have Veterans Affairs insurance, 54% are on Medicaid and Medicare for disability, and 31% receive Medicare because they are >65 years.

Diversified Funding: There are several barriers to adopting a more diversified payment structure to support the MS Day Program:

1. The program is traditionally not fee-for-service, as stipulated in our foundation agreement.
2. Accessing government funding as an adult medical day program requires compliance with policies and procedures as outlined by Maryland's Code of Regulations and best practices through the National Adult Day Services Association.
3. Maryland Medicaid's Home and Community-Based Services, which includes waivers that pay for adult medical day programs, is difficult to navigate.
4. Traditional insurance and Medicare do not cover MS day program services.

Jessica Hutchison, MS, CCC-SLP
Manager, Multiple Sclerosis Day Program
The League for People with Disabilities, Inc.
Baltimore, MD

Sources: Maryland Department of Health. Long Term Services and Supports. Available at: <https://health.maryland.gov/mmcp/longtermcare/pages/Medical-Day-Care-Services.aspx>; Maryland Department of Health. Home and Community-Based Services (HCBS). Available at: <https://health.maryland.gov/mmcp/waiverprograms/pages/home.aspx>; Maryland Department of Health. Medical Day Care Services. Available at: <https://health.maryland.gov/mmcp/longtermcare/pages/Medical-Day-Care-Services.aspx>.

TRANSPORTATION ISSUES

Transportation issues are frequently cited as barriers to regular participation in adult day center treatment programs (see Table 5). Clients may not be able to afford or access public or private transportation.

Those who use power wheelchairs need both reliable and specialized transportation options

and assistance. Many states provide specialized transit services for people with disabilities; these services vary by state and in location, frequency, and reliability. Symptoms of MS, including fatigue, bladder dysfunction, and pain, may also impact individuals during travel.

TABLE 5. CASE STUDY: PARTICIPANT ACCESS TO SERVICES

The following case study demonstrates the difficulties people with MS may have in accessing disability services.

A 38-year-old male with secondary-progressive MS and numerous symptoms attends the MS day program at The League for People with Disabilities in Baltimore, MD. He experiences issues with transportation to the program and safety in his living situation.

He lives independently with two cats on the first floor of a house, which has been modified to include bathroom grab bars and a key code for the front door. He must climb stairs to reach the front porch. He currently uses a rollator or walks using walls and furniture for balance to ambulate in the house; the bathroom is too narrow to accommodate the rollator. He requires a wheelchair for distance, but his visual deficits and impulsivity make a motorized chair an unsafe option. He utilizes a weekly meal delivery service through a private company and grocery delivery apps. His parents, who are aging and have their own health concerns, visit once a week to clean his house, take laundry, and manage the cats.

Participant Goals

Working with MS day staff and a case manager, the client's goals include:

- » Scheduling a Home Safety Evaluation with physical (PT) and occupational therapists (OT).
- » Signing up for MTA Mobility/Taxi Access instead of using Uber because of the cost.
- » Hiring a personal care assistant at home to help manage fatigue, improve his quality of life, and assist his parents with caregiving.
- » Investigating an alternative living situation.
- » Applying for community health waivers through Medicaid to access additional benefits.
- » Setting up a personal emergency response system at home.

Participant Barriers to Access

- » No designated power of attorney.
- » Does not want MS day staff to communicate directly with his parents.
- » Unable to afford a private aide for safe transportation in the community.
- » Holds Medicaid, Medicare (disability), and Care First insurance, which restricts access to some supports from Medicaid.
- » Experiences difficulties navigating state and federal programs, services, and funders, with long timelines, and no coordination of services.

Timeline for Accessing Supports

January 2023: The participant receives an MTA Mobility and Taxi Access card, but he continues to use Uber to travel to the MS day program because he does not like having to wait extra time for disability transit services.

June 2023: PT and OT complete a home safety evaluation and provide "observations and recommendations." The MS day staff expresses concerns about training/carryover of skills, lack of an accessible memory aid for remembering strategies, and follow-up with services and resources.

August 2023: MS day staff searches for options for additional services. The participant is not eligible for a Community First Choice Waiver because it is not supported by his type of Medicaid. He completes a phone assessment for a Community Options Waiver and is designated a "Level 6," meaning he does not yet present with needs imminent enough for additional benefits/services. His place in the wait line is 2.5 years. He may re-apply every three months.

October 2023: The participant completes an assessment through In-Home Aide Services (IHAS) and is qualified to receive assistance from an in-home aide for two hours a day twice a week. Wait time for implementation of services is two months.

November 2023: He re-applies for the Community Options Wavier, and is awaiting an appointment for an assessment call.

January 2024: The IHAS aide begins light cleaning at his home and provides assistance to reduce falls.

Jessica Hutchison, MS, CCC-SLP
Manager, Multiple Sclerosis Day Program
The League for People with Disabilities, Inc.
Baltimore, MD

LACK OF STAFF AND THE APPROPRIATE STAFF

Staffing issues are paramount difficulties—both hiring enough staff and hiring staff with the specialized skills and training needed to deliver services to adults with MS, who tend to be younger and more costly than elderly day center attendees, and who have evolving disease complications. Standardized assessment tools are typically utilized to determine the specific needs of clients in terms of staffing.³

In a nonmedical day program, the lack of certified nursing assistants (CNAs) or nurses to assist clients in toilet transfers is a barrier as participants decline

and age. Medicaid-certified or -approved programs require a standard ratio of staff to participants for safety. Finding staff to hire and pay rates for these positions make it difficult to achieve the required ratios in the current marketplace. Lack of appropriate staff can impact how a program can be funded, as demonstrated by the challenges presented in **Table 4** for The League for People with Disabilities.

The physical space allotted for adult day services must also be appropriate for the needs of people with MS and must be in compliance with local, state, and federal laws and regulations.³

FUTURE DIRECTIONS

Much can be inferred from the anecdotal, lived experience of people with MS who are attending day treatment programs across the United States, but there exists a strong need for high-quality research trials to validate their benefits to a variety of stakeholders, including insurance providers, individual and organizational partners, foundations, and other funders, and to improve funding channels. Gaps that have been identified thus far include a need for social and family support, education, access to peer support groups, and opportunities for relationship and family counseling, PT, and to manage ADLs. In addition, the association between reductions in loneliness and attendance at day treatment programs needs to be evaluated to further validate the benefits of regular attendance.

Core components of effective programs have been identified by the CMSC Consensus Committee and include: physical exercise/activities, cognitive wellness activities, health and wellness education related to MS, and emotional wellness and social activities to reduce isolation and loneliness. The increasing recognition today of loneliness and social isolation as significant factors in health, wellness, and longevity for all individuals and most particularly for those with disabilities and chronic illnesses like MS, represents an opportunity to shine a light on day treatment programs, which can and should be incorporated into the comprehensive care of adults with MS.

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REFERENCES

1. Gasper JM, Lewis M, Kroeger A, et al. Multiple sclerosis adult day programs and health-related quality of life of persons with multiple sclerosis and informal care partners. *Int J MS Care*. 2020;22:187-192.
2. Marrow J, Roeser A, Gasper J, LaRocca N, Frankel D. Benefits of multiple sclerosis adult day program participation for people with multiple sclerosis: A qualitative study. *Int J MS Care*. 2020;22(5):201-207.
3. National Multiple Sclerosis Society. *Serving Individuals with Multiple Sclerosis in Adult Day Programs: Guidelines & Recommendations*. 2010. Available at: https://secure.nationalmssociety.org/docs/HOM/ADC_guidelines.pdf.
4. Schapiro RT Soderberg J, Hooley M, et al. The Multiple Sclerosis Achievement Center: A maintenance rehabilitation approach toward a chronic progressive form of the disease. *J Neuro Rehab*. 1988;2:21-23.
5. DiFabio R, Soderberg J, Choi T, Hansen C, Schapiro R. Extended outpatient rehabilitation: Its influence on symptom frequency, fatigue, and functional status for persons with progressive multiple sclerosis. *Arch Phys Med Rehab*. 1998;79(2):141-146.
6. McGuire KB, Stojanovic-Radic J, Strober L, et al. Development and of a psychoeducational wellness program for people with multiple sclerosis: Description and outcomes. *Int J MS Care*. 2015;17(1):1-8.
7. Hart DL, Memoli RI, Mason B, Werneke MW. Developing a wellness program for people with multiple sclerosis: description and initial results. *Int J MS Care*. 2011;13:154-162.
8. Guagenti-Tax EM, DiLorenzo TA, Tenteromano L, et al. Impact of a comprehensive long-term care program on care partners and persons with MS. *Int J MS Care* (2000) 2 (1): 23-39.
9. Malone T. Effects on quality of life, disease impact and physical activity of a day wellness program for PwMS before and during the COVID-19 pandemic. Platform presentation DXM08, 2022 CMSC Annual Meeting, National Harbor, MD. Available at: <https://cmsc.confex.com/cmsc/2022/meetingapp.cgi/Paper/8250>.
10. Ellen Moriah E, Demaio P, Lange A, Wilson MG. Adult day center programs and their associated outcomes on clients, care partners, and the health system: A scoping review. *Gerontologist*. 2017;57(6):85-94.
11. Schmitt EV, Sands LP, Weiss S, et al. Adult day health center participation and health-related quality of life. *Gerontologist*. 2010; 50(4). 531-540.
12. Dabelko-Schoeny H, Kind S. In their own words: Participants' perceptions of the impact of adult day services. *J Gerontol Soc Work*. 2010;53:176-192.
13. McCabe MP, Ebacioni KJ, Simmons R, et al. Unmet education, psychological, and peer support needs of people with multiple sclerosis. *J Psychosom Res*. 2015;78:82-87.
14. Lonergan R, Kinsella K, Fitzpatrick P, et al. Unmet needs of multiple sclerosis patients in the community. *Mult Scler Relat Disord*. 2015;4:144-150.
15. Eizaguirre MB, Yastremiz C, Ciufia N, et al. Relevance and impact of social support on quality of life for persons with multiple sclerosis. *Int J MS Care*. 2023;25(3):99-103.

16. Golla H, Glaushko M, Pfaff H, Voltz R. Unmet needs of severely affected multiple sclerosis patients: The health professionals' view. *Palliat Med*. 2011;26:139-151.
17. US Surgeon General. *Our Epidemic of Loneliness and Isolation The U.S. Surgeon General's Advisory on the Healing Effects of Social Connection and Community*. 2023. Available at: <https://www.hhs.gov/sites/default/files/surgeon-general-social-connection-advisory.pdf>.
18. Valtorta NK, Kanaan M, Gilbody S, et al. Loneliness and social isolation as risk factors for coronary heart disease and stroke: Systematic review and meta-analysis of longitudinal observational studies. *Heart*. 2016;102(13):1009-1016.
19. Mann F, Wang J, Pearce E, et al. Loneliness and the onset of new mental health problems in the general population. *Soc Psychiatry Psychiatr Epidemiol*. 2022;57(11):2161-2178.
20. Penninkilampi R, Casey AN, Singh MF, Brodaty H. The association between social engagement, loneliness, and risk of dementia: A systematic review and meta-analysis. *J Alzheimers Dis*. 2018;66(4):1619-1633.
21. Lazzari C, Rabottini M. COVID-19, loneliness, social isolation and risk of dementia in older people: A systematic review and meta-analysis of the relevant literature. *Int J Psychiatry Clin Pract*. 2021:1-12.
22. Cohen S. Psychosocial vulnerabilities to upper respiratory infectious illness: Implications for susceptibility to coronavirus disease 2019 (COVID-19). *Perspect Psychol Sci*. 2020:1745691620942516.
23. Holt-Lunstad J, Smith TB, Baker M, et al. Loneliness and social isolation as risk factors for mortality: A meta-analytic review. *Perspect Psychol Sci*. 2015;10(2):227-237.
24. Holt-Lunstad J, Smith TB, Layton JB. Social relationships and mortality risk: A meta-analytic review. *PLoS Med*. 2010;7(7): e1000316.
25. Leavitt VM, Riley CS, De Jager PL, Bloom S. eSupport: Feasibility trial of telehealth support group participation to reduce loneliness in multiple sclerosis. *Mult Scler*. 2020;26(13):1797-1800.
26. Morrow SA, Mayer L, Brizzi K, et al. *Comprehensive Palliative Care in MS: CMSC Consensus Statement and Proposed Guidelines*. 2019. Available at: https://www.ms-care.org/resource/resmgr/2019_palliative_guide.pdf.
27. Kannan VD, Veazie PJ. US trends in social isolation, social engagement, and companionship nationally and by age, sex, race/ethnicity, family income, and work hours, 2003-2020. *SSM Popul Health*. 2022;21:101331.
28. Casey LS, Reisner SL, Findling MG, et al. Discrimination in the United States: Experiences of lesbian, gay, bisexual, transgender, and queer Americans. *Health Serv Res*. 2019;54(Suppl 2):1454-1466.
29. Kromholz G, Barak A. The experience of loneliness among gay men in Israel: A qualitative study. *J Homosex*. 2023;70(12):2784-2805.
30. Hersch CM, Morrow SA, Williams MJ, et al. Diversity, equity, and inclusion in the multiple sclerosis community: A call to action. *Int J MS Care*. 2023; 25(5):199-205.



THE CONSORTIUM OF
MULTIPLE SCLEROSIS CENTERS



3 University Plaza Drive, Suite 116, Hackensack, NJ 07601



(201) 487-1050



(862) 772-7275



info@mscare.org



www.mscare.org