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Living with Neurodegenerative Disorders: Management, Support, and Hope

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ABSTRACT

This expansive review examines the multiple challenges and the changing landscape of neurodegenerative disorders, including treatment options, support networks, and pathways to hope. The review considered the pathophysiology of neurodegenerative diseases, including Alzheimer's disease, complications of Parkinson's disease, causes of amyotrophic lateral sclerosis and Huntington's disease, and approaches to diagnosis. The review examined and compared drug therapies (including disease-modifying therapies) with nondrug treatments, including approaches such as physiotherapy, nutrition, and technology. The review underscored the need for multidisciplinary care options that embed palliative approaches to disease management across the disease trajectory. Support options were found to have family, community, and health care policy dimensions. The vital need for family support and environmental adaptations was also highlighted. Finally, the review also examined new sources of hope, including advances in research (gene therapy, immunotherapy), new technologies (neuroimaging, assistive devices), psychological resilience and meaning creation, and social movements (advocacy). This review provides perspective and insight on neurodegenerative disorder management for individuals with neurodegenerative disorders, family/friends, health care professionals, and policymakers.

Keywords: Neurodegenerative disorders, Multidisciplinary care, Gene therapy, Assistive technologies, Caregiver support

Introduction

Neurodegenerative diseases represent significant global health challenges that currently impact millions worldwide and create an enormous burden on health systems, families, and communities. These diseases involve progressive degeneration of neurons in the brain and can produce a range of debilitating symptoms that negatively impact cognitive function, motor function, emotion regulation, and quality of life.¹ The most common neurodegenerative diseases are Alzheimer's disease, Parkinson's disease, amyotrophic lateral sclerosis (ALS), Huntington's disease, multiple sclerosis, and frontotemporal dementia, and can be distinguished by differences in their pathophysiology, clinical manifestations, and disease trajectory.²

Living with a neurodegenerative disease presents complex challenges for patients and caregivers. In addition to the physical symptoms and cognitive changes associated with these diseases, there are emotional, social, financial, and existential consequences that require management and support.³ Our understanding of neurodegenerative diseases continues to evolve,

and advances in treatments, technology, and models of supportive care are paving the way for new means of improving quality of life and hope.⁴

This review explores modern-day realities of life with neurodegenerative disorders by analyzing evidence-based management strategies, comprehensive support systems, and prospective avenues for hope. The objective of this comprehensive synthesis of current knowledge, organizations' experiences, and academic research is to offer a more inclusive resource for patients, caregivers, health care professionals, and policymakers with a vested interest in neurodegenerative care.

Understanding Neurodegenerative Disorders Pathophysiological Mechanisms

Neurodegenerative diseases all involve the progressive loss of neuronal structure and function, ultimately leading to neuronal death. Current research has identified several common pathological mechanisms underlying neurodegenerative diseases, including protein misfolding and aggregation, mitochondrial dysfunction, oxidative stress, neuroinflammation, and alterations in cellular proteostasis.⁵ For example, Alzheimer's disease is exemplified by the presence of accumulating beta-amyloid plaques and tau tangles, while Parkinson's disease is characterized by the presence of the aggregating alpha-synuclein within the Lewy bodies.⁶ Understanding these molecular mechanisms has facilitated targeted therapeutic approaches as well as established potential biomarkers for early detection and monitoring of disease. Benussi et al.⁷ identified that neurodegenerative disorders vary widely in terms of clinical presentations, disease progression, and treatment response, even in individuals sharing the same diagnosis. This heterogeneity reflects the interplay of genetic factors, environmental exposures, lifestyle factors, and aging processes. Recent advances in genomics have described multiple risk genes related to specific neurodegenerative diseases, including apolipoprotein E4 (APOE4) linked to Alzheimer's disease and LRRK2 linked to Parkinson's disease, which can help inform disease susceptibility and potentially individual treatment approaches.⁸

Clinical Manifestations and Diagnosis

Neurodegenerative disorders are highly variable in terms of their clinical manifestations, depending on the brain regions and neural circuits involved. Alzheimer's disease primarily presents with memory and cognitive impairment, while Parkinson's disease is primarily a movement disorder characterized by tremors, rigidity, and bradykinesia.⁹ ALS is characterized

by motor neuron disturbances leading to progressive muscle weakness and paralysis; Huntington's disease encompasses a triad of motor, cognitive, and psychiatric symptoms.¹⁰

Diagnosis of neurodegenerative disorders is difficult due to overlapping symptoms, heterogeneous presentations, and the lack of definitive biomarkers for many of these disorders. Recent developments in neuroimaging, fluid biomarkers, and genetic testing are improving the ability to diagnose and enable earlier detection.¹¹ The development of positron emission tomography (PET) tracers specifically targeting amyloid and tau proteins in Alzheimer's disease has changed the diagnosis and clinical categorization of this condition. Cerebrospinal fluid analysis, measuring alpha-synuclein, neurofilament light chain, and other proteins, provides potential fluid biomarkers of neurodegenerative conditions.¹²

A new paradigm in the conceptualization of neurodegenerative diseases has begun to recognize the sometimes decades-long lead time for pathological changes that eventually give way to clinical symptoms, which provides an opportunity for presymptomatic identification and treatment. As Armstrong and Okun note,⁹ this can be seen as an extended pre-clinical phase, where clinicians may identify at-risk individuals by using genetic testing, biomarkers, and longitudinal surveillance. Early intervention with a disease-modifying therapy, before irreversible damage occurs, may offer some hope (Table 1).¹³

Management Approaches

Pharmacological Interventions

While there are currently no curative therapies available for most neurodegenerative disorders, pharmacological treatments remain an extremely important part of the management options available to manage symptom burden and potentially slow disease progression. In the case of Alzheimer's disease, the primary symptomatic treatments remain cholinesterase inhibitors (donepezil, rivastigmine, galantamine) and the NMDA-receptor antagonist memantine. They provide modest clinical benefit overall from a cognitive perspective.¹⁴ The recent FDA approval of amyloid-beta

targeting monoclonal antibodies such as aducanumab and lecanemab could be an important breakthrough in disease-modifying therapy, albeit with some uncertainty regarding the clinical benefit these treatments provide and the safety issues surrounding their use.¹⁵

Current pharmacological treatment for Parkinson's disease primarily remains levodopa (L-DOPA therapy), which is considered the gold standard treatment for the management and control of motor symptoms in PD. Levodopa therapy is frequently used in combination with dopamine agonists, MAO-B inhibitors, or COMT inhibitors to enhance the effect of levodopa therapy and to manage motor fluctuations.¹⁶ ALS patients are presented with the option of riluzole and, more recently, edaravone, both of which offer, at best, modest improvements in survival and functional preservation. Antisense oligonucleotide therapies targeting specific genetic mutations might be an option for some patient subgroups.¹⁷

Recent developments in pharmacogenomics have underscored the merit of personalized medicine approaches in neurodegenerative diseases. Genetic polymorphisms affecting drug metabolism, transport, and drug-target interactions can influence treatment responses and any adverse event profile.¹⁸ For example, cytochrome P450 2D6 polymorphisms affect the metabolism of many Parkinson's disease medications, while others, such as amyloid-modifying drugs, depend on the APOE genotype.¹⁹ Pharmacogenomic testing in clinical practice could improve medication selection and dosing, thereby enhancing therapeutic outcomes and reducing adverse effects.

Nonpharmacological Interventions

Nonpharmacological interventions are valuable elements within the overall management of neurodegenerative diseases. The physical, occupational, and speech therapy teams play an integral part in maintaining function, addressing impairments, and optimizing quality of life.²⁰ For Parkinson's disease, high-intensity exercise usefully impacts motor symptoms, cognitive function, and general well-being.²¹ For a variety of dementia disorders, cognitive rehabilitation, which can include cognitive rehabilitation

Table 1 | Major neurodegenerative disorders and their characteristics

Disease	Primary Pathology	Main Clinical Manifestations	Current Pharmacological Approaches
Alzheimer's disease	Beta-amyloid plaques, tau tangles	Memory loss, cognitive impairment	Cholinesterase inhibitors, NMDA-receptor antagonists, anti-amyloid monoclonal antibodies
Parkinson's disease	Alpha-synuclein (Lewy bodies)	Tremors, rigidity, bradykinesia	Levodopa, dopamine agonists, MAO-B inhibitors, COMT inhibitors
ALS	Motor neuron degeneration	Progressive muscle weakness, paralysis	Riluzole, edaravone, antisense oligonucleotide therapies
Huntington's disease	Huntingtin protein aggregation	Motor, cognitive, psychiatric symptoms	Symptom management medications
Multiple sclerosis	Demyelination, inflammation	Various motor and sensory symptoms	Disease-modifying therapies, symptomatic treatments
Frontotemporal dementia	TDP-43, tau protein abnormalities	Behavioral changes, language difficulties	Symptom management medications

therapy, cognitive stimulation therapy, and cognitive training, can be beneficial to maximize cognitive function and functional ability.²²

Nutrition-based interventions have received increased attention in the overall management of these neurodegenerative diseases. The Mediterranean-DASH Intervention for Neurodegenerative Delay (MIND) diet is a primarily plant-based diet with limited red meat and processed foods, shown in observational studies to reduce cognitive decline and likely reduce the odds of Alzheimer's disease.²³ Other forms of dietary health interventions, such as supplementing with omega-3 fatty acids, vitamins D and B12, and antioxidants, are touted to promote brain health, but there is minimal evidence of their success when applied in isolation.²⁴

Innovations in technology have broadened the repertoire of nonpharmacological treatments for neurodegenerative diseases. Virtual-reality-based rehabilitation programs provide immersive and engaging environments for both motor and cognitive training, which can influence neuroplasticity and functional recovery.²⁵ Wearable sensors and smartphone apps can now track a person's symptoms, medication adherence, and activity level, allowing timely and remote adjustments and interventions.²⁶ Transcranial magnetic stimulation, transcranial direct current stimulation, and deep brain stimulation are also growing forms of neuromodulation for which there is increasing evidence of efficacy in select neurodegenerative diseases, especially for treatment-resistant symptoms (Table 2).²⁷

Multidisciplinary Care Models

Care for patients with neurodegenerative conditions is complicated, and effective care requires multidisciplinary approaches that address the totality of the needs of patients and their caregivers. Specialized multidisciplinary clinics for specific diagnoses like ALS, Parkinson's disease, and dementia have been successful in improving quality of care, patient satisfaction, and possibly clinical outcomes and mortality.²⁸ Multidisciplinary clinics include collaboration with neurologists, psychiatrists, nurses, physical and occupational

therapists, speech-language pathologists, dietitians, social workers, and palliative care specialists to provide comprehensive, coordinated care.²⁹

Multidisciplinary care models are effective in prioritizing the patient as the focal point of care, respecting personal preferences, values, and goals, through shared decision-making and autonomy.³⁰ Triadic meetings, standardized assessment processes, and shared clinical planning facilitate communication and can optimize the alignment of the treatment with the patient's priorities and the stage of the disease.³¹ Telehealth-based multidisciplinary care models were particularly useful for patients who had difficulty moving about their communities and accessing specialized outpatient services and for those who lived in rural areas without specialized services.³² Because of these patient-centered models, disparities related to health care access can be reduced, and individual patients can maintain their continuity of care, regardless of the community services available.

Integration of palliative care is an essential element of comprehensive care for neurodegenerative disorders with a focus on symptom management, quality of life, and meeting the need for complex medical decision-making.³³ Once palliative care is started early in the trajectory of a serious illness, it can help better manage difficult symptoms such as pain, dyspnea, and psychological distress, and it encourages advance care planning conversations that respect patient values and preferences.³⁴ As stated by Creutzfeldt et al.,³⁵ palliative approaches are additive to disease-modifying or symptomatic treatments in the trajectory of a disease. They help provide many layers of support through the course of a disease and are not meant solely for end-of-life care (Table 3).³⁵

Support Systems

Family and Caregiver Support

Family members and informal caregivers take on significant responsibilities in rehabilitating and supporting individuals with neurodegenerative disorders,

Table 2 | Nonpharmacological interventions for neurodegenerative disorders

Intervention Category	Examples	Potential Benefits
Physical therapy	High-intensity exercise, gait training	Improved motor symptoms, mobility, general well-being
Cognitive interventions	Cognitive rehabilitation, cognitive stimulation therapy	Maximized cognitive function, functional ability
Nutritional approaches	MIND diet, Mediterranean diet	Potential reduction in cognitive decline
Technological interventions	Virtual reality rehabilitation, wearable sensors	Immersive training, symptom tracking, remote monitoring
Neuromodulation	Transcranial magnetic stimulation, deep brain stimulation	Treatment of resistant symptoms, functional improvement

Table 3 | Components of multidisciplinary care models

Component	Description	Benefits
Specialized multidisciplinary clinics	Collaboration between neurologists, psychiatrists, nurses, therapists, social workers	Improved quality of care, patient satisfaction, potential improved outcomes
Patient-centered approaches	Respecting preferences, values, goals through shared decision-making	Maximized fit of treatment to patient priorities and disease stage
Telehealth services	Remote access to specialized care	Improved access for patients with mobility issues or in rural areas
Palliative care integration	Focus on symptom management, quality of life, complex decision-making	Better symptom management, advanced care planning, support throughout disease trajectory

often providing long-term and considerable physical, emotional, and logistical support. Although caregiving has the potential to be rewarding, it often involves significant burden, stress, and health risks, including an increased risk of depression, anxiety, and health problems.³⁶ Family caregivers can have their burden and psychological well-being improved through targeted caregiver support interventions, including tailored education and training programs, counseling services, respite care, and support groups.³⁷

Current literature suggests that caregiver support interventions should be tailored to the caregivers' needs, context, circumstances, and culture, rather than being based on a single, one-size-fits-all approach. For example, technology-based interventions, such as education modules hosted on websites, virtual support groups, and telemedicine for counseling, could be an effective way to meet the needs of caregivers who have limited time and/or mobility in rural and remote communities.³⁸ Programs that focus on a contextual approach to challenges faced due to the unique set of issues facing young caregivers, working caregivers, or caregivers managing multiple caregiving responsibilities should be tailored to address the unique needs of these caregivers.³⁹

Financial support systems for families contending with neurodegenerative disorders are essential, but are often lacking. Significant costs related to direct care, medication, home modifications, and assistive technologies expose families to financial distress, in addition to the added potential loss of income when patients or caregivers cut back on or stop working.⁴⁰ Lack of awareness or complexity regarding insurance systems, disability benefits, and long-term care options may further complicate the financial context, underscoring the need for accessible financial counseling, advocacy, and policy change to support the economic ramifications of neurodegenerative disorders.⁴¹

Community Resources and Social Support

Community-based support services assist in improving the quality of life for people living with neurodegenerative disorders, helping reduce isolation, and promoting engagement within the community. Adult day support programs provide a framework for activities, opportunities for socialization, and respite for caregivers, while home care services help with activities of daily living, medication management, and transportation.⁴² Specialized support groups tailored to individual conditions provide a safe space to share lived experiences, practical advice, or strategies within a supportive network of others encountering similar challenges.⁴³

Adaptive housing options and environmental modifications are also important parts of community support systems for people living with neurodegenerative disorders. Universal design, smart home technology, and specific environmental modifications, such as grab bars, wheelchair ramps, and adapted bathrooms, can enhance a person's safety, independence, and quality of life, and potentially postpone their need for

institutional care.⁴⁴ Community transportation services, meal delivery, and technology access initiatives help to keep people connected to their communities and ensure other practical needs are met.⁴⁵ Environmental adaptations, such as grab bars, wheelchair ramps, and adapted bathrooms, contribute to safety, independence, and quality of life and can potentially delay the need for long-term care. Community transportation, meals on wheels, and technology access create opportunities for individuals to remain connected to the community and for assistance with practical needs.

Social engagement, as well as meaningful activities, is an important contributor to psychological well-being in neurodegenerative disorders. Community arts, adapted recreation, volunteering, and intergenerational programs provide opportunities for engagement and meaningful contribution despite disease-associated restrictions.⁴⁵ Digital inclusion initiatives, such as accessible technology training and modified devices, support social connection using virtual platforms, especially for individuals with mobility limitations and during public health emergencies.⁴⁶

Health Care Systems and Policy Support

Health care systems, structures, and policies affect access to care, treatment, and supports for individuals with neurodegenerative disorders in significant ways. Integrated care models that connect behavioral health with care in neurology, psychiatry, primary care, rehabilitation services, and community supports may improve coordination and ultimately patient outcomes.⁴⁷ Value-based care models that quantify metrics in quality of care and patient-reported outcomes rather than volume of service could encourage a comprehensive approach to managing neurodegenerative disorders that centers on the patient's goals.⁴⁸

Health insurance policies and reimbursement structures impact access to care and the quality of care delivered for neurodegenerative disorders. Reduced access to care or compromised quality of care are potential implications of restricted policies or reimbursement for necessary services.⁴⁹ Restrictions or reduced access to medications due to medication approval policies, high patient out-of-pocket costs, preapprovals for medications, and ongoing adherence monitoring can prohibit patients from getting the medically necessary medications they need.⁵⁰ It is imperative that advocacy for expanded access to coverage, improved administrative policies, and acknowledgment of the full spectrum of needs associated with neurodegenerative disorders continue to be encouraged in policy advocacy.⁵¹

National and international research initiatives and policies are accelerating recognition of the increasing public health burden of neurodegenerative diseases. The World Health Organization's *Global Action Plan on the Public Health Response to Dementia* and various similar national policies exemplify frameworks for comprehensive responses that address prevention, diagnosis, treatment, care, and research.⁵² These frameworks focus on reducing risk factors, educating

Table 4 Support systems for neurodegenerative disorders		
Support Level	Examples	Impact
Family and caregiver support	Education programs, counseling, respite care, support groups	Reduced caregiver burden, improved psychological well-being
Community resources	Adult day programs, home care services, support groups	Reduced isolation, increased engagement, caregiver respite
Environmental modifications	Universal design, smart home technology, adaptive housing	Enhanced safety, independence, delayed need for institutional care
Social engagement	Community arts, adapted recreation, volunteering	Improved psychological well-being, meaningful contribution
Health care systems	Integrated care models, value-based care	Better coordination, patient-centered outcomes
Policy support	Insurance coverage, research initiatives, national action plans	Expanded access, reduced stigma, prevention strategies

the public, reducing stigma, and providing equitable access to care and support across diverse populations and locations (Table 4).⁵³

Sources of Hope
Advances in Research and Treatment

Important advances in the understanding of the molecular mechanisms associated with neurodegenerative diseases have hastened the discovery of new therapeutic options that more directly target disease-defining pathological processes. Gene therapy options (including genes delivered by means of viral vectors, as well as gene editing approaches such as CRISPR-Cas9) hold great potential to treat genetically defined neurodegenerative diseases, with some clinical trials ongoing for Huntington’s disease and familial ALS.⁵⁴ Similarly, stem cell therapies aimed at replacing degenerated neurons or offering neuroprotective factors are also exciting new avenues in regenerative medicine for neurodegenerative diseases.⁵⁵

Immunotherapy options aimed at disrupting the pathological protein aggregates have gained traction in developing treatment options for neurodegenerative diseases, especially Alzheimer’s disease. In addition to the newest class of anti-amyloid monoclonal antibodies, there is ongoing research into immunotherapy options for tau, alpha-synuclein, and other pathological proteins involved in various neurodegenerative diseases.⁵⁶ At the same time, efforts are being made to ensure that small-molecule options are available, which target other mechanisms, such as proteostasis, mitochondrial dysfunction, and neuroinflammation, that contribute to the underlying processes of disease.⁵⁷

Drug repurposing strategies, which leverage approved drugs for new uses, could provide a potentially accelerated approach to developing new therapies

for patients with neurodegenerative disease. Through high-throughput screening methods and computational modeling, researchers have successfully identified several drug candidates, including classes of diabetes drugs, cardiovascular drugs, and anti-inflammatory drugs with putative neuroprotective activities.⁵⁸ These strategies utilize existing drug safety information and approvals, and thus may provide a quicker pathway for clinical application when compared to wholly novel compounds.⁵⁹

Technological Innovations

Technological advancements are continually developing new ways to manage, diagnose, and even live with neurodegenerative disorders. One of the avenues of discovery involves ongoing advances in neuroimaging methods such as new uses of PET tracers, new high-resolution MRI techniques, and the use of multimodality imaging approaches that are revealing new capabilities for the visualization of pathological changes, such as tracking disease progression, and evaluating the response to treatment with compelling precision.⁶⁰ Similarly, advances in biomarker analyses, particularly fluid biomarkers, such as the development of highly sensitive assays that can be used to assess blood-based markers such as phosphorylated tau and neurofilament light chain, are also exciting directions that will guide the use of noninvasive methods for diagnostics and monitoring.⁶¹

Innovations in the development of assistive technologies and adaptive devices are contributing to maximizing independence and facilitating quality of life for individuals with neurodegenerative disorders. Smart home systems, voice-activated assistants, medication management technology, and GPS tracking technology have the capacity both to enhance safety and to provide support, while also diminishing the demand for caregiver time.⁶² Innovations in mobility aids, communication devices, and environmental control systems, for example, are addressing some of the functional limitations imposed by many forms of neurodegeneration and could potentially allow people with neurodegenerative conditions to maintain a community presence and autonomy wherever possible.⁶³

Digital health platforms and remote monitoring devices are changing the way health care is delivered and how disease is managed in patients with neurodegenerative conditions. Smartphone applications and wearable sensors can continually monitor symptoms, medication adherence, and physical activity levels in the real world, rather than episodically within clinical contexts.⁶⁴ Telehealth services, virtual rehabilitation programs, and digital cognitive assessments enable more equitable access to specialized care and interventions, which is particularly important for those with mobility issues or who live in low-resource settings.⁶⁵

Resilience, Adaptation, and Meaning

Beyond medical and technological findings, hope for people diagnosed with neurodegenerative disorders includes the amazing capacity of humans to

recover, adapt, and find meaning in life's challenges. Psychological research has increasingly suggested that, despite their conditions, many people diagnosed with neurodegenerative conditions enjoy resilience and well-being amid significant difficulties, and some have reported discovering new meaning and purpose in life during their disease process.⁶⁶ We have observed that both patients and caregivers experience post-traumatic growth—the perceived positive psychological change after an individual faces traumatic and adverse experiences—as they navigate the complex realities of neurodegenerative disorders.⁶⁷

Narrative approaches to neurodegenerative disorders highlight the relevance of personal storytelling and meaning-making processes for maintaining identity and dignity throughout the disease trajectory; programs focused on life review, memoir writing, and creative expression are ways of honoring personal narratives and interdisciplinary storytelling, and are ways for people to connect with others and navigate the emotional impacts of and live with their progressive illness.⁶⁸ Narrative approaches consider that hope is not just about a medical cure or regulating symptoms, but engages with deeper elements of our humanity, including connections to others, purpose, and legacy.⁶⁹

For many living with neurodegenerative conditions, spiritual and existential aspects often appear to be important sources of strength and meaning. Religious and spiritual beliefs, practices, and communities provide frameworks for understanding suffering, comfort, and sometimes practical support systems for many patients and families.⁷⁰ Existential approaches focused on authenticity, finding freedom within limitations, and being profoundly in the moment have also provided meaningful frameworks for coping with the various uncertainties and losses associated with progressive neurological diseases.⁷¹

Community Engagement and Advocacy

Advocacy movements by patients and community engagement initiatives represent significant hope and opportunities for change for individuals living with neurodegenerative disorders. Organizations run by patients to advance research agendas, recruit for clinical trials, provide services for families and caregivers, and influence policy reforms are successful through collaboration and advocacy.⁷² Patient engagement as partners in research, working on studies or in a role on advisory committees, or as policy consultants, ensures that the patient experience is incorporated so that research and care are attuned to the needs and priorities of those who live with these conditions.⁷³

Public awareness campaigns and campaigns to reduce stigma enable individuals living with neurodegenerative disorders to live in more supportive social contexts. Public campaigns to promote the human potential of individuals living with cognitive impairment through media stories, engaging with educators, and participating in public events that illustrate the human potential, abilities, and contributions of persons living with these conditions provide a greater understanding

Table 5 | Emerging sources of hope

Category	Examples	Potential Impact
Research advances	Gene therapy, stem cells, immunotherapy, drug repurposing	Disease-modifying potential, targeted treatments
Technological innovations	Advanced neuroimaging, fluid biomarkers, assistive technologies	Earlier diagnosis, noninvasive monitoring, enhanced independence
Digital health solutions	Smartphone applications, wearable sensors, telehealth	Continuous monitoring, equitable access to care
Resilience and adaptation	Post-traumatic growth, narrative approaches, meaning-making	Psychological well-being despite challenges
Community engagement	Patient advocacy organizations, research partnerships	Patient-informed research priorities, policy reform
Public awareness	Antistigma campaigns, dementia-friendly initiatives	Supportive social contexts, community inclusion

of individuals and helps shift stereotypes and foster inclusiveness.⁷⁴ Dementia-friendly community initiatives, which encourage local organizations, services, and businesses to support cognitive impairment, illustrate how inclusion strategies can empower communities to be more engaged in supporting quality of life.⁷⁵

Using intergenerational connections and multigenerational approaches holds particular promise in addressing isolation and improving quality of life among individuals with neurodegenerative disorders. Programs that pair young and older generations to learn from each other, collaborate in creative work, and engage in shared activities facilitate meaningful engagement while also challenging age-related stereotypes.⁷⁶ While pursuing true intergenerational connections may be difficult, these programs highlight the potential for connection, contribution, and growth that can exist at all stages of engagement during the progression of neurodegenerative disease, affirming the value of an individual beyond their cognitive or physical capacity (Table 5).⁷⁷

Conclusion

Living with neurodegenerative disorders presents both ongoing challenges and emerging opportunities with respect to management, support, and hope. The complexity of these diseases necessitates multilayered approaches in their management, with numerous considerations, including pharmacological and non-pharmacological therapies, multidisciplinary service provision, appropriate and effective support, and recognition of psychological, social, and existential aspects of well-being.⁶⁸ While curative therapies are not available for most neurodegenerative disorders, there are significant advancements in our understanding of the disease mechanisms, their treatment, and the

implementation of supportive care models that provide meaningful and viable options to enhance management options and improve quality of life.⁶⁹

The neurodegenerative care landscape continues to evolve through scientific advances, technological advances, systemic changes within health care, changing social attitudes, and policy changes. Emerging paradigm shifts toward person-centeredness demonstrate respect for individual values, preferences, and goals while also recognizing that other issues are at play, such as social determinants, structural factors, and access to health care, that significantly shape the experience of living with and managing a neurodegenerative disorder.⁷⁰ Moreover, increased appreciation of the role of caregivers and communities reinforces the importance of support systems that go beyond service provision to address the added complexity associated with a neurodegenerative disorder.⁷¹

The future of living with neurodegenerative disorders requires the acceptance of new possibilities and pathways for hope through multiple forms of progress. Advances in basic and clinical science may lead to disease-modifying treatments. Advances in assistive technology may create tools for better function and independence. Advances in the system of delivery of health services may lead to a more coordinated and transparent system that improves access and quality of care. Advances in changes in everyday attitudes toward disability may create broader movements toward inclusion and dignity. Each of these hope-producing avenues leads to an increasingly expanded outlook of hope.⁷⁸ Relatedly, individuals and families draw upon their profound sources of meaning, purpose, connection, and resilience throughout the experience of neurodegenerative conditions. It is often found that individuals and families provide one another with unexpected support, strength, and a sense of community even in a very poor set of circumstances.⁷⁹ By considering a broader range of complementary possibilities for managing and supporting individuals with neurodegenerative disorders, we may create a collective future in which living with neurodegenerative disorders is not merely a matter of surviving but rather an opportunity to flourish with dignity, meaning, and quality.⁸⁰

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