SUPPLEMENTARY DIGITAL MATERIAL 1

Supplementary Table I.—Evidence synthesis of the literature.

Study/Article title	**Authors/ Organizations**	**Year**	**Literature evidence**
Rehabilitation of motor neuron disease.	Simmons Z.	2013	Benefits of physical and occupational therapy. Management of speech pathology and impaired nutrition. Respiratory function assessment. Mental health and anxiety assessment. Caregivers. Symptoms management.
Rehabilitation in amyotrophic lateral sclerosis: why it matters.	Majmudar S, Wu J, Paganoni S.	2014	Multidisciplinary care of patients with ALS.
EFNS guidelines on the clinical management of amyotrophic lateral sclerosis (MALS)--revised report of an EFNS task force.	EFNS Task Force on Diagnosis and Management of Amyotrophic Lateral Sclerosis: et al.	2012	Multidisciplinary care of patients with ALS. Respiratory and symptomatic management. Genetic testing and counselling. Enteral nutrition management. Spasticity and fatigue assessment and management. Cognitive assessment. Palliative care.
Amyotrophic lateral sclerosis: disease state overview.	Hulisz D.	2018	Disease symptoms evaluation. Diagnostic methods. Multidisciplinary management.
Cardiovascular diseases may play a negative role in the prognosis of amyotrophic lateral sclerosis.	Mandrioli J, Ferri L, Fasano A, Zucchi E, Fini N, Moglia C, et al.	2018	Certain cardiovascular diseases (hypertension, congestive heart failure, AF, disorders of thrombosis and haemostasis) are associated with worse prognosis in ALS patients.
Managing patients with amyotrophic lateral sclerosis.	Sathasivam S.	2009	Multidisciplinary approach in treatment of ALS patients Respiratory, nutritional and pain management.
Comprehensive rehabilitative care across the spectrum of amyotrophic lateral sclerosis.	Paganoni S, Karam C, Joyce N, Bedlack R, Carter GT.	2015	Exercise management (flexibility, strengthening, aerobic) and adaptive tools in early ALS. Care of ALS patients in advance stage of the disease.
Electrodiagnostic Testing for the Diagnosis and Management of Amyotrophic Lateral Sclerosis.	Howard IM, Rad N.	2018	El Escorial criteria revised, as electrodiagnostic criteria in the diagnosis of ALS. The Awai electrodiagnostic criteria for the diagnosis of ALS.

			Elements in electrodiagnostic findings
https://www.aanem.org/getmedia/1e53beb2-987d-4f06-b091-ebe56148a8b9/Who-is-Qualifed-to-Practice-EDX-2012.pdf	American Association of Neuromuscular & Electrodiagnostic Medicine (AANEM)	2012	Electrodiagnostic evaluations should be performed by Neurologist or Physiatrist, who had special training in diagnosis and treatment of neuromuscular diseases.
Electrodiagnosis in persons with amyotrophic lateral sclerosis.	Joyce NC, Carter GT.	2013	Peripheral nerve conduction studies and needle electromyography studies.
Electrodiagnostic criteria for diagnosis of ALS.	de Carvalho M, Dengler R, Eisen A, England JD, Kaji R, Kimura J, et al.	2008	Electrodiagnostic findings and criteria for ALS patients.
Assessing and treating pain in movement disorders, amyotrophic lateral sclerosis, severe acquired brain injury, disorders of consciousness, dementia, oncology and neuroinfectivology. Evidence and recommendations from the Italian Consensus Conference on Pain in Neurorehabilitation.	Bartolo M, Chiò A, Ferrari S, Tassorelli C, Tamburin S, Avenali M, et al.	2016	Multidisciplinary rehabilitation is shown to be effective in management of complex needs for patients with motor neuron disease. Pain treatment.
International Classification of Functioning, Disability and Health: ICF: World Health Organization.	Organization WH.	2001	The International Classification of Functioning, Disability and Health (ICF) as WHO framework for measuring health and disability at individual and populational levels.
Validation of the ICF core set for neuromuscular diseases.	Bos I, Stallinga HA, Middel B, Kuks JB, Wynia K.	2013	The use of ICF in evaluation of patients with neuromuscular diseases. In addition, there are generic and domain specific measuring instruments to assess activities of daily living, for example, GARS (Groningen Activity Restriction Scale) or to assess participation in life situations, for example, the IPAQ (Impact on Participation and Autonomy Questionnaire).
A systematic review of the effect of moderate intensity exercise on function and disease progression in amyotrophic lateral sclerosis.	Lui AJ, Byl NN.	2009	There is negative effect of immobilization on bone and muscle. Regular physical activity is considered a positive intervention. There is moderately strong evidence suggesting that participants who were in the early stages of ALS and exercised had slightly better

			outcomes with respect to respiratory function, strength, and function compared with early-stage participants who did not exercise.
The role of exercise in amyotrophic lateral sclerosis.	Chen A, Montes J, Mitsumoto H.	2008	Exercise may be safely applied to ALS patients who have spasticity. Significantly higher functions (as measured by the total ALSFRS and combined upper and lower extremity subtotal ALSFRS scores) and an improved qualify of life, (as measured by the 36-Item Short Form Health Survey Physical Function Subscale) at 6 months were noticed in group of ALS patients included in resistance and stretching exercise.
Physical therapy for individuals with amyotrophic lateral sclerosis: current insights.	Bello-Haas VD.	2018	It is increasingly being recognized that rehabilitation, in general, and physical therapy, in particular, can greatly enhance function, participation, and quality of life for the one with ALS. Education and training of patients, family, and caregiver, psychological support, and referral to other health care professionals influence the overall management plan across the ALS disease continuum. The current state of the evidence indicates that current practice guidelines for physical therapy management heavily relies on expert opinion and consensus, although physical therapy research is being to emerge.
Interprofessional Care for Neuromuscular Disease.	Howard I, Potts A.	2019	Care settings, evidence and barriers for interprofessional care for neuromuscular disease. Interprofessional care models – multidisciplinary, interdisciplinary and transdisciplinary
Amyotrophic lateral sclerosis: update for family physicians.	Shoesmith CL, Strong MJ.	2006	Patients with ALS are best treated in multidisciplinary clinics.
Care management in amyotrophic lateral sclerosis.	Soriani MH, Desnuelle C.	2017	Adaptive and assistive equipment for ALS patients.

			Regular assessment (every 3-6 months) of functional impairment. Respiratory function assessment, non-invasive ventilation and invasive mechanical ventilation. Palliative and end-of-life care.
Effectiveness of Home-Based Exercises Without Supervision by Physical Therapists for Patients With Early-Stage Amyotrophic Lateral Sclerosis: A Pilot Study.	Kitano K, Asakawa T, Kamide N, Yorimoto K, Yoneda M, Kikuchi Y, et al.	2018	Home-based exercise without supervision is safe and feasible for patients with early-stage ALS.
Noninvasive Respiratory Management of Patients With Neuromuscular Disease.	Bach JR.	2017	Respiratory function assessment and treatment modalities in patients with neuromuscular diseases
Experience with telemedicine in a multi-disciplinary ALS clinic.	Van De Rijn M, Paganoni S, Levine-Weinberg M, Campbell K, Swartz Ellrodt A, Estrada J, et al.	2018	Telemedicine via video televisit is feasible and can be used to provide multidisciplinary ALS care.
White book on physical and rehabilitation medicine in Europe.	Section of Physical and Rehabilitation Medicine Union Européenne des Médecins Spécialistes (UEMS); European Board of Physical and Rehabilitation Medicine; Académie Européenne de Médecine de Réadaptation; European Society for Physical and Rehabilitation Medicine.	2006	Principles of prevention. Prevention levels and settings in which preventive measures are undertaken. Goals- to incorporate new technical developments into PRM practice. Increasing technology should contribute significantly to independent living and quality of life of people with disabilities in Europe
Telemedicine in Rehabilitation.	Galea MD.	2019	There is evidence that telerehabilitation is well received by patients whether applied alone or to supplement conventional therapy and it does not add burden to the caregiver.
Organization WH. Rehabilitation in Health Systems. Geneva: Licence: CC BY-NC-SA 3.0 IGO.	World Health Organization	2017	These recommendations respond to strong calls in the *World report on disability* for Member States to “develop, implement, and monitor polices, regulatory

			mechanisms, and standards for rehabilitation services, as well as promoting access to those services” *(6, p. 122)*. The recommendations are also intended to support countries in implementing objective 2 of the *WHO global disability action plan 2014–2021*, “to strengthen and extend rehabilitation, habilitation, assistive technology, assistance and support services, and community-based rehabilitation” *(30, p. 3)*. These recommendations are intended for government leaders and health policy-makers and are relevant for various sectors, such as those involved in workforce and training. The recommendations and good practice statements may also be useful for the broad range of stakeholders involved in rehabilitation service delivery, financing, research and assistive products, such as professional organizations, academic institutions, civil society and nongovernmental and international organizations.
Comprehensive care of amyotrophic lateral sclerosis patients: a care model.	Güell MR, Antón A, Rojas-García R, Puy C, Pradas J; en representación de todo el grupo interdisciplinario.	2013	The interdisciplinary teams usually include neurologists, rehabilitation physicians, respiratory medicine specialists, nurses, physiotherapists, speech therapists, nutritionists, social workers, and they can also be more or less extended, depending on the resources of each centre, to include other members such as occupational therapists, cardiologists, psychologists, ear, nose and throat specialists, etc., or even in some cases by providing home care. External support of primary care teams and patient and family associations.
[Multidisciplinary Management and Neurorehabilitation of Patients with Amyotrophic Lateral Sclerosis].	Budinčević H, Marčinko Budinčević A, Kos M, Vlašić S,	2016	Multidisciplinary team should consist of: neurologist, family physician, nurse, physiotherapist, respiratory

	Bartolović J, Benko S, et al.		therapist, psychologist, dietitian, social worker, respiratory medicine specialist, gastroenterologist, physiatrist and stomatologist.
The role of physical therapy and occupational therapy in the treatment of amyotrophic lateral sclerosis.	Lewis M, Rushanan S.	2007	Treatment strategies and principles to guide therapists and other healthcare professionals in the treatment of persons with ALS.
The amyotrophic lateral sclerosis center: a model of multidisciplinary management.	Mayadev AS, Weiss MD, Distad BJ, Krivickas LS, Carter GT.	2008	Rehabilitative care is directed by a neurologist or physiatrist, and, in some centers, facilitated by a neuromuscular nurse practitioner. A pulmonologist who has experience in ALS should be involved early on, as should physical and occupational therapists, speech-language pathologists, and social workers.
White Book on Physical and Rehabilitation Medicine (PRM) in Europe. Chapter 1. Definitions and concepts of PRM.	European Physical and Rehabilitation Medicine Bodies Alliance.	2018	Disability interventions and evaluation. Rehabilitation as a health strategy.
White Book on Physical and Rehabilitation Medicine (PRM) in Europe. Chapter 6. Knowledge and skills of PRM physicians.	European Physical and Rehabilitation Medicine Bodies Alliance.	2018	Knowledge and skills of PRM physicians, the clinical field of competence of PRM, the place of PRM specialty in the healthcare system and society, education and continuous professional development of PRM physicians. PRM physicians are responsible for facilitating the patients' efforts to achieve as optimal as possible a life after illness or injury or in the development of someone with a health condition. Effective communication with patients and their caregivers, as giving adequate information and providing health education, play a central role in rehabilitation and is a determinant skill for prM physicians.
Caregiver burden in amyotrophic lateral sclerosis: A systematic review.	de Wit J, Bakker LA, van Groenestijn AC, van den Berg LH, Schröder CD, Visser-Meily JMA, et al.	2018	There is moderate to high quality of evidence for the relation between behavioral impairments of the patient and caregiver burden, physical functioning of the patient and caregiver burden, and feelings

			of depression of the caregiver himself or herself and caregiver burden.
A randomized controlled trial of resistance and endurance exercise in amyotrophic lateral sclerosis.	Clawson LL, Cudkowicz M, Krivickas L, Brooks BR, Sanjak M, Allred P, et al.	2018	There is no consensus on the possible benefits, or hazards, of exercise formulated for ALS. This study demonstrates that in the short term, resistance, endurance, and SROM exercises are well tolerated and safe. At longer time-points of six months, resistance exercise is equally tolerated compared to the current care for stretching and range of motion.
Strictly monitored exercise programs reduce motor deterioration in ALS: preliminary results of a randomized controlled trial.	Lunetta C, Lizio A, Sansone VA, Cellotto NM, Maestri E, Bettinelli M, et al.	2016	ALS care requires an integrated approach in which drugs, nutritional and respiratory support need to be inserted in a strictly monitored physical exercise program, early in the course of the disease.
Amyotrophic lateral sclerosis: the role of exercise.	Lisle S, Tennison M.	2015	Most of the available evidence points toward mild-to-moderate exercise as a positive treatment, and certainly no adverse outcomes are noted from the aforementioned studies.
A pilot trial of telemedicine-assisted, integrated care for patients with advanced amyotrophic lateral sclerosis and their caregivers.	Vitacca M, Comini L, Tentorio M, Assoni G, Trainini D, Fiorenza D, et al.	2010	In ALS patients, telemedicine-assisted integrated care may be a useful follow-up model, which fits the requirements for this disease, providing for autonomy, continuity of information and care, psychosocial monitoring, and interventions based on the presence of a multidisciplinary staff which is primarily organized by a nurse-tutor.
Telehealth in Physical Medicine and Rehabilitation: A Narrative Review.	Tenforde AS, Hefner JE, Kodish-Wachs JE, Iaccarino MA, Paganoni S.	2017	Telehealth is expected to contribute to the future care physiatrists provide patients.
Pulmonary Physical Therapy Techniques to Enhance Survival in Amyotrophic Lateral Sclerosis: A Systematic Review.	Macpherson CE, Bassile CC.	2016	Even though there is limited research, specific pul- monary physical therapy interventions including inspiratory muscle training, lung volume recruitment training, and manually assisted cough have at least moderate strength for effectiveness in improving

			respiratory outcome measures, participation level, and increasing survival. The existing evidence for pulmonary physical therapy techniques in individuals with ALS supports the use of initiating inspiratory muscle training in the early stage of the disease with continued use for as long as feasible.
Respiratory training improved ventilatory function and respiratory muscle strength in patients with multiple sclerosis and lateral amyotrophic sclerosis: systematic review and meta-analysis.	Ferreira GD, Costa AC, Plentz RD, Coronel CC, Sbruzzi G.	2016	Respiratory muscle training improved the strength of respiratory muscles and ventilatory function and should be an adjunct to rehabilitation of patients with neurodegenerative diseases.
Impact of expiratory strength training in amyotrophic lateral sclerosis: Results of a randomized, sham-controlled trial.	Plowman EK, Tabor-Gray L, Rosado KM, Vasilopoulos T, Robison R, Chapin JL, et al.	2019	A mild to moderate intensity, eight-week at home expiratory muscle strength training program was well tolerated in individuals with early ALS and it resulted in significant improvements in maximum expiratory pressure and oral intake, as well as maintenance of peak cough flow and swallowing function.
Pain in amyotrophic lateral sclerosis.	Chiò A, Mora G, Lauria G.	2017	Pharmacological treatment can be useful for some primary pain types, mainly neuropathic, and physical therapy might have a role in prevention and treatment of secondary pain in patients with ALS.
Intrathecal baclofen for spasticity-related pain in amyotrophic lateral sclerosis: efficacy and factors associated with pain relief	McClelland S 3rd, Bethoux FA, Boulis NM, Sutliff MH, Stough DK, Schwetz KM, et al.	2008	Our findings in eight patients with ALS indicate that intrathecal baclofen (ITB) is an effective and safe treatment modality for relief of spasticity-related pain, with no postoperative neurologic morbidity/mortality in our population. An important observation in our series is that post-operative pain score reduction was predicted by the degree of pain score reduction observed following preoperative ITB test injection.
Clinical features of pain in amyotrophic lateral sclerosis: A clinical challenge.	Delpont B, Beauvais K, Jacquin-Piques A, Alavoine V, Rault P, Blanc-	2019	Given the importance of pain in terms of quality of life for patients with ALS, physicians need to be able to identify and reduce the pain quickly or even

	Labarre C, et al.		prevent it, with pharmacological treatments being the more eficacious approach for neuropathic and secondary pain. Physiotherapy, massage, daily stretching, therapeutic ultrasound, laser therapy, transcutaneous electrical nerve stimulation (TENS) and acupuncture may also help patients with ALS and pain.
Dysphagia in stroke and neurologic disease.	González-Fernández M, Daniels SK.	2008	In patients with complaints of dysphagia or those patients with neurogenic disorders associated with a high frequency of dysphagia, a clinical bedside swallowing evaluation (CSE) should be completed. The purpose of an instrumental swallowing study is to evaluate physiologic functioning of the oropharyngeal swallowing mechanism, determine swallowing safety, and identify the effects of compensatory strategies, such as posture and bolus consistency, on deglutition. By determining the exact cause of dysfunction, therapeutic intervention can be initiated to address the specific disorder.
Dysarthria in amyotrophic lateral sclerosis: A review.	Tomik B, Guiloff RJ.	2010	Based on clinical opinion, dysarthria in ALS should be assessed early and monitored regularly. Perceptual assessment of the intelligibility of speech by the patient, carers and professionals, remains the main criterion for decisions on communication support.
Speech therapy and communication device: impact on quality of life and mood in patients with amyotrophic lateral sclerosis.	Körner S, Sieniawski M, Kollewe K, et al.	2013	Evidence-based treatment of dysarthria in the context of multidisciplinary care in ALS is therefore very important. From the current perspective and according to our results, early introduction of appropriate communication devices can sustain quality of life and prevent increase of depression in ALS patients.
Active music therapy approach in amyotrophic lateral sclerosis: a randomized-controlled trial.	Raglio A, Giovanazzi E, Pain D, Baiardi	2016	Our study showed a beneficial effect of active music therapy

	P, Imbriani C, Imbriani M, et al.		(AMT) intervention on quality of life in ALS patients.
Systematic review of the effectiveness of occupational therapy-related interventions for people with amyotrophic lateral sclerosis.	Arbesman M, Sheard K.	2014	We found limited to moderate evidence that people involved in multidisciplinary programs have longer survival than those in general care. Moderate evidence indicates that a home exercise program of daily stretching and resistance exercise results in improved function.
The provision of assistive devices and home adaptations to patients with ALS in the Netherlands: patients' perspectives.	Creemers H, Beelen A, Grupstra H, Nollet F, van den Berg LH.	2014	Assistive devices and home adaptations (ADHA) constitute one of the important healthcare interventions to support patients with ALS and their caregivers.
Eye-controlled, power wheelchair performs well for ALS patients	Elliott MA, Malvar H, Maassel LL, Campbell J, Kulkarni H, Spiridonova I, et al.	2019	Power wheelchairs are useful for prolonging mobility in patients with motor diseases. Participants reported a high level of satisfaction with the power wheelchair control system.
Brain computer interface with the P300 speller: Usability for disabled people with amyotrophic lateral sclerosis.	Guy V, Soriani MH, Bruno M, Papadopoulo T, Desnuelle C, Clerc M.	2018	The results of our study demonstrate the usability of the P300 speller by disabled patients with ALS. It may be considered a reliable input method allowing patients with ALS to communicate with their environment.
Quality of life and measures of quality of life in patients with neuromuscular disorders.	Burns TM, Graham CD, Rose MR, Simmons Z.	2012	Form (SF-36) is an example of a generic HRQOL measure that is frequently used in neuromuscular research, with varying success.
Development and testing psychometric properties of an ICF-based health measure: The Neuromuscular Disease Impact Profile	Bos I, Kuks JB, Wynia K.	2015	In clinical practice, especially in multidisciplinary rehabilitation teams, the NMDIP may contribute to better understanding the patients’ health problems when used as an assessment tool.
Patient-Perceived Outcomes and Quality of Life in ALS. Neurotherapeutics	Simmons Z.	2015	Common measures in routine clinical care include limb strength as measured by manual muscle testing or hand-held dynamometry, physical function as measured by the ALS Functional Rating Scale (ALSFRS) and its revised version (ALSFRS-R).

			In the standard clinical ALS care setting, instruments measuring global QOL will provide clinically useful information about the overall self-perceived well-being of a patient as determined by wide-ranging factors including physical, psychological, existential, religious, and financial among others. Such instruments include the WHOQOL-BREF.
Assessment of the factorial validity and reliability of the ALSFRS-R: a revision of its measurement model.	Bakker LA, Schröder CD, van Es MA, Westers P, Visser-Meily JMA, van den Berg LH.	2017	The ALSFRS-R has demonstrated good criterion-related validity, and the inter-rater, intra-rater, and test–retest reliabilities of the ALSFRS-R are excellent. Our study supports the finding that all ALSFRS-R subscales demonstrated acceptable to good internal consistency.
A novel muscle cramp scale (MCS) in amyotrophic lateral sclerosis (ALS).	Mitsumoto H, Chiuzan C, Gilmore M, Zhang Y, Ibagon C, McHale B, et al.	2019	The MCS takes only a few minutes to complete and can be accurately and effectively administered in person or by telephone. Although we still need to confirm the utility and effectiveness of the MCS in future clinical trials, our studies have successfully introduced a novel measure for muscle cramps that is simple, valid, and quick to administer.
Supportive and symptomatic management of amyotrophic lateral sclerosis.	Hobson EV, McDermott CJ.	2016	Promoting evidence-based practice should also reduce the potential for patients to be harmed by using unsafe, untested treatments. As the evidence base for supportive care increases, individual decisions become more complex. In order to participate in shared decision-making, patients and families must be fully and reliably informed about their options.
Amyotrophic lateral sclerosis.	Malik R, Lui A, Lomen-Hoerth C.	2014	Evidence-Based Compensatory or Restorative treatments.
Exercise and amyotrophic lateral sclerosis.	de Almeida JP, Silvestre R, Pinto AC, de Carvalho M.	2012	Despite limited scope, increasing evidence supports physi- cal activity prescription to patients with ALS, which may have a beneficial effect in

			terms of function and mainly a greater impact in quality of life factors such as mood, appetite and sleep. In human studies, evidence suggests that there were small to moderate effect sizes supporting the benefit of moderate exercise in early-stage ALS, with no adverse affects on disease natural course or survival time. Type of exercise should be adapted to the patient condition and needs according to major symptoms and disabilities.
Evaluation and management of amyotrophic lateral sclerosis.	Valadi N.	2015	Multidisciplinary approaches to ALS patient care can help facilitate quality of life, improve outcomes, prognosis, and decrease need for emergency care. A coordinated approach by the primary care physician and neurologist with a focus on multidisciplinary care is necessary to optimize quality of life and meet the patient's needs.
Advance care planning in progressive neurological diseases: lessons from ALS.	Seeber AA, Pols AJ, Hijdra A, Grupstra HF, Willems DL, de Visser M.	2019	Our data contributes to increasing awareness that advance care planning (ACP) is feasible from the ALS diagnosis onwards and may well be implemented in the care of patients with other CPNDs. We have shown that ACP is more than a distinct activity to make well-informed decisions on future treatment options and end-of-life issues.
Palliative Care Issues in Amyotrophic Lateral Sclerosis: An Evidenced-Based Review.	Karam CY, Paganoni S, Joyce N, Carter GT, Bedlack R.	2016	The care of patients with ALS is complex with evidence suggesting it is best done by a multi-disciplinary team led by a neuromuscular-trained ALS specialist.
End-of-life management in patients with amyotrophic lateral sclerosis.	Connolly S, Galvin M, Hardiman O.	2015	Best practice at the end of life. End-of-life discussions and decision making. Advance care directives provide patients with the option to exercise autonomy regarding preferred end-of-life management strategies, but are underused in ALS.
Therapeutic exercise for people with amyotrophic lateral sclerosis or motor	Dal Bello-Haas V, Florence JM.	2013	Well-controlled studies are needed to determine the ideal

neuron disease.			exercise prescription for people with ALS, in terms of both which exercise protocols are most beneficial or cause undue risks, and whether there is a sub-set of people with ALS who respond more positively to exercise, both physically and psychologically.
Treatment for spasticity in amyotrophic lateral sclerosis/motor neuron disease.	Ashworth NL, Satkunam LE, Deforge D.	2012	Further research is needed to determine if exercise is indeed beneficial. Research is also needed to test whether anti-spasticity medication (for example baclofen or dantrolene) is beneficial or causes harm by worsening muscle weakness and function.
Mechanical ventilation for amyotrophic lateral sclerosis/motor neuron disease.	Radunovic A, Annane D, Rafiq MK, Brassington R, Mustfa N.	2017	Future studies should examine the benefits of early intervention with NIV and establish the most appropriate timing for initiating non-invasive ventilation (NIV), in order to obtain its maximum benefit. Future studies should examine the health economics of NIV and factors influencing access to NIV. We need to understand the factors, personal and socioeconomic, that determine access to NIV.
Symptomatic treatments for amyotrophic lateral sclerosis/motor neuron disease.	Ng L, Khan F, Young CA, Galea M.	2017	There is need for: 1. appropriate study designs, robust methodology and longitudinal data which address the changing needs—of people with MND and their caregivers—associated with MND disease progression and mortality. 2. studies to assess the: • effectiveness of interventions on all symptoms relating to MND, including symptoms such as pseudobulbar lability and cognitive and behavioural difficulties;

			• benefits of interventions on quality of life (QoL); • effectiveness of specific interventions (and components), such as: • physical therapy for the treatment of cramps; • drug treatments and stretching for spasticity; • type, intensity, frequency of interventions; and • the cost effectiveness of interventions; • impact of interventions on people with MND and their families; • other factors that affect outcomes (support, adaptive aids and equipment, end-of-life issues) 3. the use of appropriate outcome measures
Correlation of Falls in Patients With Amyotrophic Lateral Sclerosis With Objective Measures of Balance, Strength, and Spasticity.	Schell WE, Mar VS, Da Silva CP.	2019	We believe this study contributes to the body of literature that exists to inform clinicians and the community about functional limitations and safety considerations for individuals with ALS. We hope this study serves as a foundation for future investigations to continue improving outcomes for this vulnerable population.

Additional articles from White Book on Physical and Rehabilitation Medicine (PRM) in Europe from PubMed/MEDLINE and ICF core set:

1. Section of Physical and Rehabilitation Medicine Union Européenne des Médecins Spécialistes (UEMS); European Board of Physical and Rehabilitation Medicine; Academie Européenne de Medicine de Readaptation; European Society for Physical and Rehabilitation Medicine. White book on physical and rehabilitation medicine in Europe. Eura Medicophys 2006;42:292-332.
2. European Physical and Rehabilitation Medicine Bodies Alliance. White Book on Physical and Rehabilitation Medicine (PRM) in Europe. Chapter 1. Definitions and concepts of PRM. Eur J Phys Rehabil Med 2018;54:156-165.
3. European Physical and Rehabilitation Medicine Bodies Alliance. White Book on Physical and Rehabilitation Medicine (PRM) in Europe. Chapter 6. Knowledge and skills of PRM physicians. Eur J Phys Rehabil Med 2018;54:214-229.
4. Bos I, Stallinga HA, Middel B, Kuks JB, Wynia K. Validation of the ICF core set for neuromuscular diseases. Eur J Phys Rehabil Med 2013;49:179-187.
5. Bos I, Kuks JB, Wynia K. Development and testing psychometric properties of an ICF-based health measure: The Neuromuscular Disease Impact Profile. J Rehabil Med 2015;47:445-453.

Grey literature:

1. Organization WH. REHABILITATION in Health Systems. France: World Health Organization; 2017. http://www.who.int/disabilities/rehabilitation_health_systems/en/.
2. https://www.aanem.org/getmedia/1e53beb2-987d-4f06-b091-ebe56148a8b9/Who-is-Qualifed-to-Practice-EDX-2012.pdf
3. Organization WH. International Classification of Functioning, Disability and Health: ICF: World Health Organization. 2001.