APS Australian Psychological Society

Psychological wellbeing and care for people living with Motor Neurone Disease (MND)

Community Resource

Motor Neurone Disease (MND) is a condition that progressively gets worse over time, and sadly, there is no cure. However, treatment and care can help maintain quality of life and manage symptoms. The key is to create a sense of control and independence. A psychologist can help people with MND make decisions about which treatment options they prefer and help improve their quality of life and mental wellbeing.

What is MND?

Motor Neurone Disease (MND) is a group of rare diseases where a persons' nerves are affected, and ultimately leads to death. A person with MND will gradually lose ability to move and control their muscles, which eventually leads to becoming paralysed. People living with MND may feel their arm and leg muscles become weak, and will find it difficult to talk, swallow, eat and breathe. MND can also affect a person's thinking.

Although the speed of progression can vary, these symptoms can get worse very quickly, and people usually live for about 27 months after they have been diagnosed. Most people with MND will eventually stop being able to breathe and pass away 3-4 years after their symptoms start. Some people live longer, and about 10% of people with MND live over 10 years.

MND is not common, and the cause is unknown. MND runs in some families, so genetics may be the cause for about 5-15% of people living with MND. Men are more likely to get MND than women, and MND usually starts when someone is between 50 to 70 years old.

Diagnosis

The symptoms of MND can easily be mistaken for other diseases. Therefore, people are often given the wrong diagnosis, and it usually takes about one year to be correctly diagnosed with MND. People usually have lots of appointments with different health professionals for several months. This experience prior to diagnosis is called "being on a diagnostic roundabout".

Being diagnosed with MND usually happens gradually during several appointments with a neurologist (nerve specialist). Once someone is diagnosed, the news is usually life-changing and devastating.

Impact of MND and the risk of psychological problems

There is no cure for MND, and people living with MND feel a sense of loss, so seeing a psychologist can help them cope. A person with MND faces many physical, social, and financial problems and changes, which can be hard to get used to. When people are diagnosed with MND they may feel angry and frustrated about the long process of being diagnosed, or the way they were given the bad news. It can be helpful to see a psychologist to discuss this and how the diagnosis will impact them.

One of the biggest challenges with MND is the feeling of losing control. Talking with a psychologist and clarifying the results of living with MND can help people accept the condition and plan. This helps people living with MND feel in control, as they can choose which treatment options they prefer. It also helps them feel in control to focus on the present and their personal values, as well as maintain a sense of identity. Feeling in control can help improve mental well-being.

Muscle weakness

People living with MND often report feeling pain. They also lose strength and muscle control, making it difficult to do things like walking, speaking, eating, and breathing. This means people living with MND need to rely on others for help and are often not able to do things they enjoy. This can cause them to feel hopeless and depressed, and sometimes suicidal.

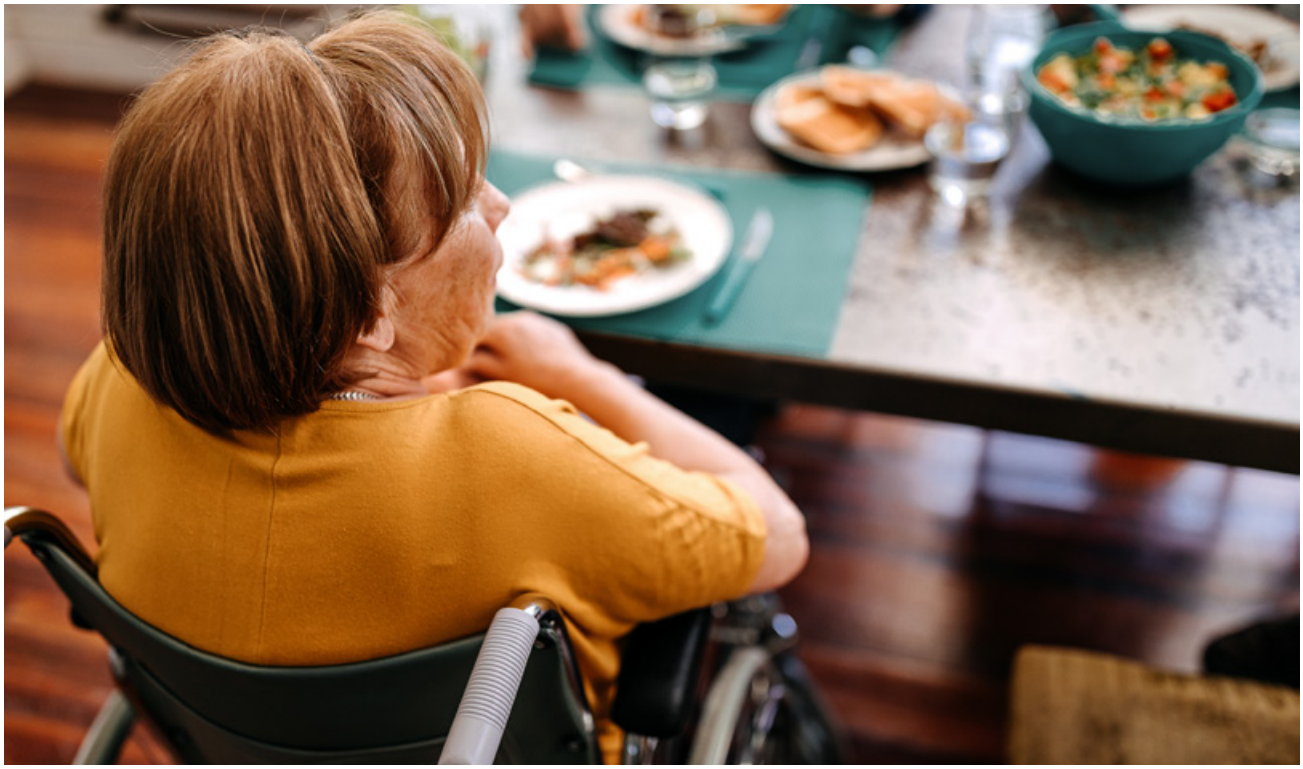
Breathing issues

People living with MND often have shortness of breath, especially when lying down, and hypoventilation (breathing extremely slowly) is common. These symptoms get worse as time goes on. These symptoms can be scary and cause people to feel distressed. Shortness of breath and tiredness are linked with anxiety, which can lead to lower quality of life and feeling depressed.

Psychologists can help people living with MND cope and decrease anxiety, allowing them to enjoy life more. Non-invasive ventilation helps people breathe and live longer, and psychologists can help people be diligent about using it.

Dysphagia (difficulty swallowing) and complications

Most people living with MND have difficulty swallowing (dysphagia) due to their muscles weakening. This causes weight loss, thirstiness, choking and infection in the lungs, which is the main cause of death for people with MND. People with MND are often very afraid of choking. Eating can be stressful as it takes more concentration and time. Food can become seen as fuel to survive and even seem dangerous. One way to help this is to remove social distractions while eating. However, to reduce isolation, it can be helpful if carers sit quietly while the person



with MND is eating. Focusing on the present while eating can help manage the issue of swallowing and reduce stress.

Eventually, people living with MND will need to have surgery to place a feeding tube into the stomach. This is a difficult decision, and people with MND often postpone it as they don't want to lose the option of eating normally. Accepting the reality of the condition sooner means that decision-making can happen faster, although some people living with MND prefer to delay this. Viewing the surgery as something to help maintain life and independence, rather than take this away, helps maintain a sense of control. Speaking to loved ones about these decisions can help improve mental health.

Communication difficulties

Difficulty speaking (dysarthria) is usually one of the first signs of MND and often one of the worst parts of the disease. Speech usually becomes slurred, slow, and hoarse-sounding. Speech loss affects people living with MND's sense of identity, self-consciousness, participation in daily activities, relationships and engagement with health and social care.

People living with MND sometimes use writing or typing when speech is too hard to understand. However, eventually, these options will not be possible when the muscles in the hand get weaker. People living with MND can use ways to communicate, including low-tech options (e.g., gestures, facial expressions, handwriting, topic and alphabet boards, eye-linking systems) or high-tech options (e.g., tablets with voice-banking outputs). These can help the person feel more in control and independent. For further information about these devices, see the MND Connect website.

Many people living with MND can have short outbursts of crying or laughing that can be difficult to control. This can be embarrassing and distressing and may lead people living with MND to isolate.

Neuropsychiatric impairments

People living with MND often experience issues in their thinking, including memory problems and difficulty understanding social situations. They may also lose their energy, become less sensitive to others and more self-focused. These issues might lead to depression and hopelessness.

Sticking to treatment advice can help people living with MND live longer. Changes in thinking and behaviours are linked to previously having a mental health condition, especially disorders like depression and anxiety.

Depression and anxiety among people living with MND

As the progression of the disease is so fast and leads to death, those with MND often suffer from depression and anxiety, which can lead to a higher risk of suicide. Females and younger people with MND are more likely to be depressed. When people first hear the news of the diagnosis or just before this, they are more likely to have symptoms of depression and/or anxiety. A sense of loss of independence is also linked to depression and anxiety.

Decision-making

Psychologists and health care professionals can help people living with MND make decisions about which treatments to use to help manage symptoms. It is important that people living with MND can make their own decisions and have the freedom to choose whether to manage symptoms early on, wait until later, or not use any treatment at all. The benefits of some MND treatments are not very clear, so it is helpful to have a professional to talk to about what is best. It can also be useful to hear from other people living with MND, to discuss the pros and cons of different treatments. A team of health professionals can assist with making decisions about treatment options, end-of-life care, and finances.

It is good to have regular discussions with a psychologist or healthcare professional about options to help with breathing and feeding. These decisions can be emotional, as using interventions can cause people living with MND to feel like they are losing independence, their identity, and normal life.

End-of-life considerations

Due to how fast the illness progresses, it can be helpful to plan ahead about how the symptoms will be managed. This is called advance care planning/yarning (ACP/ACY) and helps the treatment team know the patients' wishes. Talking about end-of-life (palliative) care early can help people living with MND accept the changes and losses they are facing. This also helps people living with MND feel more in-control of their decisions and improves their mental well-being. Some people living with MND do not want to talk about ACP/ACY until later for various reasons, for example, so that they can live in the moment.

People living with MND sometimes wish to hasten death because the symptoms progress so quickly. They might stop wanting treatment or stop eating/drinking. People living with MND are also at higher risk of suicide compared to others who do not have a disease affecting their brain and nervous system. It is common for people to have suicidal thoughts just after being diagnosed and when the symptoms get beyond their ability to cope.

Psychological treatment for people living with MND

Various psychological interventions have been trialled to see whether they help people living with MND. Several of them have been shown to reduce depression and anxiety and improve quality of life. These are some of the psychological interventions that can help people living with MND:

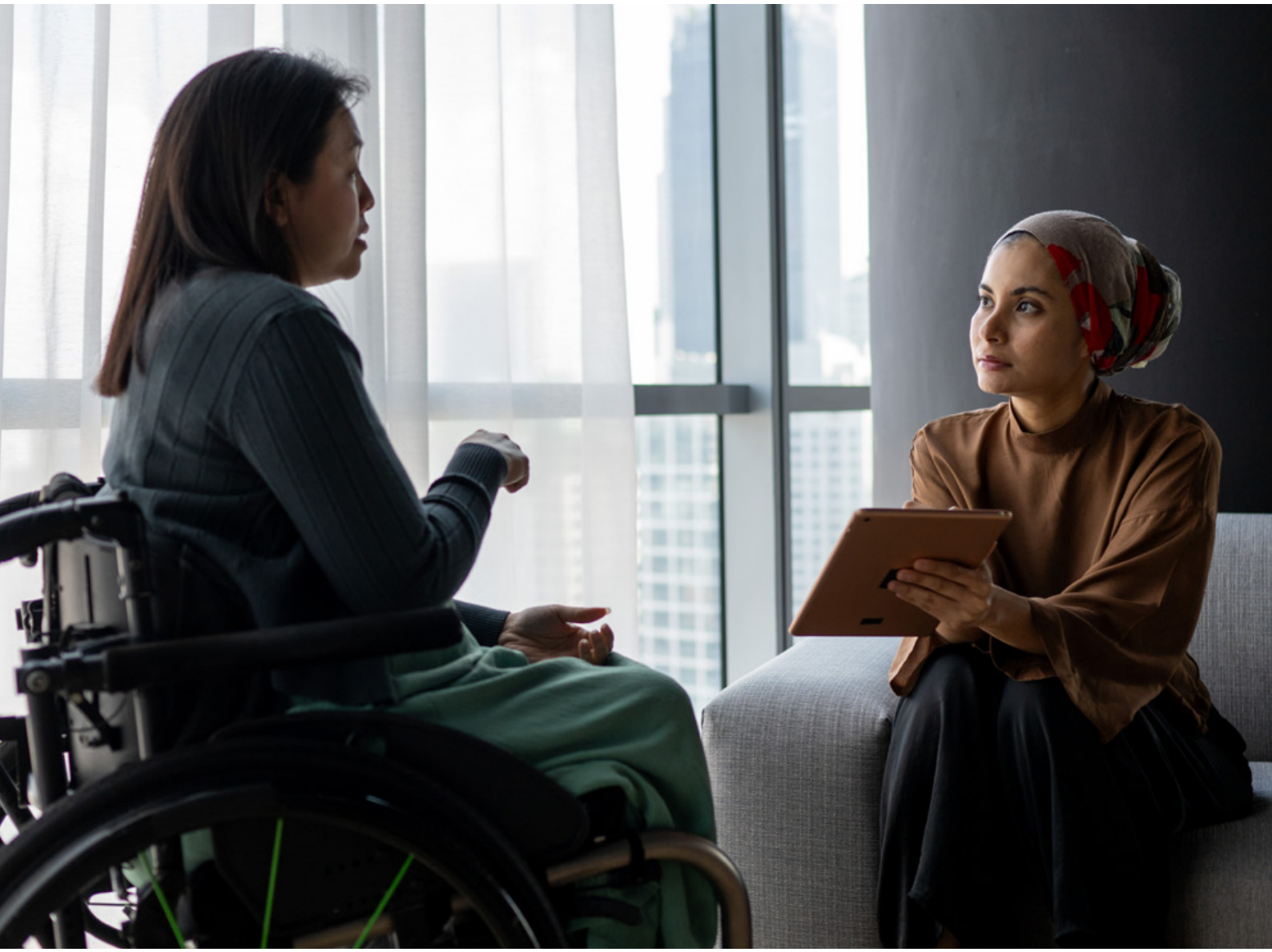
- **MND-tailored Mindfulness-Based Stress Reduction:** This can reduce depression and anxiety and improve quality of life for people living with MND. Meditative training involves focusing on the present moment and managing emotions by accepting them without judgment.
- **Acceptance and Commitment Therapy (ACT):** ACT can help reduce anxiety and depression and improve mental wellbeing. This approach combines acceptance, mindfulness, motivation, and behaviour change techniques. The aim is to decrease unhelpful attempts to control negative thoughts, emotions, physical sensations, and encourage participation in enjoyable activities.
- **Cognitive-behaviour therapy (CBT):** CBT helps people think more helpfully about their situation and choose more helpful behaviours. Studies have shown that it can improve quality of life and reduce depression and anxiety.
- **Psychodynamic hypnosis:** In this therapy, hypnosis is focused on reducing the sense of pain, and improving illness acceptance and ability to cope. An initial trial of this therapy showed that people felt like their pain reduced and sleep improved. This therapy could also help people manage their emotions and reduce anxiety and depression.

- **Dignity Therapy (DT):** This intervention involves creating a document about the patient's life based on a life-reflection interview. Important memories, achievements, and events are discussed to recognise life's dignity and meaning and reduce distress about death.

- **Expressive disclosure:** This involves either writing or speaking about one's deepest thoughts and feelings related to a person's experience with MND. The idea is that expressing rather than withholding stressful events leads to reduced psychological distress. Results have shown that this could help improve mental wellbeing, especially for people living with MND who have difficulty expressing emotions.

Not everyone with MND is the same, and each person may prefer different types of psychological interventions. However, the key factors needed in therapy for people living with MND are:

1. Assist the person to learn skills to manage negative thoughts and emotions
2. Increase personally meaningful behaviour
3. Re-direct the focus to what can be controlled
4. Increase focus on experiences in the present.



More information

MND Australia

MND Australia is the national peak body of state organisations that support people living with MND, their carers and family. MND Australia has a national free call information line 1800 777 175
mndaustralia.org.au

Each state has its own MND Association that provides information and various forms of support for people living with MND, their carers and families. Services include MND Advisors, MND support coordinators, education sessions, health professionals, access to equipment and assistive technologies, and support groups.

These services and their contact details can be found at: mndaustralia.org.au/mnd-connect/find-services/state-mnd-associations

MND Connect

MND Connect provides specialist MND information and resources for people living with MND, their carers and family.
mndaustralia.org.au/mnd-connect

FightMND

FightMND's purpose is to find effective treatments and ultimately a cure for motor neurone disease. FightMND also raises funds to provide various forms of support to people living with MND, their carers and families.
fightmnd.org.au

References

Abdulla, S., Vielhaber, S., Kollewe, K., Machts, J., Heinze, H. J., Dengler, R., & Petri, S. (2014). The impact of physical impairment on emotional well-being in ALS. Amyotroph *Lateral Scler Frontotemporal Degener, 15*(5-6), 392-397. http://dx.doi.org/10.3109/21678421.2014.932380

Aoun, S. M., Chochinov, H. M., & Kristjanson, L. J. (2015). Dignity therapy for people with motor neuron disease and their family caregivers: a feasibility study. *J Palliat Med, 18*(1), 31-37. http://dx.doi.org/10.1089/jpm.2014.0213

Averill, A. J., Kasarskis, E. J., & Segerstrom, S. C. (2013). Expressive disclosure to improve well-being in patients with amyotrophic lateral sclerosis: A randomised, controlled trial. *Psychol Health, 28*(6), 701-713. http://dx.doi.org/10.1080/08870446.2012.754891

Balendra, R., Jones, A., Jivraj, N., Knights, C., Ellis, C. M., Burman, R., Turner, M. R., Leigh, P. N., Shaw, C. E., & Al-Chalabi, A. (2014). Estimating clinical stage of amyotrophic lateral sclerosis from the ALS Functional Rating Scale. *Amyotrophic lateral sclerosis & frontotemporal degeneration*, *15*(3-4), 279–284. https://doi.org/10.3109/21678421.2014.897357

Baumrucker, S. J., Stolick, M., Carter, G. T., Mingle, P., Oertli, K. A., & Morris, G. M. (2011). Legal but not always allowed: "Physician aid in dying". *Am J Hosp Palliat Care, 28*(6), 449-454. http://dx.doi.org/10.1177/1049909111412540

Bentley, B., O'Connor, M., Kane, R., & Breen, L. J. (2014). Feasibility, acceptability, and potential effectiveness of dignity therapy for people with motor neurone disease. *PLoS One, 9*(5), e96888. http://dx.doi.org/10.1371/journal.pone.0096888

Berlowitz, D. J., Mathers, S., Hutchinson, K., Hogden, A., Carey, K. A., Graco, M., Whelan, B. M., Charania, S., Steyn, F., Allcroft, P., Crook, A., & Sheers, N. L. (2023). The complexity of multidisciplinary respiratory care in amyotrophic lateral sclerosis. *Breathe (Sheffield, England)*, *19*(3), 220269. https://doi.org/10.1183/20734735.0269-2022

Bond, L., Bowen, G., Mertens, B., Denson, K., Jordan, K., Vidakovic, B., & Mitchell, C. S. (2020). Associations of patient mood, modulators of quality of life, and pharmaceuticals with amyotrophic lateral sclerosis survival duration. *Behav Sci (Basel), 10*(1). http://dx.doi.org/10.3390/bs10010033

Brownlee, A., & Bruening, L. M. (2012). Methods of communication at end of life for the person with amyotrophic lateral sclerosis. *Topics in Language Disorders, 32*, 168–185.

Caga, J., Hsieh, S., Lillo, P., Dudley, K., & Mioshi, E. (2019). the impact of cognitive and behavioral symptoms on ALS patients and their caregivers. *Front Neurol, 10*, 192. http://dx.doi.org/10.3389/fneur.2019.00192

Castanheira, A., Swash, M., & De Carvalho, M. (2022). Percutaneous gastrostomy in amyotrophic lateral sclerosis: A review. *Amyotroph Lateral Scler Frontotemporal Degener, 23*(3-4), 176-189. http://dx.doi.org/10.1080/21678421.2021.1946089

Chamberlain, P. I. (2014). An assisted dying law might save me from a lingering and unpleasant death. *BMJ, 349*, g4784. http://dx.doi.org/10.1136/bmj.g4784

Diaz, J. L., Sancho, J., Barreto, P., Banuls, P., Renovell, M., & Servera, E. (2016). Effect of a short-term psychological intervention on the anxiety and depression of amyotrophic lateral sclerosis patients. *J Health Psychol, 21*(7), 1426-1435. http://dx.doi.org/10.1177/1359105314554819

Diver, E. M., & Regan, J. (2022). Use of pharyngeal high-resolution manometry to evaluate dysphagia in adults with motor neurone disease: A Scoping Review. *Dysphagia, 37*(6), 1697-1714. http://dx.doi.org/10.1007/s00455-022-10418-4

Edge, R., Mills, R., Tennant, A., Diggle, P. J., Young, C. A., & TONiC study group (2020). Do pain, anxiety and depression influence quality of life for people with amyotrophic lateral sclerosis/motor neuron disease? A national study reconciling previous conflicting literature. *Journal of neurology*, *267*(3), 607–615. https://doi.org/10.1007/s00415-019-09615-3

EFNS Task Force on Diagnosis and Management of Amyotrophic Lateral Sclerosis:, Andersen, P. M., Abrahams, S., Borasio, G. D., de Carvalho, M., Chio, A., Van Damme, P., Hardiman, O., Kollewe, K., Morrison, K. E., Petri, S., Pradat, P. F., Silani, V., Tomik, B., Wasner, M., & Weber, M. (2012). EFNS guidelines on the clinical management of amyotrophic lateral sclerosis (MALS)--revised report of an EFNS task force. *European Journal of Neurology*, *19*(3), 360–375. https://doi.org/10.1111/j.1468-1331.2011.03501.x

Erdmann, A., Spoden, C., Hirschberg, I., & Neitzke, G. (2022). Talking about the end of life: Communication patterns in amyotrophic lateral sclerosis - A scoping review. *Palliat Care Soc Pract, 16*, 26323524221083676. http://dx.doi.org/10.1177/26323524221083676

Fang, F., Valdimarsdottir, U., Furst, C. J., Hultman, C., Fall, K., Sparen, P., & Ye, W. (2008). Suicide among patients with amyotrophic lateral sclerosis. *Brain, 131*(Pt 10), 2729-2733. http://dx.doi.org/10.1093/brain/awn161

Felgoise, S. H., Zaccheo, V., Duff, J., & Simmons, Z. (2016). Verbal communication impacts quality of life in patients with amyotrophic lateral sclerosis. *Amyotroph Lateral Scler Frontotemporal Degener, 17*(3-4), 179-183. http://dx.doi.org/10.3109/21678421.2015.112549998

Fight MND. (2018). https://fightmnd. org.au/

Flemming, K., Turner, V., Bolsher, S., Hulme, B., McHugh, E., & Watt, I. (2020). The experiences of, and need for, palliative care for people with motor neurone disease and their informal caregivers: A qualitative systematic review. *Palliat Med, 34*(6), 708-730. http://dx.doi.org/10.1177/0269216320908775

Gale, C. (2015). Assisting patients with motor neurone disease to make decisions about their care. *Int J Palliat Nurs, 21*(5), 251-255. http://dx.doi.org/10.12968/ijpn.2015.21.5.251

Ganzini, L., Johnston, W. S., & Hoffman, W. F. (1999). Correlates of suffering in amyotrophic lateral sclerosis. *Neurology, 52*(7), 1434-1440. http://dx.doi.org/10.1212/wnl.52.7.1434

Ganzini, L., Johnston, W. S., McFarland, B. H., Tolle, S. W., & Lee, M. A. (1998). Attitudes of patients with amyotrophic lateral sclerosis and their care givers toward assisted suicide. *N Engl J Med, 339*(14), 967-973. http://dx.doi.org/10.1056/NEJM199810013391406

Glennie, N., Harris, F. M., & France, E. F. (2023). Perceptions and experiences of control among people living with motor neurone disease: A systematic review and thematic synthesis. *Disabil Rehabil, 45*(16), 2554-2566. http://dx.doi.org/10.1080/0963 8288.2022.2104942

Global Burden of Disease Motor Neuron Disease Collaborators. (2018). Global, regional, and national burden of motor neuron diseases 1990-2016: A systematic analysis for the Global Burden of Disease Study 2016. *Lancet Neurol, 17*(12), 1083- 1097. http://dx.doi.org/10.1016/S1474- 4422(18)30404-6

Gould, R. L., Rawlinson, C., Thompson, B., Weeks, K., Gossage-Worrall, R., Cantrill, H., Serfaty, M. A., Graham, C. D., McCracken, L. M., White, D., Howard, R. J., Bursnall, M., Bradburn, M., Al-Chalabi, A., Orrell, R., Chhetri, S. K., Noad, R., Radunovic, A., Williams, T., Young, C. A., ... and the COMMEND Collaboration Group (2023). Acceptance and Commitment Therapy for people living with motor neuron disease: an uncontrolled feasibility study. *Pilot and feasibility studies*, *9*(1), 116. https://doi.org/10.1186/s40814-023-01354-7

Goutman, S. A. (2017). Diagnosis and clinical management of amyotrophic lateral sclerosis and other motor neuron disorders. *Continuum (Minneap Minn), 23*(5, Peripheral Nerve and Motor Neuron Disorders), 1332-1359. http://dx.doi.org/10.1212/CON.0000000000000535

Gysels, M. H., & Higginson, I. J. (2011). The lived experience of breathlessness and its implications for care: a qualitative comparison in cancer, COPD, heart failure and MND. *BMC Palliat Care, 10*, 15. http://dx.doi.org/10.1186/1472-684X-10-15

Hecht, M., Hillemacher, T., Gräsel, E., Tigges, S., Winterholler, M., Heuss, D., Hilz, M. J., & Neundörfer, B. (2002). Subjective experience and coping in ALS. *Amyotrophic lateral sclerosis and other motor neuron disorders: Official publication of the World Federation of Neurology, Research Group on Motor Neuron Diseases*, *3*(4), 225–231. https://doi.org/10.1080/146608202760839009

Hogden, A., Greenfield, D., Caga, J., & Cai, X. (2016). Development of patient decision support tools for motor neuron disease using stakeholder consultation: A study protocol. *BMJ Open, 6*(4), e010532. http://dx.doi.org/10.1136/bmjopen-2015-010532

Johnson, J., Leigh, P. N., Shaw, C. E., Ellis, C., Burman, R., & Al-Chalabi, A. (2012). Eating-derived pleasure in amyotrophic lateral sclerosis as a predictor of non-oral feeding. *Amyotroph Lateral Scler, 13*(6), 555-559. http://dx.doi.org/10.3109/174829 68.2012.704925

Khin Khin, E., Minor, D., Holloway, A., & Pelleg, A. (2015). Decisional capacity in amyotrophic lateral sclerosis. *J Am Acad Psychiatry Law, 43*(2), 210-217.

Kleinbub, J. R., Palmieri, A., Broggio, A., Pagnini, F., Benelli, E., Sambin, M., & Soraru, G. (2015). Hypnosis-based psychodynamic treatment in ALS: A longitudinal study on patients and their caregivers. *Front Psychol, 6*, 822. http://dx.doi.org/10.3389/fpsyg.2015.00822

Labra, J., Hogden, A., Power, E., James, N., & Flood, V. M. (2020). Gastrostomy uptake in motor neurone disease: A mixedmethods study of patients' decision making. *BMJ Open, 10*(2), e034751. http://dx.doi.org/10.1136/bmjopen-2019-034751

Leite Neto, L., & Constantini, A. (2017). Dysarthria and quality of life in patients with amyotrophic lateral sclerosis. *Revista CEFAC, 19*(5), 664-673. http://dx.doi.org/10.1590/1982-02162017195401792

Levi, B. H., Simmons, Z., Hanna, C., Brothers, A., Lehman, E., Farace, E., Bain, M., Stewart, R., & Green, M. J. (2017). Advance care planning for patients with amyotrophic lateral sclerosis. *Amyotrophic Lateral Sclerosis & Frontotemporal Degeneration*, *18*(5-6), 388–396. https://doi.org/10.1080/21678421.2017.1285317

Linse, K., Aust, E., Joos, M., & Hermann, A. (2018). Communication matters-pitfalls and promise of hightech communication devices in palliative care of severely physically disabled patients with amyotrophic lateral sclerosis. *Front Neurol*, 9, 603. http://dx.doi.org/10.3389/fneur.2018.00603

Lisiecka, D., Kelly, H., & Jackson, J. (2021). How do people with Motor Neurone Disease experience dysphagia? A qualitative investigation of personal experiences. *Disabil Rehabil, 43*(4), 479-488. http://dx.doi.org/10.1080/09638288.2019.1630487

Londral, A. (2022). Assistive technologies for communication empower patients with ALS to generate and self-report health data. *Front Neurol, 13*, 867567. http://dx.doi.org/10.3389/fneur.2022.86756799

Longinetti, E., & Fang, F. (2019). Epidemiology of amyotrophic lateral sclerosis: An update of recent literature. *Curr Opin Neurol, 32*(5), 771-776. http://dx.doi.org/10.1097/

Luker, J., Woodman, R., & Schultz, D. (2023). The incidence and prevalence of motor neurone disease in South Australia. *Amyotroph Lateral Scler Frontotemporal Degener, 24*(3-4), 195-202. http://dx.doi.or g/10.1080/21678421.2022.2108326

Marconi, A., Gragnano, G., Lunetta, C., Gatto, R., Fabiani, V., Tagliaferri, A., Rossi, G., Sansone, V., & Pagnini, F. (2016). The experience of meditation for people with amyotrophic lateral sclerosis and their caregivers - a qualitative analysis. *Psychology, health & medicine*, *21*(6), 762–768. https://doi.org/10.1080/13548506.2015.1115110

Marin, B., Fontana, A., Arcuti, S., Copetti, M., Boumédiene, F., Couratier, P., Beghi, E., Preux, P. M., & Logroscino, G. (2018). Age-specific ALS incidence: a dose-response meta-analysis. *European journal of epidemiology*, *33*(7), 621–634. https://doi.org/10.1007/s10654-018-0392-x

Masrori, P., & Van Damme, P. (2020). Amyotrophic lateral sclerosis: A clinical review. *Eur J Neurol, 27*(10), 1918-1929. http://dx.doi.org/10.1111/ene.14393

McHutchison, C. A., Leighton, D. J., McIntosh, A., Cleary, E., Warner, J., Porteous, M., Chandran, S., Pal, S., & Abrahams, S. (2020). Relationship between neuropsychiatric disorders and cognitive and behavioural change in MND. *Journal of Neurology, Neurosurgery, and Psychiatry*, *91*(3), 245–253. https://doi.org/10.1136/jnnp-2019-321737

MND Australia. (2024). https://www.mndaustralia.org.au/

MND Connect. (2024). https://www.mndaustralia.org.au/mnd-connect

Morélot-Panzini, C., Perez, T., Sedkaoui, K., de Bock, E., Aguilaniu, B., Devillier, P., Pignier, C., Arnould, B., Bruneteau, G., & Similowski, T. (2018). The multidimensional nature of dyspnoea in amyotrophic lateral sclerosis patients with chronic respiratory failure: Air hunger, anxiety and fear. *Respiratory medicine*, *145*, 1–7. https://doi.org/10.1016/j.rmed.2018.10.010

National Institute for Clinical Excellence. (2016). *Motor neurone disease: Assessment and management*. London: NICE Guideline [NG42] (updated 2019).

Niedermeyer, S., Murn, M., & Choi, P. J. (2019). Respiratory failure in amyotrophic lateral sclerosis. *Chest, 155*(2), 401-408. http://dx.doi.org/10.1016/j. chest.2018.06.035

Oberstadt, M. C. F., Esser, P., Classen, J., & Mehnert, A. (2018). Alleviation of psychological distress and the improvement of quality of life in patients with amyotrophic lateral sclerosis: Adaptation of a short-term psychotherapeutic intervention. *Front Neurol, 9,* 231. http://dx.doi.org/10.3389/fneur.2018.00231

Oh, J., An, J., & Park, K. (2021). Coping in people with amyotrophic lateral sclerosis and motor neuron disease: Systematic review. *J Clin Nurs, 30*(13-14), 1838-1853. http://dx.doi.org/10.1111/jocn.15692

Oh, J., & Kim, J. A. (2017). Supportive care needs of patients with amyotrophic lateral sclerosis/motor neuron disease and their caregivers: A scoping review. *J Clin Nurs, 26*(23-24), 4129-4152. http://dx.doi.org/10.1111/jocn.13945

Pagnini, F., Marconi, A., Tagliaferri, A., Manzoni, G. M., Gatto, R., Fabiani, V., Gragnano, G., Rossi, G., Volpato, E., Banfi, P., Palmieri, A., Graziano, F., Castelnuovo, G., Corbo, M., Molinari, E., Riva, N., Sansone, V., & Lunetta, C. (2017). Meditation training for people with amyotrophic lateral sclerosis: a randomized clinical trial. *European Journal of Neurology*, *24*(4), 578–586. https://doi.org/10.1111/ene.13246

Palmieri, A., Kleinbub, J. R., Calvo, V., Soraru, G., Grasso, I., Messina, I., & Sambin, M. (2012). Efficacy of hypnosis-based treatment in amyotrophic lateral sclerosis: A pilot study. *Front Psychol, 3*, 465. http://dx.doi.org/10.3389/fpsyg.2012.00465

Park, J., Kim, J. E., & Song, T. J. (2022). The global burden of motor neuron disease: An analysis of the 2019 Global Burden of Disease Study. *Front Neurol, 13*, 864339. http://dx.doi.org/10.3389/fneur.2022.864339

Pavey, A., Allen-Collinson, J., & Pavey, T. (2013). The lived experience of diagnosis delivery in motor neurone disease: A sociological-phenomenological study. *Sociological Research Online, 18*(2), 36-47. http://dx.doi.org/10.5153/sro.2927

Paynter, C., Cruice, M., Mathers, S., Gregory, H., & Vogel, A. P. (2019). Communication and cognitive impairments and health care decision making in MND: A narrative review. *Journal of Evaluation in Clinical Practice, 25*(6), 1182-1192. http://dx.doi.org/https://doi.org/10.1111/jep.13219

Paynter, C., Mathers, S., Gregory, H., Vogel, A. P., & Cruice, M. (2022). The impact of communication on healthcare involvement for people living with motor neurone disease and their carers: A longitudinal qualitative study. *Int J Lang Commun Disord, 57*(6), 1318-1333. http://dx.doi.org/10.1111/1460-6984.12757

Pizzimenti, A., Aragona, M., Onesti, E., & Inghilleri, M. (2013). Depression, pain and quality of life in patients with amyotrophic lateral sclerosis: A cross-sectional study. *Funct Neurol, 28*(2), 115-119. http://dx.doi.org/10.11138/FNeur/2013.28.2.115

Plahuta, J. M., McCulloch, B. J., Kasarskis, E. J., Ross, M. A., Walter, R. A., & McDonald, E. R. (2002). Amyotrophic lateral sclerosis and hopelessness: Psychosocial factors. *Soc Sci Med, 55*(12), 2131-2140. http://dx.doi.org/10.1016/s0277-9536(01)00356-2

Ryan, M., Heverin, M., McLaughlin, R. L., & Hardiman, O. (2019). Lifetime risk and heritability of amyotrophic lateral sclerosis. *JAMA Neurol, 76*(11), 1367-1374. http://dx.doi.org/10.1001/jamaneurol.2019.2044

Stavroulakis, T., Baird, W. O., Baxter, S. K., Walsh, T., Shaw, P. J., & McDermott, C. J. (2014). Factors influencing decisionmaking in relation to timing of gastrostomy insertion in patients with motor neurone disease. *BMJ Support Palliat Care, 4*(1), 57-63. http://dx.doi.org/10.1136/bmjspcare-2013-000497

Tomik, B., & Guiloff, R. J. (2010). Dysarthria in amyotrophic lateral sclerosis: A review. *Amyotroph Lateral Scler, 11*(1-2), 4-15. http://dx.doi.org/10.3109/17482960802379004 93

Tomik, J., Tomik, B., Wiatr, M., Skladzien, J., Strek, P., & Szczudlik, A. (2015). The Evaluation of Abnormal Voice Qualities in Patients with Amyotrophic Lateral Sclerosis. *Neurodegener Dis, 15*(4), 225- 232. http://dx.doi.org/10.1159/000381956 94.

Tripodoro, V. A., & De Vito, E. L. (2008). Management of dyspnea in advanced motor neuron diseases. *Curr Opin Support Palliat Care, 2*(3), 173-179. http://dx.doi.org/10.1097/SPC.0b013e32830c9049

van Eenennaam, R. M., Koppenol, L. S., Kruithof, W. J., Kruitwagen-van Reenen, E. T., Pieters, S., van Es, M. A., van den Berg, L. H., Visser-Meily, J. M. A., & Beelen, A. (2021). Discussing Personalized Prognosis Empowers Patients with Amyotrophic Lateral Sclerosis to Regain Control over Their Future: A Qualitative Study. *Brain sciences*, *11*(12), 1597. https://doi.org/10.3390/brainsci11121597

van Eenennaam, R. M., Rave, N., Kruithof, W. J., Kruitwagen-van Reenen, E. T., van den Berg, L. H., Visser-Meily, J. A., & Beelen, A. (2023). Control in the absence of choice: A qualitative study on decisionmaking about gastrostomy in people with amyotrophic lateral sclerosis, caregivers, and healthcare professionals. *PLoS One, 18*(9), e0290508. http://dx.doi.org/10.1371/journal.pone.0290508

van Es, M. A., Hardiman, O., Chio, A., AlChalabi, A., Pasterkamp, R. J., Veldink, J. H., & van den Berg, L. H. (2017). Amyotrophic lateral sclerosis. *Lancet, 390*(10107), 2084-2098. http://dx.doi.org/10.1016/S0140-6736(17)31287-4

van Groenestijn, A. C., Kruitwagen-van Reenen, E. T., Visser-Meily, J. M., van den Berg, L. H., & Schroder, C. D. (2016). Associations between psychological factors and health-related quality of life and global quality of life in patients with ALS: A systematic review. *Health Qual Life Outcomes, 14*(1), 107. http://dx.doi.org/10.1186/s12955-016-0507-6

van Groenestijn, A. C., Schroder, C. D., Visser-Meily, J. M., Reenen, E. T., Veldink, J. H., & van den Berg, L. H. (2015). Cognitive behavioural therapy and quality of life in psychologically distressed patients with amyotrophic lateral sclerosis and their caregivers: Results of a prematurely stopped randomized controlled trial. *Amyotroph Lateral Scler Frontotemporal Degener, 16*(5-6), 309-315. http://dx.doi.org/10.3109/21678421.2015.1038276

Weeks, K. R., Gould, R. L., Mcdermott, C., Lynch, J., Goldstein, L. H., Graham, C. D., McCracken, L., Serfaty, M., Howard, R., Al-Chalabi, A., White, D., Bradburn, M., Young, T., Cooper, C., Shaw, D. P. J., & Lawrence, V. (2019). Needs and preferences for psychological interventions of people with motor neuron disease. *Amyotrophic Lateral Sclerosis & Frontotemporal Degeneration*, *20*(7-8), 521–531. https://doi.org/10.1080/21678421.2019.1621344

Young, C. A., Ealing, J., McDermott, C., Williams, T., Al-Chalabi, A., Majeed, T., Burke, G., Pinto, A., Dick, D., Talbot, K., Harrower, T., Walsh, J., Chandran, S., Hanemann, C. O., Mills, R., & Tennant, A. (2019). The relationships between symptoms, disability, perceived health and quality of life in amyotrophic lateral sclerosis/motor neuron disease. *Amyotrophic Lateral Sclerosis & Frontotemporal Degeneration*, *20*(5-6), 317–327. https://doi.org/10.1080/21678421.2019.1615951

Young, C., Ealing, J., McDermott, C., Williams, T., Al-Chalabi, A., Majeed, T., Roberts, R., Mills, R., Tennant, A., & Tonic Study Group (2022). Fatigue and anxiety mediate the effect of dyspnea on quality of life in amyotrophic lateral sclerosis. *Amyotrophic Lateral Sclerosis & Frontotemporal Degeneration*, *23*(5-6), 390–398. https://doi.org/10.1080/21678421.2021.1990343

Young, C. A., Ealing, J., McDermott, C. J., Williams, T. L., Al-Chalabi, A., Majeed, T., Talbot, K., Harrower, T., Faull, C., Malaspina, A., Annadale, J., Mills, R. J., Tennant, A., & Tonic Study Group (2023). Prevalence of depression in amyotrophic lateral sclerosis/motor neuron disease: multi-attribute ascertainment and trajectories over 30 months. *Amyotrophic Lateral Sclerosis & Frontotemporal Degeneration*, *24*(1-2), 82–90. https://doi.org/10.1080/21678421.2022.2096410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