Allied Professionals Forum

Program Book

2022

INTERNATIONAL ALLIANCE
OF ALS/MND ASSOCIATIONS

ALS/MND Connect

Presenters: Phil Green, Eugene Brandon, Dr. Caroline Ingre, Dr. Angela Genge & Dr. Colleen O´Connell

ALS/MND Connect is an open session which allows people living with ALS/MND and their caregivers to attend an afternoon of presentations by neurologists and researchers. This session is live-streamed on Facebook, so people with ALS/MND from around the world can attend and ask questions online.

Keynote: The Right to a Quality of Life

Presenter: Dr. Colleen O´Connell

Ultimately, our goal is to end ALS; until then people with ALS and their families must continue to live despite the disease. For most, this means that in addition to fighting the disease, they must also fight for the essential needs to be mobile, to communicate, to breathe. This is not right. It should not be a fight to access necessary equipment such as specialized mobility aids, or services such as multi disciplinary care, counselling and home support. Rehabilitation is an essential health service, yet these needs of persons with ALS are typically undervalued or unavailable in health systems. The pandemic saw rehabilitation services interrupted more than any other area of care, and persons living with ALS lost access to care workers, therapies and equipment, while fearing a deprioritization for emergency care during the crises. Globally, support for essential rehabilitation needs are lacking; no one should have to choose between bankruptcy or breathing. No one should be told they are either too disabled, or not disabled enough.

This session will promote the concept of rehabilitation as an essential health service, from emergency planning such as during a pandemic to full access in communities so persons can live a dignified quality life despite a diagnosis of ALS/MND.

Panel: History and evolution of multidisciplinary care

Presenters: Dr. David Taylor, Dr. Orla Hardiman & Dr. Terry Heiman-Patterson, Sara Feldman & Rachael Marsden

This panel will take us through a journey to understand how multi-disciplinary care has evolved in ALS/MND, why some regions have been slow in adopting this model of care, changes over time, current hurdles and what the future looks like. Not to be missed!

One year later, an update on My ALS Decision Tool™ and information guides

Presenter: Anne Marie Doyle

Since ALS/MND progresses differently for everyone, it's important that people diagnosed with ALS/MND receive clear and relevant information early in their diagnosis so they can find a treatment plan that works for them. My ALS Decision Tool™ provides a more personalized approach and empowers people living with ALS/MND to make early and informed decisions about their care, which can contribute to improved health outcomes. Over the last year, feedback from the ALS/MND community provided guidance and future direction of the development of new resources.

"Positive Tiredness": A Concept to challenge fatigue management for people with ALS/MND

Presenter: Helen Carey

Occupational therapists consider fatigue management as a fundamental intervention. This study demonstrates that excessive focus upon fatigue management for people with mild/moderate symptomatology ALS/ MND, can potentially decondition and reduce function. A multiple case study design which delivered a six week period of rehabilitation for people with ALS/MND found there was a direct correlation between participant improvement of performance and their satisfaction of performance, and their level of doing. In addition, their perception of tiredness changed during the study. Tiredness was perceived as a positive experience and linked to accomplishment and aspiration. The objectives of this session is to: Identify how enabling “positive tiredness” for people with ALS/MND can have positive impact in functional ability. Illustrate the potential of fatigue management education and techniques in deconditioning for people with ALS/MND. Challenge the predominance of fatigue management as an intervention. This presentation aims to initiative lively debate to the concept of utilizing positive tiredness in interventions for people with ALS/MND rather than educating people with ALS/MND in fatigue management.

Using and creating educational resources for families

Presenter: David Meissner & Kim Hughes

Our new ALS Home & Daily Living Guide aims to help families navigate activities of daily living and experience a better quality of life. After introducing this free online resource, we will share Your ALS Guide’s behind-the-scenes content development process and offer practical tips that can help you create effective educational resources for the families you serve.

The wheelchair alliance

Presenter: Nick Goldup

The Wheelchair Alliance is a group of volunteers committed to the guidance and empowerment of those who use a wheelchair, their families and carers in the UK, working hard to ensure the right voices are heard by the right people, and drive forward lasting positive change. Nick Goldup is the Chair of the Alliance in in this session will introduce the work of the Alliance and their aims and ambitions.

Establishing a neuro-palliative care clinic in the hospital setting: lessons learnt for ALS care

Presenter: Gargi S Kumar

There is growing interest in the application of palliative care principles to improve the care for patients and families affected by neurological diseases, including ALS. Family being the cornerstone of care in India, the care models should ideally be tailor-made to provide care support for home-based care. Palliative care needs of people with ALS and families that can and should be addressed in an outpatient setting include discussing goals of care, caregiver support, complex symptom management, working with difficult emotions and referral to other disciplines. From December 2021 till date, 210 patients with ALS and caregivers have been supported through the clinic. Common referral reasons to neuro-palliative clinic include psycho social support, symptom management, financial assistance and advance care planning. The care is continued through phone follow ups and home care visits on need basis. Educational initiatives are needed to train general neurologists and other allied health professionals in primary palliative care.

Augmentative and alternative communication (ACC): the AISLA model for evaluating and providing devices in Italy.

Presenter: Prof. Massimiliano Filosto
Co-Authors: Giordana Donvito, Stefania Bastianello, Amelia Conte & Riccardo Zuccarino

Communicating is an essential need for all the people. Through communication everyone expresses himself and enters into relationship with others. People with ALS have motor speech disorder (dysarthria), but a global loss of communication can be related to several issues i.e. weakness of upper limbs, respiratory failure with necessity of mechanical ventilation support and, eventually, locked-in syndrome. In managing ALS patients, it is critical to provide appropriate devices for augmentative and alternative communication (ACC) which may improve quality of life, assist with decision making and avoid social isolation. Different ACC devices, including no-technology, low-technology and high-technology ones, are available to date. A comprehensive evaluation of residual speech and motor, respiratory and cognitive skills of ALS patients is essential as well as knowing home environment and early defining communication needs. AISLA proposes a national model to supply ACC devices to Italian ALS people, including the following phases: definition of communication needs followed by identification, testing, prescription and dispensing an ACC device. It is recommended that the device testing takes place at home or in a care setting within one month of the first evaluation and different types of ACC systems should be tested. ACC device is provided by national care service for free within one month of prescription. Six-monthly reassessment of the supplied CAA device is suggested in order to verify the use of the tool (including withdrawing the device if not used), adapt the system to disease progression and provide technology update. The AISLA model for evaluation and supply of ACC devices aims to guarantee all SLA patients equal access to communication systems, reduce the time to obtain them and create a monitoring path to avoid the waste of health economic resources (also providing the recycling devices).

ALS Canada support group model

Presenter: Kim Barry

During COVID 19, our organization has restructed our support group model. We have have created a provinical model that we are able to provide virtual support along with our other tools such as home visits, education sessions and webinars to allow us to meet the needs of those dealing with a ALS diagnosis. During this time we have seen a increase of 250% in attendance in the new model in just over a year. Our team has created a sustianable program for our staff to supporting clients, caregivers, and also in 2022 a bereavement program. The staff lead program has created a screening tool for intake and a both faciliator handbooks for those curently living with ALS and those who managing the bereavement program.

How to break the news in ALS/MND

Presenters: Dr. Angela Genge, Dr. Melinda Kavanaugh, Dr. Colleen O´Connell & Cathy Cummings

Research has shown that the manner in which an ALS/MND diagnosis is delivered is a source of discontent for many people living with the disease and their caregivers. This is not surprising given that conveying sensitive news to patients is an arduous and emotionally challenging task for healthcare professionals (HCPs), which many feel ill prepared for given the lack of medical training curricula devoted to this area. How to Break the News in ALS/MND: A Primer for Physicians and Allied Health Professionals has been designed to improve HCP comfort and confidence in this task by providing them with the skills required to deliver challenging news effectively. The program centers around the A–L S–PIKES protocol which uses well-established principles of communication and counselling that are aimed at improving patient quality of life and promoting the well-being of HCPs involved in the care and management of people living with ALS/MND.

Developing a web resource on experiences of inherited MND for patients, families and healthcare professionals

Presenter: Jade Howard

This session presents a new resource on inherited MND/ familial ALS, published in June 2022 on the award-winning patient experience website healthtalk.org. Based on a qualitative interview study with individuals from across the UK, this offers a lasting source of information and support to patients, families and healthcare professionals.

Making sense: An online meaning centred psychological intervention for individuals with MND

Presenter: Sandra De Moree

Being diagnosed with a terminal illness such as MND (ALS and PMA) is shocking and deeply affects one's personal existence and identity. Stress and dysphoria often follow the diagnosis, with some adapting quickly and finding a new balance, while others struggle to come to terms with the diagnosis and continue experiencing high levels of emotional distress.

We have adapted the Dutch group protocol for the purpose of such an online approach specifically for individuals diagnosed with ALS or PMA patients and this resulted in the Making Sense training.

Mitigating stressors through building systems of support for children and young adults impacted by ALS

Presenter: Lily Cola

In 2018, the American Psychological Association (APA) conducted its 12th annual Stress in America survey to understand the external stressors that are faced by children, young, and older adults. Over half of the participants felt that they needed more emotional support. External and internal stressors are continuously changing from individual to individual especially those faced with caring for a loved one who has ALS. When examining these results, the one thing that we shouldn't lose sight of is our next generation and how to strengthen support for them. These youth are desperately seeking to keep a legacy alive while supporting efforts to finding a cure for ALS. By forming additional support groups within school systems, ALS Association Chapters, non-profit organizations who support ALS, and educating more on coping techniques to help self-regulate will offer a safe landing space for these youth. This presentation will focus on strategies and provide the audience with tools to help support our youth and young adults who are affected by ALS while working towards building a stronger support system for them.

E-Learning on palliative and end-of-life care in ALS for all caregivers accompanying ALS patients in Belgium

Presenter: Liesbet Casier

The rapidly progressive nature of ALS and the high need for care make starting the conversation about palliative care timely crucial so that the patient and their loved ones can consider the end-of-life care. However, experience has taught us that palliative care is often avoided by patients, their relatives and caregivers. As a result, medical decisions often have to be made quickly, especially in cases of urgency. Sometimes there is not even a conversation, so that the patient’s wishes cannot be recorded and respected, there is inadequate symptom control and a lack of psychosocial and spiritual support, resulting in a lower quality of life. With the creation of this e-learning we aim at breaking through the taboo still shrouding palliative care. It is, today, still associated to strongly with terminal care which often leads people to defer from the important conversation. The goal of the e-learning is to inform anyone who comes into contact with ALS, about what it entails and how the various aspects of ALS can be implemented in the palliative care conversation. We want them to explore their own strengths and boundaries and give them an overview of what is possible in palliative care in various settings. Our hope is that this will lead to a higher quality of life for all ALS patients up until the very end.

My ALS/MND patient mentioned wanting to die, now what? A brief guide to conversations about death, dying, and suicide screening for nonmental health

Presenter: Amber Johnstone

Conversations about death, dying, and even suicide are common among individuals with a life-limiting diagnosis. Many providers feel uncomfortable or unprepared to have these conversations. Learning how to support an individual through conversations about death and dying are important and appropriate. Basic questions or conversation prompts can help a provider understand the patient's needs and acuity and urgency for a mental health referral. Conversations surrounding death and dying among the ALS/MND population can also help a patient feel heard, understood, supported, and improve quality of life outcomes.

Voice Banking - what is the current status of the technology and where do we go from here to help ensure it meets the needs of people with MND/ALS?

Presenter: Richard Cave & Nick Goldup

More than 1600 people living with ALS/MND are forecast to create their voice bank in 2022 in the UK, and the demand is growing year on year. Many choose to voice bank in the expectation that it will help retain a sense of identity - as natural voice changes and communication aids become helpful in daily life. This session will discuss the reality of voice banking technology today, the changing nature of the voice banking process that seeks to more closely align with preservation of identity in all its forms, and the upcoming technology innovation that people living with MND/ALS should help with as co-designers.

DuoRhythmo: a collaborative accessible digital musical interface for PALS and CALS

Presenters: Ivanyl Balazs & Truls Tjemsland
Co-Authors: Balazs Ivanyi, Christian Tsalidis, Lilla Toth, Marcus Dyrholm, Scott Naylor, Truls Tjemsland, Stefania Serafin & Ali Adjorlu

We present the creation of DuoRhythmo which provides a collaborative and accessible musical leisure activity for PALS and CALS. We share insights about designing an app for the needs of PALS with eye-tracking technologies and other accessible input methods. We reflect on improving the quality of life with user-centred design and digital technologies and show the accessible present and ambitious future of DuoRhythmo.

Guidelines for Healthcare Professionals Working with Individuals with Complex Communication Needs

Presenter: Lisa Bruening

Healthcare professionals may have limited experience in working with individuals who use augmentative and alternative communication strategies as well as those with other complex communication needs. When communication struggles exist, patient safety can be at risk. Healthcare professionals can benefit from training in the use of alternative communication strategies as well as implementing guidelines to improve communication with those individuals who use augmentative and alternative communication strategies. This session offers strategies to improve client/provider communication when using augmentative and alternative communication strategies.

What we learned about making videogames more enjoyable to play for people living with MND: insights from a scoping review

Presenters: Ben O´Mara, Kirsten Harley, Matthew Harrison & Natasha Dwyer

In this presentation, we explain what evidence tells us about how people living with MND, their carers and loved ones may benefit from research and development that focus on ways of making it easier to use computers, tablets, smartphones and other devices for playing video games. It's important that future work consider focusing on support for communication, motor disability, fatigue and other issues associated with MND, using advanced and more easily available forms of technology, and developing games that are fun and easy to play.

Building Local Mental Health Support Through Education and Collaboration

Presenter: Melissa Enfinger

This presentation will review the development of the ALS Association Alabama's Mental Health Program, focusing primarily on the building of a statewide Mental Health Referral Network for persons affected by ALS. We will review the key collaborations and partnerships that helped to build, grow, and promote the network, lessons learned, and next steps to help expand its impact on persons living with ALS and their families.

Eating with Dignity: Exploring how eating can be improved for people with Amyotrophic Lateral Sclerosis

Presenter: Gudlaug Gisladóttir
Co-Authors: Gudlaug Gisladottir, Bryndis Eva Birgisdottir & Marianne Klinke

Much can be done to improve the food environment of pwALS. Easy access to attractive molded pureed diets in hospitals, nursing homes, home-food delivery, and supermarkets is important. Better education needs to be established and policies clear, i.e., by drawing up care pathways and using quality indicators. Awareness must also be raised about the importance of eating-related well-being of pwALS which entails a higher quality of pureed food.

Neck Weakness in MND/ALS: An Investigation of the impact of neck weakness on walking ability

Presenter: Stephanie Zhao

In this session, we will share with audience the results of a collaborative project between Calvary Health Care Bethlehem, MND Victoria and Monash University. The project aims to investigate the various aspects of MND related neck weakness. In 2021, we presented on the prevalence of neck weakness in MND and physiotherapy management strategies. This year, we will share our results on the relationship between neck weakness and walking ability.

BowALS: understanding changing bowel habit in amyotrophic lateral sclerosis

Presenter: Jan Clarke
Co-Authors: Clarke J, Howard R, Marsden R, Sidle k, Talbot K, Thompson AG, Turner MR

Amyotrophic lateral sclerosis (ALS, also known as motor neuron disease, MND) causes progressive weakness and death due to loss of motor nerves. Changes in bowel habit are common in ALS. The aetiology of this issue is not well understood; it has been attributed to immobility, dehydration and dietary changes. Alteration in bowel motility may be an intrinsic element of ALS in a minority of patients. This study aims to provide a clearer understanding of the prevalence of changing bowel habit in this patient group, how this differs by stage of disease and how it impacts on daily life. This will be used to inform future multidisciplinary care of ALS patients.

Let's Talk about Sex and ALS

Presenter: Joanna Nunez
Co-Authors: Poletti, Barbara; Carelli, Laura; Solca, Federica; Pezzati, Rita; Faini, Andrea; Ticozzi, Nicola; Mitsumoto, Hiroshi; Silani, Vincenzo

There are less than thirty published journal articles on Sex, Intimacy and ALS, yet sex and intimacy are often a presenting issue at two-thirds of couples counseling sessions. Using the multi-disciplinary team approach, all team members should be educated and comfortable with answering questions, offering educational guidance and physical aids, and projecting a judgement free zone to our ALS patients and their caregivers.

Gendered meaning making of caregiving among spouses of persons with ALS: implications for care

Presenter: Manjusha Warrier G, Dr. Priya Treesa Thomas & Nalini Atchayaram

Introduction: Existing literature recognises the gender differences in caregiving. Gender, as a social construct has played a major role in determining the societal expectations from spouse caregivers in ALS. People who live through and experience the journey as caregivers of chronically ill partners are significantly influenced by these societal gender norms. Aim: The aim of the study was to explore how gender influences the lived experience of spouses of persons with ALS and to understand gender influences in the meaning the spouse caregivers make out of their experiences. Method: A longitudinal home- based study with in- depth interviews at three-time points were conducted among thirteen spouse caregivers of persons with ALS residing at Bangalore. The persons with ALS, who were in different stages of illness, were taking treatment from the quaternary service centre for neurological disorders in South India. The interviews which were recorded and transcribed were subjected to interpretative phenomenological analysis (IPA). The experiences of the spouses derived from the analysis, which was strengthened by the home visit observations were interpreted through the lens of socio-cultural gender perspective for identifying the influence of gender in those experiences. Result: The participants were in the study were predominantly females, (8: 5). The prevalence of motor neuron disease is more among males than females which is reflected in this group. The essence of the phenomena from a gendered perspective were gender influences the expression of emotions, association between age and gender, socio cultural expectations from being a woman caregiver and the women’s experiences tagged along with that of her husband. Despite the socio cultural, religious, economic and educational diversity in the background of the participants, there were significant similarities in the gendered nature of caregiving experiences. Conclusion: As found from the current study, the participants’ gender becomes a significant lens to understand the meaning they make from their experiences. Hence routine neurological care plans should involve therapeutic intervention programs which aims at supporting the spouse caregivers . such programmes should take into account the gender of the caregivers as a major factor.

Strengthening the Paradigm of Science and Patient Collaboration

Presenter: Allison Bulat

Through the NEALS Clinical Research Learning Institute (CRLI), people impacted by ALS are given the opportunity to engage with the science community in a two-day educational program targeted at understanding the basics of research and advocacy. At completion of the program, graduates are certified as NEALS Research Ambassadors, and serve as active members on the NEALS Patient Education & Advocacy (PEACe) Committee, as well as participate in a multitude of projects throughout many organizations within the ALS community.

A qualitative evaluation of the revised Amyotrophic Lateral Sclerosis Functional Rating Scale (ALSFRS-R) by the patient community

Presenter: Danielle Boyce

The revised Amyotrophic Lateral Sclerosis Functional Rating Scale (ALSFRS-R) is the most commonly used outcome measure in ALS studies. The aim of this study was to qualitatively identify potential limitations of the ALSFRS-R from the perspective of people living with ALS and their caregivers.

Abstract, research staff satellite meeting

Presenters: Tommy Bunte, Corey Straub, Juliette Foucher & Romy Verschoor
Authors: Tommy Bunte, Corey Straub, Mathias Couillard, Vanessa Bertone, Juliette Foucher & Romy Verschoor

The number of clinical trials is growing dramaticly over the years. This is an window of oppertunity to come closer to an potential treatment. The question is are centers ready to enroll patients?

MND professionals' community of practice

Presenter: Jennifer Bedford

An introduction to the MND Professionals' Community of Practice. A community for health and social care professionals practicing or interested in the field of MND care. It is a peer led group encouraging and supporting the development of good care for people living with, or affected by, MND.

The ALS Association's rapid access communication kit distribution program

Presenter: Alisa Brownlee

That ALS Association offers free Rapid Access Communication Kits to any person with ALS, their caregivers, ALS Centers, VA Clinics, and individual allied healthcare professionals. The boards in the kit are in English, however, information is provided on how to obtain communication boards in other languages. These kits contain various types of communication boards that include both text and symbol-based boards. The communication boards can be used by those who still use their hands to point, and for those that have no hand function though the use of partner assisted scanning. There are directions printed directly on the laminated boards for each technique.

Your voice, your choice – Speech language pathologist navigation of the ever-evolving process of voice banking for people with Motor Neurone Disease.

Presenter: Rachel Robinson

This presentation will outline the key advancements in the field of voice banking in recent years. Practical strategies and interventions will be shared, drawing on the experience of Speech Language Pathologists as well as client surveys from Victoria’s Statewide Progressive Neurological Disease Service (based at Calvary Health Care Bethlehem, Melbourne, Australia). The presentation will also explore the barriers and facilitators to successful completion of the voice banking process.