



INTERNATIONAL  
ALLIANCE OF  
ALS/MND  
ASSOCIATIONS

# Allied Professionals Forum

**4 December 2014 | Brussels, Belgium**

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To give you a bit of incentive, please note that one lucky evaluator, chosen at random, will receive a **32GB hard drive**. To be eligible for the prize drawing, you must submit an evaluation before **18 December**. All evaluations will remain anonymous.

Again, thank you for being a part of the APF. We look forward to hearing from you!

# 12<sup>th</sup> Annual Allied Professionals Forum

THON Hotel EU, Brussels, Belgium | 4 December 2014

## PROGRAMME

8.30	<b>Welcome and Introductions</b>	Steve Bell, Rod Harris	
8.40	About the International Alliance of ALS/MND Associations	Carol Birks	Australia
8.50	Executive function disorders: Engaging the team	Laurie Sterling	USA
9.10	To do or not to do? The conundrum the therapist faces in advising level of "doing" in ALS/MND	Helen Carey	UK
9.30	Role of the speech-language therapist in the multidisciplinary ALS/MND clinic: Insights learned and shared	Emily K. Plowman	USA
9.50	Developing an outreach service to set up NIV for patients with ALS/MND in their homes thereby averting hospital admission	Bernie Corr	Ireland
10.10	An evaluation of the airway clearance adjuncts prescribed in an Irish ALS/MND multidisciplinary clinic	Rachel McConnell	Ireland
10.30	<b>Morning Tea</b>		
11.00	Examining the impact of YouTube to teach patient care skills in ALS/MND	Beth Stephens	USA
11.20	Looking beyond the drug: A study exploring the experiences of ALS/MND patients attending a drug trial	Malabika Ghosh	UK
11.40	Care services navigators: Supporting personalisation and choice for people with ALS/MND	Pauline Matheson	UK
12.00	Developing a comprehensive and candid guide on end-of-life decisions for people with ALS/MND	Kaye Stevens	UK
12.20	Emotional legacies: What children need to know and how leaving it for them assists closure	Gabrielle Eirew	Canada
12.40	<b>Lunch and Networking</b>		
14.00	Compassion fatigue and burnout: Supporting staff with coping strategies	Sara Jane Murray	UK
14.20	Helping staff and volunteers to deal with compassion fatigue	Kathleen O'Hara	UK
14.40	The end-of-life experience of people with ALS/MND: Bereaved family carers' accounts	Moirá O'Connor	Australia
15.00	Exploring experience and awareness of bereavement support in family carers of people with ALS/MND	Mary O'Brien	UK
15.20	<b>Afternoon Tea</b>		
15.50	Equipment utilization in the ALS/MND population: Trends and timing	Sara Feldman	USA
16.10	Eyes That Speak: Social inclusion, work dignity and life quality for ALS/MND patients	Eduardo Jauregui	Argentina
16.30	ALS digitalk (ALS/MND and communication)	Aline Ollevier	Belgium
16.50	Use of a myoelectric orthotic to enhance functional performance in persons with ALS/MND	Amber Ward	USA
17.10	<b>Close</b>		

**Co-Chairs: Steven Bell, MND Association; Rodney Harris, MND Victoria**



INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

## **ALLIED PROFESSIONALS FORUM**

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### **Speaker**

Carol Birks, Chairwoman of the International Alliance of ALS/MND Associations

### **Biography**

Carol trained and worked as a registered nurse at St. Bartholomew's Hospital, London, before immigrating to Australia in 1983.

She worked in a variety of specialties including oncology, aged care and research before focusing on palliative care nursing. Carol graduated from the Australian Catholic University with a Graduate Diploma in Nursing (Palliative Care) in 1996.

Carol has been working with people living with ALS/MND since January 2000, when she took on the role of managing and developing the MND Association of New South Wales' family support service. In October 2006, she was appointed the National Executive Director of MND Australia, which is the national peak advocate for ALS/MND. Together with the state MND associations, we advance, promote and influence ALS/MND care and research with a vision to achieving a world free of ALS/MND.

MND Australia has been involved in the International Alliance of ALS/MND Associations since it was founded in 1992. Carol joined the Board of Directors of the International Alliance in December 2010 and in December 2014 she was elected Chairwoman.

**Author**

Carol Birks

[carolb@mndaust.asn.au](mailto:carolb@mndaust.asn.au)

**Title of Presentation**

About the International Alliance of ALS/MND Associations

**Background**

The International Alliance of ALS/MND Associations was founded in 1992 to provide a community for support and the exchange of information between ALS/MND Associations from around the world. Today, 45 patient support and advocacy organisations representing more than 30 countries have joined in this effort.

The Alliance works in partnership with the MND Association of England, Wales and Northern Ireland on the International Symposium on ALS/MND each year, with an Alliance member serving as the host organisation.

The Alliance holds its own Annual Alliance Meeting to coincide with the Symposium. This meeting provides a global forum for members to exchange information about the care and support of people with ALS/MND everywhere. Members discuss issues that specifically affect them and share initiatives and ideas that have the potential to affect change and create new programmes in other parts of the world.

**Objectives**

- To increase awareness of ALS/MND worldwide
- To exchange and disseminate information
- To improve the quality of care for people with ALS/MND everywhere
- To stimulate and support research
- To establish an international identity

**Programmes**

- The Annual Alliance Meeting, a 2-day meeting held before the Symposium, provides a forum for member associations to exchange information and ideas on fundraising, ALS/MND service programs, research and more.
- The Allied Professionals Forum, a 1-day meeting held after the Alliance Meeting, provides a forum for health care professionals from around the world to share ideas on good practice in the daily management of ALS/MND.
- The Support Grant Programme helps underfunded members travel to the annual Meetings or helps new associations with infrastructure funding.
- The Partnership Programme encourages member associations to exchange information and resources across national and regional boundaries.
- The Humanitarian Award and the Forbes Norris Award, administered by the Alliance annually, honour dedicated members of the international ALS/MND community.
- The Patients' Rights Campaign encourages members to stand up for the basic rights of people living with ALS/MND worldwide.



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### **Speaker**

Laurie Sterling

[lsterling@houstonmethodist.org](mailto:lsterling@houstonmethodist.org)

### **Biography**

Laurie Sterling is the speech-language pathologist for the MDA/ALS Clinic at Houston Methodist Neurological Center in Houston, Texas. She has been honored to work with this clinic since coming to Houston 15 years ago. Laurie has been practicing speech pathology for over 20 years and specializes in swallowing disorders. She sits on the American Board of Swallowing and Swallowing Disorders and is actively involved at multiple levels with the American Speech-Language Hearing Association (ASHA).

**Author**

Laurie Sterling, MS, CCC-SLP, BCS-S

**Title of Presentation**

Executive function disorders: Engaging the team

**Background**

Historically, ALS/MND was considered a disease of the motor neurons that deprived patients of the ability to ambulate, speak and swallow, but spared cognitive function. The majority of literature now points to a significant incidence of cognitive change, primarily that of executive functions disorders (EFD). The increased evidence of the prevalence of mild cognitive deficits in ALS/MND patients has resulted in the recommendation of screening for cognitive impairment in these patients by the American Academy of Neurology (Miller, Jackson, Kasarkis et al., 2009).

**Objective**

- Participants will learn approaches for functionally assessing for EFD in ALS/MND
- Participants will recognize the need for ongoing caregiver education and training re EFD

**Programme Description**

Official diagnosis of EFD requires formal neuropsychological assessment. American Academy of Neurology (AAN) guidelines recommend cognitive screening for ALS/MND patients but there is no consensus in the literature on the appropriate screening tool. Many clinics and/or allied health clinicians do not have access to formal neuropsychological consults for their patients on a regular basis for assessment of EFD.

The speech-language pathologist (SLP) in conjunction with our clinic neuropsychologist developed neuropsychological probes that could be employed by clinicians of various professions (SLP, PT, OT) to clinically assess EFD. Clinicians are also educated on the utilization of teaching and recommendation of strategies to assist families and caregivers in reducing the potential frustrations when working with those with EFD.

**Clinical Outcomes**

Our clinic staff has become more educated regarding the signs of EFD. Clinicians of multiple disciplines are recognizing when the patients may be experiencing executive function disorders that are impairing their ability to adhere to recommendations. Identifying this allows clinicians to employ strategies that improve adherence to clinical recommendations. Additionally, with all disciplines more cognizant of EFD, increased family/caregiver education and understanding regarding EFD as well as strategies to employ at home (e.g. placing the AAC device in front of the patient who has trouble initiating) are being utilized which families/caregivers have reported have provided a level of stress relief.

**Recommendations to the Field**

A formal neuropsychological evaluation is the best means for evaluating EFD. In lieu of neuropsychological testing, cognitive screening can provide valuable information to the ALS/MND team. It is vital for those treating the ALS/MND patient to be familiar with EFD to avoid labels such as “non-compliant”. Educating families/caregivers regarding EFD and teaching strategies to circumvent issues that may arise is recommended.



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### **Speaker**

Helen Carey

[h.carey@glyndwr.ac.uk](mailto:h.carey@glyndwr.ac.uk)

### **Biography**

Helen Carey has an all encompassing experience of ALS/MND.

Helen is an occupational therapist with 23 years experience of working within neurology with a specialist interest in ALS/MND. She has managed therapy services between 1996 and 2004. In 2004, Helen moved into education and is now Professional Lead for Occupational Therapy in Glyndwr University, North Wales where she leads the occupational therapy subject area and facilitates the Allied Health Professions Research Network for North Wales.

In 1997, Helen's father was diagnosed with MND and died in 1998. Helen is an active member of the local MND Association branch and sits on North Wales Neurological Alliance Academic Group.

Helen was successful in 2012 to gain PhD Fellowship funding to study "Purposeful Occupation within MND."

Helen is in a unique position as having experience of ALS/MND at a clinical, educational and personal level. She has presented frequently to service users, professionals and academics sharing her perceptions from both personal and professional experience. Helen is passionate to apply this experience to contribute positive outcomes for people with ALS/MND.

**Author**

Helen Carey

**Title of Presentation**

To do or not to do? The conundrum the therapist faces in advising level of “doing” in ALS/MND

**Background**

At the 2013 International Symposium the author presented the poster “Purposeful Occupation is Effective in Treating Motor Neurone Disease” which produced lively discussion with international therapists. The debate challenged whether therapy intervention should be within a rehabilitation or compensational framework given new evidence. The author has since collaborated with therapists worldwide sharing professional experience as to balance in encouraging “doing” for people with ALS/MND. The question received fellowship funding from Welsh Research Network.

**Objective**

To present the concept of increasing activity ("doing") for people with ALS/MND as a means of plateauing symptoms.

**Programme Description**

There is developing evidence that regular aerobic and resistance exercise can maintain function in mild/moderate presentations of ALS/MND (Almeida et al 2012). There is evidence that engagement in purposeful occupation improves health and well-being in a variety of chronic conditions (Wilcox 1993, Thorson et al 2011). There is anecdotal experience from therapists internationally that people with ALS/MND who “push themselves” to engage in activity achieve a plateau in symptoms whilst those with occupational deprivation have a more marked decline.

This presentation asks why, given the above knowledge, do therapists persist to support intervention approaches which focus upon rest and compensation; it presents an argument for cautious change in practice.

Firstly, evidence for exercise and occupational science is outlined. Secondly, case study observations outlined from multiprofessional therapists internationally who contributed to study. Thirdly, validation through intervention study results where increased “doing” shows positive change in function. Conclusion proposes change of intervention where patients are empowered to “do” to an extent where positive physiological change occurs.

**Clinical Outcomes**

- Mild to moderate aerobic exercise and muscle resistance can plateau function in mild to moderate disease phase.
- Engagement in purposeful occupation improves health and wellbeing within ALS/MND.

**Recommendations to the Field**

- Intervention focused upon rehabilitation framework in mild and moderate phase of disease.
- Dominant compensational focus utilised in severe stage of disease progression.
- Encouragement of “doing” rather than “cease doing” should be focus of intervention.

**References**

- Almeida et al (2012) Exercise and Amyotrophic Lateral Sclerosis. *Neurological Sciences*. 33 (1) 9-15  
Thorson et al (2011) Cancer Patients Need for Rehabilitation Services. *ActaOncologica*. 50 (2) 212-222  
Wilcox A (1993) A Theory of the Human Need for Occupation. *Journal of Occupational Science*. 1 (1) 17-24



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### **Speaker**

Emily K. Plowman

[plowman@usf.edu](mailto:plowman@usf.edu)

### **Biography**

Emily Plowman, Ph.D., CCC-SLP is an Assistant Professor at the University of South Florida (USF) where she is jointly appointed in the departments of Communication Sciences and Disorders and Neurology. She is a certified Speech-Language Pathologist with a Doctorate Degree in Neurorehabilitation and a Post-Doctoral Fellowship in Neuroscience. Dr. Plowman provides clinical services at the USF ALS Multidisciplinary clinic where she is committed to advancing the treatment and care of bulbar dysfunction in individuals with ALS/MND through the provision of clinical services, patient education and translational research. She teaches Dysphagia, Medical Speech-Language Pathology and Research Methodology courses to graduate students at USF.

Dr. Plowman holds current funding in both her basic science (NIDCD) and human clinical laboratories (NICHD) from the National Institute of Health to conduct innovative research aimed at developing therapies for respiratory, cough and swallowing function in neurodegenerative disease populations (Parkinson's disease and Amyotrophic Lateral Sclerosis). The mission of her research laboratory is to improve bulbar function, reduce morbidity and mortality, and improve quality of life in individuals suffering from devastating neurologic diseases. Currently, she is conducting a Randomized Clinical Trial to examine the efficacy of a targeted respiratory strength training home program on respiratory, cough and swallow function in ALS/MND.

Dr. Plowman is a member of the NEALS Ventilation Committee, is on the Board of Directors for the Dysphagia Research Society and a medical advisor for A Life Story Foundation (a non-profit patient advocacy ALS/MND organization). She is an accomplished clinician and educator who lectures extensively both nationally and internationally and was recently recognized with the 2013 American Speech and Hearing Association Specialty Board in Swallowing Disorders Award for her research in the treatment of bulbar dysfunction in ALS/MND.

**Authors**

Dr. Emily K. Plowman, Ph.D., CCC-SLP; Lauren Tabor

**Title of Presentation**

Role of the speech-language therapist in the multidisciplinary ALS/MND clinic: Insights learned and shared

**Background**

Dysarthria and dysphagia are highly prevalent in people with ALS/MND (PALS) and contribute to reductions in quality of life, social isolation, malnutrition, aspiration pneumonia and mortality (Kuhnlein et al., 2008; Yang et al., 2011). Timely identification and management of bulbar symptoms by Speech Language Therapists (SLT) is therefore imperative and documented to increase survival in this patient population (Spataro, 2011). In the context of a busy multidisciplinary clinic, this can represent a daunting task for the SLT who is responsible for screening, assessment and education of bulbar pathology within a limited time frame. We have therefore developed a fifteen-minute screening tool and patient educational packets for SLTs to implement in a multidisciplinary ALS/MND clinic.

**Objectives**

- Describe the SLT screening protocol developed and utilized at the University of South Florida multidisciplinary ALS/MND clinic.
- Share educational resources for effective communication, safe swallowing, voice banking and Augmentative and Assistive Communication (AAC) for PALS.

**Programme Description**

A fifteen-minute bulbar screen developed at the University of South Florida (USF) will be presented. This screen includes the: 1) Yale Swallow Protocol (Suiter and Leder, 2013); 2) Eating Assessment Tool (EAT-10) (Belafsky et al., 2008); 3) Functional Oral Intake Scale (FOIS) (Crary, 2005); 4) Communication Effectiveness Survey; and 5) American Speech and Hearing National Outcome Measure Scale (NOMS) for speech, voice and swallowing. Rationale for the inclusion of each test will be detailed and the utility of each measure in this patient population highlighted with the provision of patient examples. The development of patient educational resources/packets will be detailed and patient education packets for: 1) safe swallowing, 2) Augmentative and Assistive Communication (AAC), 3) effective communication strategies, and 4) voice banking that are distributed at the University of South Florida will be shared.

**Clinical Outcomes**

- A fifteen-minute Clinical Screening tool utilizing validated measures of speech and swallowing impairment.
- Patient educational packets for safe swallowing, Augmentative and Assistive Communication (AAC), effective communication strategies and voice banking.

**Recommendations to the Field**

Timely identification and education of speech and swallowing impairment is crucial for maintaining quality of life and well being in PALS. The use of a sensitive screen of bulbar dysfunction is recommend in addition to education on safe swallowing, non-oral feeding alternatives, AAC and voice-banking options, early in the disease.



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### **Speaker**

Bernie Corr

[berniecorr@eircom.net](mailto:berniecorr@eircom.net)

### **Biography**

Bernie Corr is the ALS/MND Clinical Nurse Specialist in Beaumont Hospital Dublin. Bernie provides a liaison service for patients, their carers and health-care professionals nationwide. She works very closely with community, hospital and hospice based multidisciplinary teams providing advice, support and ongoing educational programmes. Topics of special interest to Bernie include the loss of sexuality and intimacy in patients with ALS/MND, patient compliance with non-invasive ventilation, end-of-life issues and advance care planning.

**Authors**

Bernie Corr MSc, SCRn, RGN; Prof. Orla Hardiman BSc, MD, FRCPI

**Title of Presentation**

Developing an outreach service to set up non-invasive ventilation for patients with ALS/MND in their home thereby averting hospital admission

**Background**

Most patients with ALS/MND die from respiratory failure and a distinguishing feature of the management of the disease is whether the patient is offered and tolerates NIV. Recent changes in the Irish health care delivery system, in particular the difficulties in arranging timely hospital admissions, have resulted in a shift of patients needing increasing acute care in the home setting. The decision to initiate an outreach service to set up NIV was as a direct result of the ongoing delay and failure to arrange timely admission for patients with ALS/MND identified with respiratory difficulties.

**Objective**

To develop an outreach service to set up non-invasive ventilation for patients with ALS/MND in their homes and thereby averting hospital admissions.

**Programme Description**

Patients attending the ALS/MND clinic in Beaumont hospital routinely have respiratory assessment performed. This ensures that we identify and provide timely and appropriate respiratory support in particular non-invasive ventilation. A very close working relationship has developed between the ALS/MND team the company Respi Care who provide the non-invasive ventilator. This collaboration ensures that patients can be fast tracked for trial of NIV in their home, in many cases within a week of identifying their need. Ongoing assessment regarding the use and settings of the NIV are carried out at home and following analysis the settings are adjusted if required.

**Clinical Outcomes**

The number of NIV set up in the patient's home: 2010 = 10, 2011 = 18, 2012 = 29, 2013 = 35. Setting up NIV at home has facilitated an opportunity to provide an educational programme for the patient, their carer and their community multidisciplinary teams. This service has resulted in significant financial savings while continuing to provide a timely and appropriate service to maintain and improve the quality of life of these terminally ill patients.

Patients and their carers are less anxious when NIV is introduced in the home environment and resulting in more success. The setting up of NIV at home affords an opportunity to discuss end-of-life issues and advance care planning. It provides an opportunity to determine the patient's end-of-life wishes and ensures that the community multidisciplinary team are included in these difficult and challenging discussions.

**Recommendations to the Field**

Developing an outreach service to set up NIV for patients in their home thereby averting admission to hospital may be beneficial to other clinics. The ability to fast track patients ensures timely and appropriate respiratory support and significant financial savings.



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### **Speaker**

Rachel McConnell

[rmcconne@tcd.ie](mailto:rmcconne@tcd.ie)

### **Biography**

Rachel McConnell graduated with a BSc. in Physiotherapy from Trinity College Dublin in 2010. She is currently working as a member of the Motor Neurone Disease (MND) Multidisciplinary Team (MDT) in Beaumont Hospital, Dublin, with a remit for research. Her role at the ALS/MND clinic includes assessment of Sniff Nasal Inspiratory Pressure (SNIP) and Amyotrophic Lateral Sclerosis Functional Rating Scale (ALS-FRS) in each patient at each clinic visit. This data is used in clinical decision making and also amalgamated into the Irish MND Register. Rachel's primary areas of interest include neurological rehabilitation and management of neuromuscular respiratory problems.

### **Collaborators**

Roisin Vance, Orla Hardiman, Deidre Murray

### **Biographies**

Roisin Vance qualified as a Physiotherapist in 2003 and is currently a senior physiotherapist in Neurology and a member of the MND MDT in Beaumont Hospital. Roisin completed a Master's in Neurology and Gerontology in 2012 and a postgraduate diploma in Botulinum toxin injection in 2013. She is involved in teaching and promotion of best practice in the physiotherapy management of neurological conditions at a national level and is a member of the European Parkinsons Disease Guideline development group.

Prof. Orla Hardiman is a consultant neurologist in Beaumont Hospital, Dublin and leads the MND MDT. She is a Health Research Board (HRB) Clinician Scientist and Professor of Neurology at Trinity College, University of Dublin. Prof. Hardiman's primary research interests include the epidemiology and pathogenesis of ALS/MND with particular reference to the identification of genetic and environmental susceptibility factors. Her internationally-recognized group recently identified an important new susceptibility gene for ALS/MND, which occurs with higher frequency in populations of Celtic extraction. The group is in active collaboration with many of the major ALS/MND centres in Europe and the USA, and is a member of the US based Genome Wide Association Consortium for ALS/MND. Recent work has also focused on the clinical and genetic overlap between ALS/MND and frontotemporal dementia, for which she has received one of only eight prestigious HRB Clinician Scientist Awards. In 2011 she received the Forbes Norris Award from the International Alliance of ALS/MND.

Dr. Deirdre Murray graduated from University College Dublin in 2001 with a BSc. in Physiotherapy and was awarded her PhD. from the Royal College of Surgeons in Ireland in 2014. She has worked in Beaumont Hospital since 2004 and is currently the Clinical Specialist Physiotherapist in Neurosciences. Deirdre is a member of the MND team and promotes education in the management of ALS/MND at a national level. She is actively involved in clinically based research primarily in the areas of neuromuscular disease.

**Authors**

Rachel McConnell; Roisin Vance; Prof. Orla Hardiman; Dr. Deirdre Murray

**Title of Presentation**

An evaluation of the airway clearance adjuncts prescribed in an Irish ALS/MND multidisciplinary clinic

**Background**

The Multidisciplinary Team (MDT) at the Motor Neurone Disease (MND) clinic, at Beaumont Hospital, Dublin cares for the majority of Irish ALS/MND patients. ALS/MND patients often present with neuromuscular respiratory weakness resulting in an impaired cough and an inability to clear secretions. A Peak Cough Flow (PCF) of over 270 L/min is required for an effective cough (Bach et al.1997). Physiotherapists in this setting assess for respiratory symptoms and prescribe airway clearance techniques and adjuncts. These include Mechanical Insufflation-Exsufflation (MI-E) and manual breath stacking.

**Objective**

To identify the number of patients prescribed an Airway Clearance Adjunct (ACA) between January 2013 and May 2014. To identify what ACA was prescribed. To evaluate the measurements used to prescribe the ACA. To determine if appropriate assessment methods were utilised.

**Programme Description**

A review of all ALS/MND physiotherapy charts from January 2013 until May 2014 was completed. The patients prescribed an ACA were identified. The type of ACA prescribed was established and the assessment measures were evaluated.

**Clinical Outcomes**

A total of 189 patients were reviewed by physiotherapy between January 2013 and May 2014. Fifty-eight patients (30.7%) were prescribed an ACA. MI-E was prescribed for 28 patients (48.3%) and manual breath stacking was prescribed for 37 (63.8%). Nine patients (15.5%) were prescribed both MI-E and manual breath stacking. All patients had Sniff Nasal Inspiratory Pressure (SNIP) assessed unless they were unable to perform the required procedure. PCF was not routinely performed on all patients, with 31 patients (53.4%) prescribed an ACA completing this assessment. The mean PCF for the prescription of MI-E was 175 (80-350) L/min. The mean PCF for the prescription of manual breath stacking was 195 (100-350) L/min. The decision to prescribe an ACA was based on symptoms reported and patient preference with objective findings of a PCF supporting this decision in half of cases.

**Recommendations to the Field**

The decision to prescribe an ACA is multifactorial and takes consideration of symptoms reported, objective measures and patient preference. A follow-up evaluation of the efficacy ACAs prescribed is required. Further research will evaluate patient comfort and carer experience with the use and efficacy of an ACA in the home setting. In addition, 131 patients (69.3%) were assessed but were not prescribed an ACA. Thus, alternative airway clearance techniques for ALS/MND patients requires consideration. An algorithm to guide prescription of ACAs would be beneficial to direct physiotherapy assessment and treatment.



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### **Speaker**

Helen Elizabeth Stephens

[hstephens1@hmc.psu.edu](mailto:hstephens1@hmc.psu.edu)

### **Biography**

Helen (Beth) Stephens is the Neuromuscular Project Manager of the Penn State Hershey ALS Clinic and Research Center. Beth has a Master's Degree in Industrial/Organizational Psychology and is a Certified Clinical Research Professional. Beth co-directs the Clinical Management Research Program at the Hershey ALS Clinic and Research Center. Beth has extensive experience in program evaluation methodology and evidence-based research design.

**Authors**

Helen Elizabeth Stephens MA; Susan Walsh RN; Zachary Simmons MD

**Title of Presentation**

Examining the impact of YouTube to teach patient care skills in ALS/MND

**Background**

Skills and techniques for patient care must be taught, but a one to one lesson often is insufficient because the information may not be retained. YouTube, originally created for entertainment, is now a vehicle to provide education about medical conditions. A recent patient and caregiver needs assessment completed by the ALS Association, Greater Philadelphia Chapter, revealed that social media is seen as an opportunity for learning about ALS/MND. We developed 3 ALS/MND-specific patient care videos and posted to our Chapter's YouTube channel. The videos were disseminated via posting to the Chapter's webpage and via Facebook.

**Objective**

Demonstrate the use of video analytics to evaluate a patient care video.

**Programme Description**

The passive range of motion in the upper extremities video was selected for analytics to examine view count, playback locations, traffic sources, demographics, and audience retention.

**Clinical Outcomes**

The range of motion video was among the highest viewed videos produced by the Chapter. The video received 957 views over 208 days. Viewers from Pennsylvania represented only 13% of the United States viewers. Viewers represented 47 of the 50 states. Viewers were from the United States (72%), Canada (6.3%), and Southeast Asia, UK, and Europe in smaller numbers. The video averaged 7 views per day consistently over the lifetime. The video duration was 6:35 minutes, but the average viewer observed only the first 44% of the video. After one minute of play 40% terminated the view. Playback locations included YouTube watch page (94%) and less so on embedded players on other websites (3.9%), mobile devices (1.6%) or other venues (1%). YouTube searches generated about 34% of the views with YouTube suggested video feature providing 13% of views, external websites (11%) of the views and Google search generating 4.2% of views. 29% of the views came from unknown referrer.

**Recommendations to the Field**

Video can be an effective means to demonstrate skills and techniques for ALS/MND patient care in a user-controlled manner. Online videos can provide education for a wide geography and has potential to reach a global audience. Video length of 3 minutes or less may be most appropriate. Examination of the video analytics has encouraged us to pursue future video productions and create ways to maximize use of these videos.



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### **Speaker**

Malabika Ghosh

[malabika.ghosh@lthtr.nhs.uk](mailto:malabika.ghosh@lthtr.nhs.uk)

### **Biography**

Malabika Ghosh is employed as Clinical Lead for Rehabilitation within Integrated Therapies. As part of her clinical duties she works for the Motor Neurone Disease Team based at Lancashire Teaching Hospitals. Her post has been very kindly funded by the MND Association. Malabika qualified as an Occupational Therapist following which she completed a Master's Degree in Neurological Occupational Therapy. More recently, she did a PhD from Lancaster University. Malabika has a passion for research based in clinical settings. She has led several funded, multidisciplinary research studies working with a variety of professionals based both within the NHS, and Academic settings. She has presented nationally and internationally on rehabilitation after stroke, brain injury and long term conditions. Her study based within the MND Team titled 'Cognitive impairment in MND and its impact on decision making' was presented at the International ALS Conference at Milan in 2013. Another study based on 'Looking beyond the Drug in MND' will be presented at Brussels in December, 2014. Malabika has been involved with teaching at several University, Professional and Clinical forums. She is currently developing a GP Training Module aimed at the management of ALS/MND, in conjunction with Northampton University and MNDA. Additionally she continues to contribute to evidence based practice by reviewing for peer reviewed journals and funding grants for example for the NIHR. Malabika would like to congratulate the Motor Neurone Disease Association, for being proactive with regards instilling a research culture, and for aiming to bring innovation at the heart of clinical practice within the NHS.

### **Collaborator**

Pauline Callagher

[pauline.callagher@lthtr.nhs.uk](mailto:pauline.callagher@lthtr.nhs.uk)

### **Biography**

Pauline Callagher qualified as a registered general nurse in 1989 and began a career in neuroscience nursing at Lancashire Teaching Hospitals in England where she worked for many years on the acute neurology and the neurosurgical wards holding several posts including Infection Control Nurse, Clinical Nurse Practitioner and Ward Manager. Her time working on the neurology ward gave her a special interest in looking after people living with motor neurone disease. In 2005 the MND Association funded Pauline in the role as Care Centre Coordinator in the Preston MND Care and Research Centre. In this role she led the team in implementing various developments such as nurse-led clinics in hospices, introduction of advance planning using the document 'preferred Priorities Care' and assisted in developing the respiratory services so that patients did not have to travel to another county to be commenced on non-invasive ventilation. Pauline was also on the development group for the NICE guidelines on NIV in ALS/MND and also the Red Flag diagnostic tool to help reduce inaccurate referrals for those living with ALS/MND. Pauline also has a keen interest supporting people living with ALS/MND in participating in research, acting as a research nurse in commercial drug trials and also research studies to improve care or quality of life.

**Authors**

Malabika Ghosh; Pauline Callagher; Mariane Hare; Kerry Ward; Suresh Chhetri

**Title of Presentation**

Looking beyond the drug: A study exploring the experiences of ALS/MND patients attending a drug trial

**Background**

Attendance at drug trials is a common requirement for specialities with high research priority such as ALS/MND (MNDA, 2013). In view of this, patients diagnosed with motor neurone disease, attending a drug trial, at an acute regional hospital were asked about their experiences regarding their attendance.

**Objective**

This practice analysis aimed to explore the experiences of patients attending a drug trial.

**Programme Description**

Semi-structured interviews were completed, with 6 patients, using a patient feedback questionnaire. The questions explored various aspects of their journey through the drug trial and the gains they have made. Results were analysed to look at what went well; what patients expect from a drug trial; whether they have any ongoing needs and how best these can be supported.

**Clinical Outcomes**

Patients reported that attendance at the drug trial was important due to the contact this allowed with other people with a similar diagnosis. It allowed them an opportunity to share personal tragedy which made it more bearable at a personal level. The Social relationships they built during this time helped them share their personal stories and improve confidence. They found regular contact with specialist members of the Team empowering.

**Recommendations to the Field**

This study exposed us to the multiple perceived benefits patients experience when receiving treatment in groups. Patients with long term conditions such as ALS/MND, often feel isolated and unable to share their fears with anyone, even at a professional level. Attending a Group setting, meeting the same people on a regular basis improved their ability to accept their condition despite being aware of the inevitable change the terminal condition brought with it. Improved health behaviours were seen due to increased social support (Schulze et al, 2008). A drug trial in a group setting therefore should be seen as an opportunity bigger than a drug providing session.

Research through drug trials is important but the setting and the collateral benefits for patients with long term conditions needs to be considered. This study adds new knowledge to this area of clinical practice that would add quality to the care of the patient with Motor Neurone Disease. As a result of this analysis, a Group Drop In Clinic has been set up to meet the ongoing needs of the patients and has been a service expansion opportunity for staff.

**References:**

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INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

## **ALLIED PROFESSIONALS FORUM**

THON Hotel EU, Brussels, Belgium | 4 December 2014

### **Speaker**

Pauline Matheson

[pauline.matheson@mndassociation.org](mailto:pauline.matheson@mndassociation.org)

### **Biography**

As Project Manager for the Motor Neurone Disease (MND) Association, Pauline manages two Department of Health funded projects worth just over £1million. In addition to this, Pauline has led on the implementation of mapping software across the Association.

Pauline has over 10 years experience in project management and prior to joining the Association in 2013 she spent a number of years working in the Public Sector. Her previous role was very much focused on process improvement resulting in improved customer experience and efficiency savings.

**Author**

Pauline Matheson

**Title of Presentation**

Care Services Navigators: Supporting personalisation and choice for people with ALS/MND

**Background**

A three year pilot has been funded in a largely rural part of the UK to consider the following:

- Empowering people to take control of decisions about their care by using a new volunteer role (Care Services Navigator or CSN) to navigate services
- Supporting informal carers to recognise signs of breakdown and ensure they receive support to assist
- Providing a source of knowledge for commissioners to help shape future services

**Objective**

The project supports the Government's vision for volunteering by providing support that complement the care/support provided by the NHS and local councils. The second phase of the project will focus on the Government's personalisation agenda by enabling people living with and affected by ALS/MND to have greater choice.

**Programme Description**

The project is being evaluated by an independent organisation called DEMOS. The project has been running for just over 12 months and has recruited four CSNs (all with a background in health and social care at a senior level) to work directly with service users and professionals. The CSNs are beginning to have valuable role in health and social service delivery and this is backed up from the baseline survey carried out by DEMOS in January 2014 where there was agreement that the CSNs had:

- put people in touch with support they didn't know about before
- helped speed up support where there was a delay
- helped the professionals to communicate with one another

**Clinical Outcomes**

Since June 2013 CSNs have given 543 hours which equates to 78 days. They have supported 54 service users and numerous professionals. The evaluation indicates that there is a significant variation within and between areas in access to services.

CSNs reported high levels of confidence in their ability to fulfil their role and that past professional experience was a pre-requisite due to:

- Existing contacts/knowledge of the health & social care structures
- Ability to liaise with professionals in positions of authority with 'empathy' – realistic of limitations of the role

**Recommendations to the Field**

- Volunteers with the right skills can be meaningfully engaged in supporting families
- Mockford and Jenkinson reports that many families feel that engaging with services can be stressful and that families benefit from being empowered to access the right support at the right time



INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

## **ALLIED PROFESSIONALS FORUM**

THON Hotel EU, Brussels, Belgium | 4 December 2014

### **Speaker**

Kaye Stevens

[kaye.stevens@mndassociation.org](mailto:kaye.stevens@mndassociation.org)

### **Biography**

As Care Information Manager for the Motor Neurone Disease (MND) Association, Kaye manages nearly 50 publications about ALS/MND for the lay reader, including core guides and information sheets for England, Wales and Northern Ireland. Her mission is to:

- inform people living with ALS/MND and affected families about the disease
- help them manage the impact of ALS/MND on everyday life
- enable them to be proactive and seek out available support
- help them achieve the best possible quality of life with the disease.

In addition to development and revision of content, Kaye achieved The Information Standard certification for the MND Association in 2011 (as governed by NHS England). This requires a rigorous process when producing public health and social care information, to ensure content is trustworthy.

Kaye's early career involved systems analysis and working as a documentation and training analyst in the corporate sector. Prior to joining the MND Association in 2010, she spent ten years teaching in the UK prison system, with additional work in the adult learning disabilities sector. Kaye is a professional author and playwright in her spare time.

Kaye can be contacted at the following address:

MND Association

PO Box 246

Northampton

NN1 2PR

Telephone: 01604 611840

### **Acknowledgements:**

Our thanks to everyone with or affected by ALS/MND who contributed with courage and the wide panel of expert reviewers, including project mentor Dr David Oliver, Consultant in Palliative Medicine, Wisdom Hospice, Rochester, and Honorary Reader, Centre for Professional Practice, University of Kent. Full acknowledgements: page 114-115 of the guide.

### **Development Team at the MND Association:**

Kaye Stevens, Care Information Manager

Hilary Fairfield, Regional Care Development Adviser

Sue Smith, Regional Care Development Adviser

**Author**

Kaye Stevens

**Title of Presentation**

Developing a comprehensive and candid guide on end-of-life decisions for people with ALS/MND

**Background**

Between 2011 and 2013, the MND Association investigated perceptions about end of life care. Over 500 people with ALS/MND responded, indicating they needed more information about end of life decisions.

These decisions are often emotional and difficult. Many are reluctant to broach the subject, including some professionals. Speech and communication problems with ALS/MND can make discussion increasingly difficult and mental capacity may be affected. Daily challenges with ALS/MND and respiratory problems can also create fatigue, making it harder to concentrate.

The MND Association recognised the need to make these discussions easier. This included development of a new end of life guide.

**Objective**

The guide will help people with ALS/MND plan ahead in a timely way and according to their wishes, by supporting difficult conversations with candid end of life information.

**Programme Description**

The presentation will focus on the impact of our publication, 'End of life: a guide for people with motor neurone disease', during the first six months of launch in 2014. This will include case study feedback from readers and professionals.

**Clinical Outcomes**

For the person with ALS/MND, the guide helps reduce fear through knowing facts and options, provides opportunity to start and manage conversations about end of life, and helps people regain a sense of control over future care.

For health and social care professionals, the guide provides a way of introducing and expanding on difficult subjects, directions to further information and assistance, and clarification on areas that can cause doubt.

"A much needed guide that will act as a bridge between families affected by ALS/MND and the health and care professionals who support them." – Dr Bee Wee, National Clinical Director for End of Life Care at NHS England

**Recommendations to the Field**

That everyone involved in the care of someone with ALS/MND uses this guide, or a similar tool, to assist open conversations about end of life, as soon as the person is ready to consider their wishes.



INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

## **ALLIED PROFESSIONALS FORUM**

THON Hotel EU, Brussels, Belgium | 4 December 2014

### **Speaker**

Gabrielle Eirew

Director, [www.RecordMeNow.org](http://www.RecordMeNow.org)  
[familyeirew@hotmail.com](mailto:familyeirew@hotmail.com)

### **Biography**

Trained in the UK as an educator and counsellor, Gaby focuses on the Psycho-social impact of illness and death on families, and the importance of making emotional legacies. She has run a large children's charity and was on the Board of Hospice Society. She was made a Woman of the Year in 2013 and one of British PM David Cameron's Points of Light in September 2014. The RecordMeNow.org app has been downloaded tens of thousands of times by people in 32 countries. Gaby trains and lectures to hospice and hospital staff worldwide on working well with patients and their families, for everyone's wellbeing. Please contact her for workshops or more support.

**Authors**

Gabrielle Eirew; J. Leong; B. Kennedy; Dr. P. Eirew

**Title of Presentation**

Emotional legacies: What children need to know and how leaving it for them assists closure

**Background**

There was little research into what bereaved children needed to know from or about their dead parent. Many children suffer with significant psycho social issues after the early death of a parent; questions about guilt, perfectionism, sexual orientation acceptance. The author wanted to understand what children needed to know at the time of death and subsequently into adulthood.

**Objective**

People worry about being a burden and losing function for themselves and for the subsequent impact on their family. We were interested in what bereaved children who lost their parent before age 16, wished they knew from or about that parent both at the time of death and subsequently.

**Programme Description**

What do bereaved children need to know - especially after a long term degenerative condition? The author is able to share what we learnt from interviewing over 100 children who experienced the death of one or both parents during childhood. We were interested in understanding from the child's perspective what they wished they had been told that might have helped with the early loss and subsequent challenges as they grew up.

We created a free question prompting video recording app for people to use to record answers to important questions that might give their child most solace and less guilt after the person's death. Trialling it, we found that many people using the app found it helped them both with closure and with the onerous task of trying to create a loving emotional legacy for their children.

**Clinical Outcomes**

This is too early to say yet but take up has been considerable. Over 32 countries are using our app and research and we have between several hundred and 14,000 page views a day. Children wanted to know that the disease was not their fault, that they were encouraged to live on, what their parent wished for them, how their parent romanced, how they dealt with work-life balance, as well as recipes and perfumes and how their parent wanted them to grieve.

Many people have found it cathartic to leave messages while they can and the format of the app is to enable it to be used in a piecemeal fashion for people with ALS/MND or others with degenerative conditions or in palliative stages. This is already used by the Huntingdon Association in BC, Canada at Summer camps by all staff working alongside Huntingdon's sufferers. Used with people with metastatic cancers, it was reported as offering considerable closure.

**Recommendations to the Field**

- To encourage parents who wish to, to record free emotional legacies while they can on specific themes significant to the children who will be bereaved.
- Leaving such messages can feel cathartic and aid closure.
- To leave honest stories of their life as this helps children, especially young children who may have little recollection.
- To use manageable recording so the project is not overwhelming.



INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

## **ALLIED PROFESSIONALS FORUM**

THON Hotel EU, Brussels, Belgium | 4 December 2014

### **Speaker**

Sara Jane Murray

[sara.murray@mndassociation.org](mailto:sara.murray@mndassociation.org)

### **Biography**

Sara has been a Regional Care Development Adviser (RCDA) in Kent and East Sussex with the MND Association for 7 years. Before this she worked as a Paramedic in London before moving into service development and health promotion. She has a particular interest in the training and support needs of both professionals and volunteers working with people with a terminal illness.

Sara's role as an RCDA involves supporting and supervising a team of volunteer visitors; building relationships with professionals and decision makers to improve standards of care; advising on the management of complex cases; and facilitating education and training for health and social care professionals.

She has been a member of the South East MND Forum since 2007 and continues to be a member of the South East MND Network Steering Group, taking a lead in organising the education events for the Network after stepping down as chair of the Steering Group in 2012.

Contact Details:

Tel: 0845 375 1849

**Authors**

Catherine Knight; Sara Jane Murray

**Title of Presentation**

Compassion fatigue and burnout: Supporting staff with coping strategies

**Background**

The South East MND Network is open to all health and social care professionals across the South East of England who have an interest in ALS/MND. In 2011 the Network ran a series of compassion fatigue workshops across the region in response to feedback from members on the challenges of working with people with ALS/MND. Most network members work with people with ALS/MND as part of a mixed caseload and many do not have robust support systems in place compared to specialist teams.

Evaluation of the workshops showed that they were very successful with some changes in practice reported. Since 2011 the membership of the Network has grown considerably and current members have indicated there is a demand for more work in this area.

**Objective**

- Increase awareness of compassion fatigue in health and social care professionals
- Promote resilience in staff working with people with ALS/MND
- Analyse which professionals select to attend and identify any trends and gaps
- Undertake detailed evaluation on the usefulness of the training and changes in practice to identify outcomes

**Programme Description**

Building on the evaluation of the workshops delivered in 2011, 4 new ½ day sessions are planned for 2014, spread between June and September to allow as many professionals as possible to attend. These events will give new members an opportunity to participate and allow members who attended in 2011 to refresh their learning and reflect on changes in practice. Evaluation of the workshops will include analysis of who attends the sessions broken down by job role and geographical area covered; reported changes in practice and reported confidence in resilience pre and post workshop. Follow up evaluation will take place in 2015 to ascertain longevity of any changes made.

**Clinical Outcomes**

Reported outcomes from the 2011 workshops include:

- Changes in working practices
- One Social Services team set up formal peer support group
- One team set up informal support group
- One team formally requesting regular supervision
- Requests from professionals for further workshops

**Recommendations to the Field**

The Network recognises that compassion fatigue and burnout is a risk for professionals working with people with ALS/MND. Workshops are one way of addressing this resulting in some changes in practice. It is suggested that these workshops should be part of a rolling programme and evaluation should include follow up with participants after 1 year to measure long term impact of the programme.



INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

## **ALLIED PROFESSIONALS FORUM**

THON Hotel EU, Brussels, Belgium | 4 December 2014

### **Speaker**

Kathleen O'Hara

[keohara@aol.com](mailto:keohara@aol.com)

### **Biography**

Chris Wade is Director of Engagement at the Motor Neurone Disease Association with a responsibility for volunteering, HR and learning. He brings extensive knowledge of working with volunteers and NGOs. He is a trustee of the National Council for Voluntary Organisations, an advisor to the Institute of Volunteering Research and a former board member of several charities, statutory organisations and professional bodies. Chris spent 14 years working with volunteers at Victim Support, helping them provide emotional support to victims of sexual violence, domestic abuse and to people bereaved through homicide.

Kathleen O'Hara, MA LPC is a victim services specialist who has worked with victims of trauma for the past 13 years and is a consultant for the Federal Office for Victims of Crime in the US. She is an author, psychotherapist and trainer. She has developed innovative workshops for victim service providers in Europe, the US and Canada. She is an expert on compassion fatigue and vicarious traumatization. She now resides in London, where she continues her work with organizations and individuals.

**Authors**

Chris Wade; Kathleen O'Hara

**Title of Presentation**

Helping staff and volunteers to deal with compassion fatigue

**Background**

Compassion fatigue is a serious issue among staff and volunteers who work to support with people with ALS/MND. Compassion fatigue or vicarious trauma can be a contributing factor to rapid turnover of personnel as well as causing additional stress and health issues we all have a duty of care to our staff and volunteers, ensuring that their activities do not affect their own wellbeing. This presentation will help you understand compassion fatigue and provide strategies from both an individual and organization approach to help avoid "burnout" and support your staff and volunteers.

This workshop will show how learning from other care sectors can be transferred to help people with ALS/MND.

**Objective**

To help you understand compassion fatigue and help your staff and volunteers to develop good care models for themselves as they help others

**Programme Description**

Kathleen O'Hara is an expert in compassion fatigue and will present a 15 minute program highlighting strategies on individual and organizations strategies to deal with compassion fatigue.

**Clinical Outcomes**

Participants will learn individual and organizational strategies for dealing with compassion fatigue that they can use with their staff and volunteers

**Recommendations to the Field**

These are effective strategies for dealing with compassion fatigue that have presented in the field of Victimology and caring for staff and volunteers of victim service organizations.



INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

## **ALLIED PROFESSIONALS FORUM**

THON Hotel EU, Brussels, Belgium | 4 December 2014

### **Speaker**

Moira O'Connor

[m.oconnor@curtin.edu.au](mailto:m.oconnor@curtin.edu.au)

### **Biography**

Dr. Moira O'Connor is a Senior Research Fellow who is looking at the psychological and social aspects of living with a life limiting illness, and the experiences of both people living with the condition and their families (including family carers and also children). Moira has a background in psychology and has over 50 published papers in this area and has attracted funding to lead and be part of teams conducting research in this area.

**Authors**

Dr. Moira O'Connor; Ms. Brenda Bentley; Dr. Rob Edis

**Title of Presentation**

The end-of-life experience of people with ALS/MND: Bereaved family carers' accounts

**Background**

Traditionally palliative care has been mainly provided to cancer patients. Expansion of palliative care services into non-malignant conditions has led to improvements in symptom control, quality of life and caregiver burden for people with ALS/MND. However, there are still gaps for people with ALS/MND and their families when it comes to access to specialist palliative care services. When there are gaps or problems in the provision of care at the end of life for people with ALS/MND, the burden falls squarely on family carers who are often overburdened and already experiencing high levels of distress. Identifying where the gaps are and what are unmet needs will help provide best practice end of life care for all people with ALS/MND and will help to reduce the burden on family carers and ALS/MND health professionals.

**Objective**

This qualitative study explored the accounts of bereaved family carers about their perceptions of the end-of-life experience of people with ALS/MND.

**Programme Description**

Semi-structured interviews were used to elicit accounts of the experience of the end of life and the death of the person with ALS/MND from 12 bereaved family carers who were bereaved between three and fifteen months. A social constructionist approach was used to elicit people's own experiences as the study was exploratory and applied. The study focused on three main areas: 1) the health care services used in the last three months of life with a special focus on the last week of life, 2) the information provided about the end of life to families from health care providers, and 3) the family carer's view of the death experience. The semi-structured approach allowed for people to give other information they felt relevant. Thematic analysis of the transcribed interviews was conducted. A former ALS/MND family carer and four ALS/MND specialist health care providers associated with an ALS/MND Clinic served as the Project Advisory Group to provide input into all aspects of the study.

**Clinical Outcomes**

Three key themes emerged: The provision of support; information seeking; and preparation and readiness for death. Sub-themes included who people received support from, unmet needs, what worked well and personal strategies for coping. Recommendations for enhancing support and providing best care at the end of life are discussed.

**Recommendations to the Field**

Communication needs to be clear. Information may need to be tailored to the individual. Palliative care provides a framework and way of working that includes holistic care at the end of life.



INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

## **ALLIED PROFESSIONALS FORUM**

THON Hotel EU, Brussels, Belgium | 4 December 2014

### **Speaker**

Mary O'Brien

[obrienm@edgehill.ac.uk](mailto:obrienm@edgehill.ac.uk)

### **Biography**

Dr. Mary O'Brien is a Reader in Health Research in the Evidence-based Practice Research Centre (EPRC) at Edge Hill University in Ormskirk, Lancashire, UK. Following a nursing career which culminated in nine years as a Nurse Specialist for Motor Neurone Disease (MND), Mary joined Edge Hill University in 2003, initially as a Research Fellow, then Senior Lecturer, before taking up her current position in 2012.

An experienced health researcher, her particular interests are end-of-life and palliative care research and carers' needs focusing on non-malignant illness, particularly neurological conditions, and specifically ALS/MND. Mary was awarded her PhD from Lancaster University in 2009 for her thesis entitled 'Hopes transitions and letting go: living with ALS/MND as documented in published and unpublished first-person illness narratives'.

Working with colleagues and NHS partners, she completed one of the first studies funded through the National Institute for Health Research (NIHR) Research for Patient Benefit (RfPB) stream in the Northwest of England exploring health, social and palliative care provision for people with ALS/MND. She has published over 25 peer-reviewed papers, is a member of the Editorial board of the British Journal of Neuroscience Nursing and is a peer-reviewer for journals including Journal of Advanced Nursing, Qualitative Health Research and the International Journal of Palliative Nursing. Mary has presented her work internationally and is peer-reviewer for a number of NIHR research schemes. She is also a member of the MND Clinical Studies Group, nationally convened subject experts responsible for overseeing and developing a portfolio of studies in ALS/MND in the UK.

Mary can be contacted via

EPRC

Faculty of Health & Social Care

Edge Hill University

Ormskirk L39 4QP UK

+44 1695 650918

**Authors**

Dr. Mary O'Brien; Professor Barbara Jack; Andrew Kirkcaldy; Steve Bell; Dr. Katherine Knighting; Professor Brenda Roe

**Title of Presentation**

Exploring experience and awareness of bereavement support in family carers of people with ALS/MND

**Background**

It is well-established that family carers' needs should be assessed, and also met, especially during end-of-life care and into bereavement (Arthur et al., 2010). Bereaved carers tend to experience higher rates of physical and mental illness and mortality than the general population. We know that caring can be a positive and rewarding experience, but this is not so for all carers (Cohen et al., 2002). Amongst those with a greater likelihood of negative grieving outcomes are carers of people with advanced or progressive illness, such as ALS/MND. These carers are at greater risk of grieving the death of a loved one in an unusually intense manner, beyond the length of time typically considered normal, a condition known as Prolonged Grief Disorder (PGD) (Prigerson et al., 2009). Carers of people living with ALS/MND (plwMND) have likened their experience of caring as akin to experiencing a series of bereavements. Fragmented, poorly communicated and generally dissatisfying service provision also means carers of plwMND are under considerable strain.

**Objective**

To seek the views of carers and health/social care professionals on the subject of bereavement support.

**Programme Description**

This paper will present findings relating to a small-mixed methods study. Two focus groups were conducted with carers (n=16) and an online survey administered to health/social care professionals (n=59) in England.

**Clinical Outcomes**

Our data suggest bereavement-related support for carers could be improved, that Prolonged Grief Disorder (PGD) may be experienced at a higher level than previously thought and that health/social care professionals struggle to reliably identify the risk of PGD amongst carers of plwMND.

**Recommendations to the Field**

Despite the current emphasis placed on caring for carers, at present there are relatively few screening tools examining negative grieving outcomes pre-death, and those which do exist are limited in some way. There is broad support for the future development of an alert system based on the preferences of carers, health and social care staff and other professionals, to enable those working with carers of plwMND to identify carers at risk of developing PGD which will impact positively on the likelihood of appropriate and timely referrals occurring.

**References:**

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- Prigerson HG., Horowitz M J., Jacobs S et al. (2009) 'Prolonged grief disorder: Psychometric validation of criteria proposed for DSM-V and ICD-11' PLoS Medicine. 6 (8) pp. e1000121.



INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

## **ALLIED PROFESSIONALS FORUM**

THON Hotel EU, Brussels, Belgium | 4 December 2014

### **Speaker**

Sara Feldman

[sara.feldman@drexelmed.edu](mailto:sara.feldman@drexelmed.edu)

### **Biography**

Sara Feldman, PT, DPT has been the physical therapist for the MDA/ALS Center of Hope at Drexel University College of Medicine since 1994. She received her BS from Temple University in Physical Therapy in 1987, her Master's from the University of Pennsylvania in Environmental Science in 1997 and her Doctorate in Physical Therapy from Drexel University in 2012. In addition to her role as the physical therapist at the multidisciplinary team clinic she is an Assistive Technology Professional. She is the Clinical Evaluator for outcome measures of clinical trials and is the Clinical Evaluator Member on the Board of the Northeast ALS (NEALS) Consortium. In 2013, she joined the Board of Directors of the International Alliance of ALS/MND Associations as the delegate from the ALS Hope Foundation.

### **Collaborator**

Peggy Allred

[peggy.allred@cshs.org](mailto:peggy.allred@cshs.org)

### **Biography**

Peggy Allred, PT, DPT is currently the Research Administrator and ALS Program Manager at Cedars-Sinai Medical Center in Los Angeles. She develops and implements clinical research programming for the Neuromuscular Division and facilitates the multidisciplinary ALS clinic. She received her Bachelor's of Science in Physical Therapy from Texas Woman's University and her Doctor of Physical Therapy from Simmons College in Boston. She has worked in the ALS/MND field for 25 and was previously with Washington University in St. Louis and Methodist Neurological Institute/Baylor College of Medicine in Houston, Texas.

**Authors**

Peggy Allred PT, DPT; Sara Feldman PT, DPT, ATP

**Title of Presentation**

Equipment utilization in the ALS/MND population: Trends and timing

**Background**

Equipment use by those with ALS/MND has long been established as a mechanism for enhancing safe function and improving quality of life. Just as ALS/MND has highly variant presentations and progression rates, the types and timing of equipment utilized by those with ALS/MND also varies. Multidisciplinary teams and coordination of care have greatly enhanced proactive equipment recommendation, but consistency in the timing of recommendations based on ALS/MND disease progression parameters has not been established. Equipment for those with ALS/MND in the US must often be deemed medically necessary before being paid for by insurance companies. Establishing trends and timelines for equipment utilization based on functional measures may assist in procuring equipment earlier. These timelines may also assist patients, families, and outside care teams to increase awareness of equipment needs over the disease duration.

**Objective**

The objective of our work is to investigate what type of equipment is being utilized by individuals with ALS/MND and at what time point in the disease duration to potentially develop predictive algorithms for equipment recommendations.

**Programme Description**

Retrospective chart review was performed at two large ALS/MND centers in the US. Information on the types of equipment recommended, prescribed, and/or utilized by ALS/MND patients throughout their disease duration was collected. Disease parameters such as ALS Functional Rating Scale – Revised scores, vital capacity measures, strength, and disease duration were correlated with the time of equipment recommendation and use.

**Clinical Outcomes**

Proactive recommendation of equipment was evident in the documentation, but notes regarding the utilization of recommended equipment were highly variable. Specific timelines for equipment recommendation and correlations with disease progression parameters will be provided in the presentation.

**Recommendations to the Field**

Proactive management of symptom progression is a primary goal in ALS/MND care. Establishing timeframes for equipment utilization based on commonly collected disease parameters may allow practitioners to prepare people with ALS/MND for equipment use prior to emergent need. Standardized flow sheets of equipment recommendations and actual utilization are suggested as a mechanism for consistent and accurate documentation across all medical records.



INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

## **ALLIED PROFESSIONALS FORUM**

THON Hotel EU, Brussels, Belgium | 4 December 2014

### **Speaker**

Eduardo Jauregui

[info@asociacionela.org.ar](mailto:info@asociacionela.org.ar)

### **Biography**

Eduardo Jauregui (Spain 1970), senior engineer and MBA, founded in 2013 the company IRISBOND ([www.irisbond.com](http://www.irisbond.com)) together with the Applied Technology Center VICOMTECH ([www.vicomtech.org](http://www.vicomtech.org)). IRISBOND develops a system based on the Eye Tracking principle, permitting accurate and intuitive computer control by eye movement. Its direct application in the world of disability, and more specifically for people with reduced mobility (ALS/MND, Cerebral Palsy, stroke, etc.), is the starting point for a course to explore new developments in assisted communication.

**Authors**

Pablo Aquino, Eduardo Jaregui, Dario Ryba (President of Asociacion ELA Argentina)

**Title of Presentation**

Eyes That Speak: Social inclusion, work dignity and life quality for ALS patients

**Background**

In the Argentine market, assistive communication systems are insufficient to allow an efficient insertion to social, community and work life of ALS patients. Eye readers for communication are crucial for patients that are totally paralyzed as a result of the unstoppable progression of the disease. Causes:

- ALS is a disabling, degenerative and chronic pathology.
- It produces, among others, loss of speech and phonation.
- Alternatives to achieve communication are scarce and expensive.

Effects:

- Psychological: depression, sadness and exclusion.
- Social: isolation and lack of communication.

**Objective**

- Facilitate inclusive and assertive communication means for ALS-disabled persons.
- Promote insertion of ALS patients through the development of a systematic, periodic and paid activity.
- Promote a collective construction of shared responsibility with individual contribution of patients.

**Programme Description**

The core aim of the programme is to develop a protected workshop for disabled and prostrated ALS patients in their environment by using, as a sole communication means and work tool, eye readers that facilitate written language with only the blink of the eyes.

**Clinical Outcomes**

Teach and adapt ocular communication devices in ALS patients for their work needs, thus avoiding isolation and other psychological outcomes.

**Recommendations To The Field**

Ocular Control technology is highly beneficial for any disabled person that has his or her look as motor expression, crucial for communication. Nowadays, it is possible to achieve communication with only a voluntary, conscious and focused movement of the eye. Assistive technology must be of great consideration within the necessary care that ALS patients require. The ability to communicate allows reintroducing the patient to family and community life while improving relationships. At the same time, allows gaining autonomy and making decisions with respect to his or her treatment. For this reason, an anticipated information survey on this technology is never hasty. It is worth considering the time that it consumes, and the time and work taken by the patient to learn to use these devices, as well as the facility to install and compatibility with free AAC applications. Consideration of these variables may save great frustrations for patients and their social settings.



INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

## **ALLIED PROFESSIONALS FORUM**

THON Hotel EU, Brussels, Belgium | 4 December 2014

### **Speaker**

Aline Ollevier

[aline.ollevier@vives.be](mailto:aline.ollevier@vives.be)

### **Biography**

Aline Ollevier holds a Master's Degree in Occupational Therapy. She is a lecturer and Research Coordinator at the House of Innovation in Care at the University College Vives, Belgium. She serves as the Chairwoman of the Support and Knowledge Center in Belgium and a Board Member of the Flemish Professional Association of Occupational Therapy.

**Authors**

Aline Ollevier; Mia Mahy; Dirk De Valck; Kurt Coolbrandt; Kamran Vahedi; Joke Dessin; Evy Reviërs

**Title of Presentation**

ALS Digitalk (ALS/MND and communication)

**Background**

In Flanders there are about 600 people with ALS/MND, with a mortality rate of 120 patients a year and about the same yearly incidence rate.

Flanders' Care is an initiative of the Flemish government to improve the quality of healthcare by innovation. A consortium of ALS Mobility & Digitalk (ALS M&D; division of ALS Liga België), company SKIL nv, and University College Vives carries out the Flanders' Care demonstration project 'ALS Digitalk' to the benefit of ALS/MND patients with communication problems.

**Objective**

Patients with ALS/MND often experience oral and/or written communication difficulties with severe negative impact in quality of life. Because of the progressive nature of the disease, ALS/MND patients need access to a fast service that offers consecutive assistive communication devices adapted to the different stages of their illness.

**Programme Description**

Currently, 55 participants are included in the project, exceeding the goal of 50 to reach the premised statistical power. Following baseline measurement of communication ability and quality of life at intake, project partner ALS M&D offers the ALS/MND patients multiple sequential assistive communication devices that optimally fit with the patients evolutionary needs. Therefore it has set up a fast and free of charge lending service that is accompanied by a survey using the CETI-M (self-evaluation of communication ability) and D-Quest (satisfaction on use of the assistive devices) questionnaires. Company SKIL nv provides the technical support. University College Vives is involved in the outcome measurements (ALSAQ-40 questionnaire), and analysis of the data.

**Clinical Outcomes**

Currently, the project is up and running. The deadline for final inclusion of participants in the project is July 20th 2014. Analysis of the primary outcome starts on November 1st 2014.

The primary outcome concerns the effect of the use of multiple sequential assistive communication devices in quality of life within ALS/MND patients, measured by the validated ALSAQ-40 questionnaire (licensed from Isis Innovation, University of Oxford, UK).

**Recommendations to the Field**

Recommendations to the field await analysis of the primary outcome. They will be discussed during the presentation at the APF.



INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

## **ALLIED PROFESSIONALS FORUM**

THON Hotel EU, Brussels, Belgium | 4 December 2014

### **Speaker**

Amber L. Ward

[amber.ward@carolinashealthcare.org](mailto:amber.ward@carolinashealthcare.org)

### **Biography**

Amber Ward has been a treating occupational therapist for 20 years; 10 years in inpatient rehabilitation, and 10 years as full time Occupational Therapy Coordinator with persons with ALS/MND and muscular dystrophies. She has treated a wide variety of patients, of all ages and functional levels. She currently is an adjunct professor at the OTA program at Cabarrus College of Health Sciences in addition to working in the clinic. She received the RESNA Assistive Technology Professional certification in 2004, a Seating and Mobility Specialist in 2013 and became AOTA board certified in physical rehabilitation in 2010. She is the author of an article about power wheelchairs with persons with ALS/MND published in Archives of Physical Medicine and Rehabilitation in 2010, and numerous other book chapters and articles. She is currently the President of the North Carolina Occupational Therapy Association.

**Author**

Amber L. Ward, MS, OTR/L, BCPR, ATP/SMS

**Title of Presentation**

Use of a myoelectric orthotic to enhance functional performance in persons with ALS/MND

**Background**

Myoelectric Prosthetics have been used by amputees for years, and relatively recently, the technology has been integrated into an orthotic. This orthotic has typically been used in the stroke and spinal cord populations, but there have been few persons with ALS/MND who have ordered one. The orthotic in the ALS/MND population would enhance weak muscles to continue to allow functional movement at the elbow in flexion and extension. The person gives minimal muscle contraction, and the device amplifies that contraction into full elbow flexion for self-feeding or grooming.

**Objective**

To educate allied health staff from around the world in the myoelectric orthosis and its applications with the ALS/MND population.

**Programme Description**

Members of our team have extensive experience with assistive technology options, and use this experience to develop a study to look at the functional use of the myoelectric orthosis. We designed a pilot study with one person with ALS/MND, and one custom myoelectric orthotic, to determine how the orthotic could be used functionally, and for how long. The pilot study is ongoing, but we wanted to share the interesting and exciting preliminary functional results for this person with ALS/MND.

**Clinical Outcomes**

The clinical outcomes are currently in the preliminary stage, but the study will be well under way by the symposium. We hope to track initial strength and functional performance, and ongoing performance with and without the device for certain tasks in a single subject design study. We will let the person with ALS/MND take home the device once programmed, and have them keep a log about what the device was used for and perceptions about its assistance. We will video and photograph performance, and have that to share at the symposium. We hope to show that the device is useful to maintain function and independence for much longer for tasks like self-feeding and grooming, without overtiring the fragile muscles.

**Recommendations to the Field**

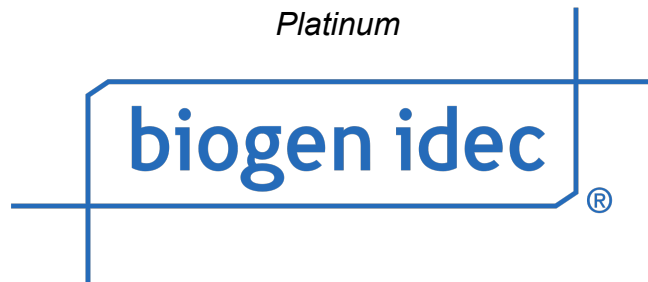
This device is just beginning to be trialed in the ALS/MND population with this study, and it may not be the device for all patients. We would like to share the information about the orthotic option to potentially increase knowledge about new and blue sky options for this population.

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