# Allied Professionals Forum

## 10 December 2015 | Orlando, FL, USA

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# 2015 Evaluations

Thank you for attending the 2015 Allied Professionals Forum (APF) and we hope that you enjoy this year's programme.

Your feedback matters to us!

After today's forum, please visit https://www.surveymonkey.com/r/2NXB2NC to complete an evaluation survey. The organising committee will consider attendees' responses as we plan and organise the APF programme for 2016 and beyond.

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 **24 December**.

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

—*The APF Programme Committee*

# 13th Annual Allied Professionals Forum

JW Marriott Grande Lakes, Orlando, FL, USA | 10 December 2015

## PROGRAMME

| | | | |
|---|---|---|---|
| 8.30 | **Welcome and Introductions** | Steve Bell & Sara Feldman | |
| 8.40 | About the International Alliance of ALS/MND Associations | Carol Birks | Australia |
| 8.50 | Caregivers' academy: A MULTIdisciplinary support program | Tanya Peterson | USA |
| 9.10 | Developing a carer-led approach for support | Steve Bell | UK |
| 9.30 | Identifying and addressing the support needs of family caregivers of people with ALS/MND: a feasibility study | Samar Aoun | Australia |
| 9:50 | Communicating with PALS/MND that have dementia | Tammy Soukup | USA |
| 10.10 | Transitioning a research tool into clinical practice: Use of the Edinburgh cognitive and behavioral ALS/MND screen in ALS/MND clinic | Judy Lyter | USA |
| 10.30 | **Morning Tea** | | |
| 11.00 | Parental disclosure of familial ALS/MND diagnosis and mutation status to children: Perceptions of young-adult offspring | Samantha Neumann | USA |
| 11.20 | Psychosocial benefits of participating in research: A supportive tool for ALS/MND young carers | Melinda S. Kavanaugh | USA |
| 11.40 | Burnout can happen to patients too: How to address in the clinical setting | Rebecca Axline | USA |
| 12.00 | From subjective to objective: Useful tools for initiating end-of-life discussions with ALS/MND patients | Shivangee Thorne | USA |
| 12.20 | PDA (Personal Death Awareness) | Laurie Fieldman | USA |
| 12.40 | **Lunch and Networking** | | |
| 14.00 | What ALS/MND health professionals need to know about today's respiratory therapies | Jennifer Armstrong | USA |
| 14.20 | Improving the respiratory referral and assessment pathway | Julie Young | UK |
| 14.40 | Updates in the evaluation and treatment of airway protection and dysphagia in ALS/MND | Emily K. Plowman | USA |
| 15.00 | Improving the eating experience for people with ALS/MND | Crystal Collinge | Canada |
| 15.20 | **Afternoon Tea** | | |
| 15.50 | Anticipatory approaches to wheelchair provision | Karen Pearce | UK |
| 16.10 | Assistive equipment use by people with ALS/MND in Australia | Karol Connors | Australia |
| 16.30 | Voice banking: Just do it! | Jennifer Benson | UK |
| 16.50 | Using mainstream technology as a communication system for people with ALS/MND | Alisa Brownlee | USA |
| 17.10 | **Close** | | |

**Co-Chairs: Steve Bell, MND Association; Sara Feldman, ALS Hope Foundation**

**Thank you: Rod Harris, Co-Founder and Co-Chair until September 2015**

INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

# ALLIED PROFESSIONALS FORUM

JW Marriott Grande Lakes, Orlando, FL, USA | 10 December 2015

**Speaker**
Carol Birks, Chairwoman of the International Alliance of ALS/MND Associations
carolb@mndaust.asn.au

**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. MND Australia is the national peak advocate for ALS/MND which together with the state MND associations, advances, promotes and influences ALS/MND care and research with a vision to achieving a world without 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 2013 she was elected Chairwoman.

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**Author**
Carol Birks

**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, more than 50 patient support and advocacy organisations representing 35 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 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, advocacy, 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 and Mentorship Programme provides support to new and emerging ALS/MND organisations and 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.

Please complete the 2015 APF evaluation: https://www.surveymonkey.com/r/2NXB2NC

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JW Marriott Grande Lakes, Orlando, FL, USA | 10 December 2015

**Speaker**
Tanya Peterson
tanya@alsa-michigan.org

**Biography**
Tanya Peterson is the Care Services Coordinator for The ALS Association Michigan Chapter. She has a degree in Social Work and currently holds a limited license in Social Work. She attends three clinics in West Michigan, Spectrum ALS Clinic, Bronson ALS Clinic and the Hauenstein Clinic, working with ALS/MND patients and their families. She works hard to provide patients and families with needed resources in their community, including such programs as the Caregiver Training Program offered by The ALS Association in conjunction with Helpers of Holland Home, a private duty home care agency located in Grand Rapids, Michigan.

INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

**Authors**
Kristen J. Munyan, RN, MSN, Paula Morning, CEO

**Title of Presentation**
Caregivers' academy: A MULTIdisciplinary support program

**Background**
Few people are prepared for the enormity of caring for a loved one with ALS/MND. Caregivers experience a steep learning curve in meeting the physical needs of the family members while still taking time to care for themselves. In Michigan, there was a demand among our patient population for a program that educated caregivers on basic physical care and provide social support, reliable information and practical skills. The Chapter responded with the creation of The ALS Association, Michigan Chapter's Caregivers' Academy, a multidisciplinary, grant-funded initiative to address the needs of the caregiving family.

**Objective**
To provide a comprehensive offering of much-needed educational services to families who are caring for persons with ALS/MND.

**Programme Description**
Piloted on the west side of our state in partnership with a local licensed home care agency, caregivers are given the opportunity to learn essential physical care skills for their family members and loved ones. Skills such as safe transfers, assistance with activities of daily living and good body mechanics are discussed in an interactive, four-hour class taught by a registered nurse. Future sessions will incorporate strategies for self-care and preventing burn-out, with roots in the work of Watson and her Theory of Human Caring. Classes are to be held in various areas of the state in order to serve the greatest population. Partnerships are being forged with local schools of nursing and allied health sciences that have simulation laboratories with equipment that will allow for the most hands-on learning experience. Classes are limited to four caregivers at a time, to allow each caregiver ample time to learn and demonstrate each skill. The small class size additionally provides a safe, non-threatening environment to learn in. This program has also seen a pilot of children's support activities, which invite kids to participate in a fun activity while sharing encouragement and support strategies with their parents and grandparents. Partnerships are being explored with local hospital Child Life Specialty services and local college programs in early childhood development and social work.

**Clinical Outcomes**
Under this multidisciplinary, grant-funded endeavor, the Chapter hopes to provide easy accessibility of organized, reliable, uplifting and practical information that equips caregivers to safely and effectively care for their loved ones and themselves.

**Recommendations To The Field**
Home caregivers require greater support services that provide education in the basic skills of caregiving. For the lay person, this skill set can initially seem overwhelming. The integration of this education into interactive, social, supportive programs will best facilitate caregiver success in adapting to their changing role.

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**Speaker**
Steve Bell
Steve.Bell@mndassociation.org

**Biography**
Steve Bell is the Director of Care (North) for the MND Association covering North of England, Wales and Northern Ireland. Steve currently leads on the strategic development of the Association's service provision for Carers; Children and Young People; Welfare Benefits; the National helpline; FTD and CI; Health Informatics and regional delivery.

INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

**Authors**
Steve Bell

**Title of Presentation**
Developing a carer-led approach for support

**Background**
The MND Association sponsored a carers survey during 2015, designed to assess what the needs of those caring for PALS/MND were. A significant response of 448 completed surveys highlighted that the main needs of carers focussed around the need for advice and support regarding benefits available and giving up work to care; the need for respite care for the PALS/MND; ensuring the right for the carers needs to be assessed by services as well as the PALS/MND and having their own needs met; and peer support from other carers looking after a person with ALS/MND.

**Objective**
To identify how a patient/membership organisation can best support and meet the needs of those caring for someone with ALS/MND.

**Programme Description**
The MND Association will be developing a campaign to ensure that carers needs are assessed by statutory services and identified need met through statutory funding. Internally, the MND Association has recognised the need for the development of peer support groups and this talk will focus as well on some of the learning from that programme – i.e., the need to separate groups of carers such as past carers and current carers.

**Clinical Outcomes**
- Development of a carers assessment tool
- Campaign to ensure carers needs are assessed
- Campaign for appropriate access to respite care
- Development of a welfare and benefits service

**Recommendations To The Field**
Engaging with the carers of those living with ALS/MND helps to define key priorities for service design to meet the practical and emotional needs of those caring for someone with ALS/MND. Carers often do not readily identify themselves as being in a caring role, but by engaging with and listening to those carers, appropriate programmes of support can be developed with obvious benefit to the person living with ALS/MND.

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JW Marriott Grande Lakes, Orlando, FL, USA | 10 December 2015

**Speaker**
Professor Samar Aoun
s.aoun@curtin.edu.au

**Biography**
Professor Samar Aoun (Curtin University, Western Australia) is a palliative care researcher with a public health approach and a focus on under-served population groups such as people with Motor Neurone Disease, terminally ill people who live alone and family caregivers pre- and post-bereavement. Professor Aoun has undertaken a number of projects that informed policy on service planning and the development of support structures for the palliative care community at the state and national levels.

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**Authors**
Professor Samar Aoun, Ms Kathy Deas, Professor Linda Kristjanson, Professor David Kissane

**Title of Presentation**
Identifying and addressing the support needs of family caregivers of people with ALS/MND: a feasibility study

**Background**
Family caregivers of people with Motor Neurone Disease (ALS/MND) experience adverse health outcomes as a result of their caregiving experience. This may be alleviated if their support needs are identified and addressed in a systematic and timely manner.

**Objective**
The objective of this study was to assess the feasibility and relevance of the Carer Support Needs Assessment Tool (CSNAT) in home based care during the caregiving period, from the perspective of family caregivers of people with ALS/MND and their service providers.

**Programme Description**
The feasibility study was conducted during four months in 2014 in Western Australia (WA) through the MND Association of WA. Thirty family caregivers and four care advisors participated in trialing the CSNAT intervention which consisted of two visits from care advisors (6-8 weeks apart) to identify and address support needs. Family caregivers' feedback was obtained via telephone interviews and care advisors' feedback via a self-administered questionnaire.

**Clinical Outcomes**
Twenty four participating caregivers completed the study (80% completion rate) and identified support priorities being "knowing what to expect in the future", "knowing who to contact if concerned" and "equipment to help care", "dealing with your feelings and worries", and "having time for yourself in the day". The majority found the form easy to complete and that it has adequately addressed their needs and it gave them a sense of validation, reassurance and empowerment. Care advisors advocated the CSNAT approach as an improvement to standard practice, allowing them to more clearly assess needs and offer a more structured follow-up and a focus on the caregiver and family.

**Recommendations To The Field**
The CSNAT approach for identifying and addressing family caregivers support needs was found to be relevant and feasible by ALS/MND family caregivers and care advisors and a larger trial is needed next to ascertain its effectiveness. The tool provided a formal structure to facilitate discussions with family caregivers to enable needs to be addressed. Such discussions can also inform an evidence base for the ongoing development of services, ensuring that new or improved services are designed to meet the explicit needs of family caregivers of people with ALS/MND.

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**Speaker**
Tammy Soukup
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**Biography**
Tammy Soukup is certified as an Adult Health Clinical Nurse Specialist. She has worked for 10 years in the specialty of neurology focusing on disease management of the patient with neurological diseases including stroke, ALS/MND, and Parkinson's disease. Tammy developed education for nursing staff on neurological assessments and developed an online tutorial for nurses on care of the patient with dementia. Tammy currently works at the VA Medical Center in Milwaukee in the Outpatient Neurology Clinic.

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**Authors**
Tammy Soukup, ACNS-BC, APNP

**Title of Presentation**
Communicating with ALS/MND patients that have dementia

**Background**
Research findings state up to 50% of patients with Amyotrophic Lateral Sclerosis (ALS/MND) have cognitive or behavior issues, with 20% of the patients progressing to Frontal Temporal Dementia (FTD), resulting in a deterioration of memory with behavior changes. The VERA communication tool stands for
V=validation
E= emotion
R=reassure
A=activity
The framework provides an easy mnemonic for professionals and caregivers to use when communicating, redirecting, and caring for ALS/MND patients.

**Objective**
To introduce and engage stakeholders with an evidence-based communication tool to utilize in caring for patients.

**Programme Description**
A non-experimental Likert scale was used to determine staff nurses knowledge , skill, and ability to alter patient responses when using the VERA communication tool. The rating determined if nurses had the opportunity to use the VERA communication tool and if patient responses could be redirected. Knowledge of staff using the VERA communication tool was evaluated to test if knowledge was retained three months after an educational session.

**Clinical Outcomes**
Expected outcomes were increased confidence and ability of the nursing staff, caregivers and families to apply the VERA communication tool when communicating, redirecting, and caring for ALS/MND patients.

**Recommendations To The Field**
Stakeholder input of the VERA communication framework tool was rated by nursing staff as an easy to use, effective tool that has a far-reaching impact to enhance the patients' quality of care.

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JW Marriott Grande Lakes, Orlando, FL, USA | 10 December 2015

**Speaker**
Judy Lyter, LPC, NCC, MS, RN
judy@alsphiladelphia.org

**Biography**
Judy Lyter, LPC, NCC, MS, RN is a licensed professional counsellor and an RN who works as the nurse counselor at Penn State Hershey with the ALS Association Greater Philadelphia team. Her career span also has included that as an oncology research nurse; having a private practice for those dealing with chronic or terminal illness; and a nurse educator for the Oncology Nurse Society.

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**Authors**
Judy Lyter, RN, MS, LPC, NCC, Travis Haines, MA, CCRC, Susan Walsh, RN, ACNS-BC, Anne Morris, MPH, Sharon Abrahams, PhD, & Zachary Simmons, MD2

**Title of Presentation**
Transitioning a research tool into clinical practice: Use of the Edinburgh cognitive and behavioral ALS/MND screen in an ALS/MND clinic

**Background**
The presence of cognitive and behavioral dysfunction in ALS/MND is well documented. Identifying such changes is an important part of clinical care, yet there is no consensus on the best instrument for screening for cognitive and behavioral dysfunction in an ALS/MND clinic. An ALS/MND-specific screen, the Edinburgh Cognitive and Behavioral ALS Screen (ECAS), has been developed and validated, but has not been tested for feasibility and usefulness in an ALS/MND clinic setting.

**Objective**
To evaluate the administration of the ECAS in an ALS/MND clinic and the use of the results in the care of patients in a multidisciplinary ALS/MND care setting.

**Programme Description**
Two members of a university-based, multidisciplinary ALS/MND clinic, a nurse counselor and research coordinator, were trained and certified in the administration of the ECAS by the developer, Dr. Sharon Abrahams. Patients were eligible for screening during their second or third multidisciplinary ALS/MND clinic visit. Patients were excluded from screening if they had depression or a prior history of neurological or mental health diagnosis, were too fatigued or weak, or had limited clinic time. The behavioral portion of the screen was completed with the caregiver. The results were scored and reviewed with the clinic team. Screening results that demonstrated significant cognitive or behavioral changes were communicated to the caregiver with appropriate psychoeducational support from the counselor.

**Clinical Outcomes**
The ECAS has successfully been administered to 55 patients in clinic. Administration takes 15-20 minutes. Nonverbal patients can also be assessed. Scoring is completed and results reported to the clinic team for input. The results provide an important framework for the clinic team to make recommendations for safety, monitoring, and follow-up care. The ECAS results assist clinicians in developing strategies specific to cognitive areas that are affected. Administration of the behavioral portion of the screen provides an opportunity to hear concerns from the caregiver that may not have been shared in front of the patient. It provides the screener an opportunity to educate the caregiver regarding potential behavioral problems that may require monitoring. The ECAS has been adopted as standard of care for screening cognitive and behavioral dysfunction in the ALS/MND clinic.

**Recommendations To The Field**
The ECAS is a valid ALS/MND-specific cognitive screen that can easily be administered and interpreted in a busy ALS/MND clinic. It provides an opportunity for both patient assessment and caregiver teaching. The ECAS provides information to the multidisciplinary team to develop specific recommendations for care as they relate to cognitive and behavioral changes.

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**Speaker**
Samantha Neumann
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**Biography**
Samantha received a bachelor's degree in biology from Emory University and a master's degree in genetic counseling from Northwestern University. Currently she is a full-time prenatal genetic counselor and also helps coordinate send-in laboratory services at Insight Medical Genetics in Chicago, IL. This research originated in fulfillment of her Master's thesis and has helped contribute to the care and support protocols offered at the Les Turner ALS Foundation in Chicago.

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**Authors**
Samantha Neumann, MS; Lisa Kinsley, MS, CGC; Nailah Siddique, RN, MSN; Susan Magasi, PhD; Suzanne O'Neill, PhD; Laurie Fieldman, MSW, LCSW; Teepu Siddique, MD.

**Title of Presentation**
Parental disclosure of familial ALS/MND diagnosis and mutation status to children: Perceptions of young-adult offspring

**Background**
With every diagnosis of FALS/MND comes the decision of when and how to disclose it to family members and loved ones. There are currently no guidelines for helping patients disclose a diagnosis of FALS/MND to their families or studies describing how patients diagnosed with ALS/MND disclose this information to their families, and very few about disclosure in other diseases. Perspectives of children have not been studied to see if they want this information and how they feel about the disclosure process.

**Objective**
This qualitative study examined parents' communication with their children about the diagnosis of ALS/MND and the genetic component of the disease, and explored if there was a relationship between the disclosure experience and decision-making about genetic testing options. Our goal was to determine whether there is a need for genetic counselors and other healthcare professionals to assist FALS/MND patients with strategies for sharing their diagnosis and consequent options for genetic testing with their young adult children.

**Programme Description**
We spoke with 8 individuals utilizing a semi-structured interview. Participants had a parent with a SOD1 or C9orf72 FALS/MND mutation, and were ages 20-33 years. Interviews attempted to identify whether timing and content of disclosure of parental FALS/MND influences the outlook of young adult offspring on FALS/MND genetic testing.

**Clinical Outcomes**
Participants were most likely to prefer open honest communication during the disclosure process, but they also acknowledged that everything changes the moment the diagnosis is disclosed and that "ignorance is bliss". Communication was dictated by disease awareness within the family. Participants each had a unique experience with the presence of ALS/MND in their lives once the diagnosis was made; yet this was often tied to a sense of loss of control of their own futures. Most participants referred to a duty to protect their family from the emotional pain and anxiety experienced from the knowledge of the diagnosis.

**Recommendations To The Field**
Opinions about testing were determined by wanting to gain back control over their lives, or an avoidance of the stress testing would cause them. In conclusion, information obtained from this study may help genetic counselors guide their patients in the disclosure process and assist at-risk young adult family members during the genetic testing decision-making process.

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**Speaker**
Melinda S. Kavanaugh, PhD, LCSW
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**Biography**
Melinda S. Kavanaugh, PhD, is an Assistant Professor in the Helen Bader School of Social Welfare, University of Wisconsin – Milwaukee. Dr. Kavanaugh's primary research focus is on young carers in the U.S. Having conducted a study of young carers in Huntington's disease, she is currently the PI of a national pilot study of young carers in ALS/MND, and Co-PI of a collaborative family caregiving study of Latino caregivers, including youth caregivers, in Milwaukee. She holds a PhD in social welfare from the University of Wisconsin, Madison, where she was a National Institutes for Mental Health (NIMH) pre-doctoral fellow in family caregiving. Her interest in young carers developed over her years as a clinical social worker for the Huntington's Disease Center of Excellence at Washington University School of Medicine, in St. Louis, MO, where she worked with families affected by Huntington's disease, Parkinson's disease and other neurological disorders.

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**Authors**
Melinda S. Kavanaugh, PhD, LCSW; Lori Banker Horner, BA, LPN; Paul Barkhaus, MD

**Title of Presentation**
Psychosocial benefits of participating in research: A supportive tool for ALS/MND young carers

**Background**
Caregiving is a critical component of how ALS/MND patients (PALS/MND) survive with a quality of life (QOL). Thus, supporting caregivers is a vital for the well-being of both caregivers and PALS. Despite the numerous groups and programs for adult caregivers, little attention is paid to children and youth who provide care. An estimated 1.4 million young carers (< 19 years of age) live in the U.S (including young carers in ALS/MND). Young carers experience depression, anxiety, limited social support and peer isolation. With the lack of young carer programs in the US, young carers have few outlets to discuss their caregiving experience, leaving them unacknowledged and unsupported. Thus, finding new and unorthodox ways to support ALS/MND young carers is vital.

**Objective**
To describe how the act of participating in a research study on caregiving, and the effects of caregiving, may have a positive affect on the psychosocial well-being, and sense of isolation in ALS/MND young carers.

**Programme Description**
A pilot study of 19 young carers was carried out in the Midwest U.S. Each young carer participated in a one-on-one interview with a social work researcher, asking about their caregiving experience, support and family life. The goal of the research was to provide initial data into the previously undocumented lives of ALS/MND young carers in the U.S., supporting the development of programs and services targeting ALS/MND young carers.

**Clinical Outcomes**
An unexpected outcome came at the end of each interview when the researcher asked how the participant felt talking about ALS/MND and being a young carer. It was expected that the youth would feel emotional and need some time to decompress. However, the opposite happened. The youth described feeling “happy”, “open” and “good to feel free to talk about something they never mention to anyone, even their own family”. Young carers felt less isolated and more supported – simply by being a part of the study. By sharing their stories, young carers felt less alone and for the first time, many stated they felt “heard” and “acknowledged”.

**Recommendations To The Field**
View youth participation in research as an extension of the support and acknowledgement needed for young carers. Given the isolation of this population, the results highlight the need for more research on youth affected by ALS/MND, including young carers. Research not only supplies vital data towards the development of support programs for young carers, but also allows the much needed opportunity for youth to tell their caregiving stories.

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JW Marriott Grande Lakes, Orlando, FL, USA | 10 December 2015

**Speaker**
Rebecca Axline, LCSW-S
raxline@houstonmethodist.org

**Biography**
Rebecca Axline, LCSW-S is Supervisory Clinical Social Worker at the Houston Methodist Neurological Institute.

Rebecca completed her undergraduate degree in 1976 at Oklahoma State University and her graduate degree in 1982 at University of Wisconsin-Madison.

Rebecca has over 30 years of clinical social work experience working in a variety of settings including medical centers, active duty military bases, Veteran Administration Medical Centers, employee assistance, hospice care, and school districts. She has management experience in the areas of psychiatric care, employee assistance and customer service.

Her current role starting in 2006 has been the development of an outpatient Social Work program at Houston Methodist Neurological Institute. She continues to provide program development and clinical intervention with a primary focus of helping patients and family members cope with the stress of diagnosis and treatment of neurological disorders and illnesses.

Additionally, Rebecca provides teaching and mentorship to graduate Social Work students and clinical supervision guidance to LMSW social workers. She has been a speaker at informal and formal presentations to community groups, support groups, and continuing education attendees.

INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

**Authors**
Rebecca Axline, LCSW-S; Dagmar Munn, M.A.

**Title of Presentation**
Burnout can happen to patients too: How to address in the clinical setting

**Background**
Research has indicated that individuals diagnosed with ALS/MND may experience feelings of emotional exhaustion, irritability, insomnia, guilt, resentment, depression, anger, and loneliness. Negative feelings may stem from lack of socialization, self-expression, self-value and/or loss of control. Addressing these emotions may be important as a grounding force, especially in times of physical changes.

**Objective**
To explore use of evidence based techniques such as screening questionnaires, motivational interviewing, and mindfulness training with individuals with ALS/MND. Techniques focused on increasing socialization, self-expression and self-value as possible means of bringing balance back into the life of the individual with ALS/MND.

**Programme Description**
One-on-one counseling between patient and ALS/MND clinic social worker for assessment, education and support. Assessment done using Ryff scales of Psychological Well-Being. Baseline scale completed. Post scale collected 30 days post intervention. Self-directed activities and resource material shared with patient in person and through email. Education includes use of Bill Hettler “Six Dimensions of Wellness” and open ended questions. Significant support person included in educational piece, if possible.

**Clinical Outcomes**
- 26 individual sessions completed. Data collection continues at an average of 20 per month.
- Baseline scores indicated levels of well-being in the higher range for purpose in life, positive relationships and in the lower range for environmental mastery.
- Sessions averaged 40 minutes in length.
- Open ended questions elicited increased engagement, sharing of emotional responses, and opportunity for validation and affirmation.
- While many knew of concept of “wellness”, they thought it pertained specifically to physical activity.
- Project was initiated based on writings of person with ALS/MND who used self-education and wellness dimensions to maintain balance; this information validated process to participants.
- Participants and significant others reported enthusiasm for receiving additional resource material.

**Recommendations To The Field**
Incorporating clinical techniques of mindfulness and motivational interviewing may provide an excellent way of enabling individuals with ALS/MND to regain or maintain a sense of choice, self-worth, and power over their lives – in the midst of often rapidly changing physical abilities. This in turn may offer additional strategies for addressing negative and often uncomfortable emotions. By modeling this practice, providing educational tools, and ongoing encouragement in the clinical setting, ALS/MND teams could enhance their holistic approach to treatment of ALS/MND.

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JW Marriott Grande Lakes, Orlando, FL, USA | 10 December 2015

**Speaker**
Shivangee Thorne, LCSW
shivangee.thorne@carolinas.org

**Biography**
Shivangee Thorne, MSW, LCSW is a clinical social worker with Carolinas HealthCare System Neurosciences Institute ALS/MND Clinic in Charlotte, NC. She received her Masters of Social Work from Washington University in St. Louis' George Warren Brown School of Social Work in 2003, where she was a Whitney M. Young Scholar. Shivangee has been a medical social worker for 12 years, serving patients in a variety of settings, including acute care, emergency room, Hospice, outpatient and for the past year at the ALS/MND clinic. She has a passion for working with patients and their families as they experience chronic and terminal illnesses, providing resource referral, emotional support, as well as assisting patients with advanced care planning and end of life discussions.

INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

**Authors**
Louise Frumkin, MSW, LCSW and Shivangee Thorne, MSW, LCSW

**Title of Presentation**
From subjective to objective: Useful tools for initiating end of life discussions with ALS/MND patients

**Background**
The Carolinas ALS Center in Charlotte, NC treats approximately 200 patients diagnosed with ALS/MND. As social workers serving terminally ill patients, we are committed to offering the additional medical, emotional and spiritual support of hospice. Given the divergent viewpoints regarding hospice within our multi-disciplinary team, we recognized a need for an objective and unified approach to discussing end of life decisions and interventions. Coinciding with underutilization of hospice, our entire team had a growing concern about the increasing number of patients who were receiving a tracheostomy under emergency circumstances without adequate education, planning or understanding of quality of life implications. In an effort to unify our team and to better educate patients and caregivers regarding end of life decisions, our entire multi-disciplinary team developed two tools which are now an integral part of our practice.

**Objective**
To help other ALS/MND centers standardize their approach to end of life discussions.

**Program Description**
This program will discuss the different perspectives amongst multi-disciplinary team members regarding end of life discussions, and will outline the process our team went through to arrive at a consensus regarding best practices for introducing hospice vs. tracheostomy as treatment options. We will review the two documents we created which now serve as integral tools in our clinical practice. The documents, “Points to consider when thinking about hospice” and “Tracheostomy Ventilation: Points to consider” offer specific guidelines and answer many of the questions raised by patients and family members.

**Clinical Outcomes**
These documents have greatly enhanced the quality and quantity of discussions we have with our patients regarding end of life decisions. The criterion have provided us with objective measures which help neutralize the very difficult task of discussing critical end of life decisions. Patients who choose to have the tracheostomy are better educated and better prepared for the life altering impact of this procedure. Patients who choose either to accept or decline hospice are better educated about the services offered and are more realistic about why they will benefit from the additional support. As a multi-disciplinary team, we have a greater understanding of each discipline’s perspective and are able to work together in a more cohesive fashion.

**Recommendations to the Field**
Presenting objective criterion and openly discussing the implications of hospice vs. tracheostomy with patients and family members in advance of emergent situations helps prepare everyone involved for the next stage of the disease.

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# ALLIED PROFESSIONALS FORUM

JW Marriott Grande Lakes, Orlando, FL, USA | 10 December 2015

**Speaker**
Laurie B. Fieldman
lfieldman@lesturnerals.org

**Biography**
Laurie B. Fieldman is the Director of Social Services for the Les Turner ALS Foundation in Skokie, IL and has been with the Foundation for sixteen years. She provides in-home counseling to patients and family members, as well as facilitates monthly support groups. Ms. Fieldman completed her graduate work at the University of Chicago School of Social Service Administration and she also holds a Masters of Management degree from National Louis University.

Credentials:
1999–Present Director of Social Services, Les Turner ALS Foundation, Skokie, IL
1993–2003 Founder and Director, Marcie's Place Camp for Grieving Children, Chicago, IL

Lectures:
2014 ALSA Clinical Conference in Phoenix, AZ, "ALS Families"
2014 ALSA Clinical Conferece in Phoeniz, AZ, "Children in ALS Families"
2013 FALS Summit at the National ALSA Advocacy Day and Public Conference, "Communicating with Children and Young Adults"
2012 International ALS/MND Symposium, "Helping Children in ALS Families"
The 2012 Les Turner ALS Foundation Annual Education Meeting, "Coping Strategies for the ALS Couple"
Managing the Emotional Impact and Improving the Quality of Life for ALS
2012 ALS/MND Nursing Symposium, "The ALS Couple"
2011 ALS/MND Nursing Symposium, "Coping with ALS"
2009 ALS/MND Nursing Symposium, "Helping Children Cope with ALS in the Family"

INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

**Authors**
Laurie B. Fieldman, LCSW

**Title of Presentation**
PDA (Personal Death Awareness)

**Background**
Working with ALS/MND is particularly taxing for the professionals who do not yet have a treatment or cure for their patients. There are times when professionals feel less able to cope with the pain and loss than others, and many variables affect one's emotional stamina. Personal Death Awareness is a variable that should be understood in order to provide patients with the best care possible.

**Objective**
This presentation will help to raise the awareness of the professional about her/his personal experiences with illness and death, and how those experiences affect his/her ability to care for ALS/MND patients and families.

**Programme Description**
This programme will consist of a guided exercise to increase self-awareness of the professional's feelings about illness and death, known as PDA or Personal Death Awareness. The lecture will utilize the results of the exercise to help the professional gain insight into her/his own feelings, and how these may affect the professional's level of compassion and emotional stamina.

**Clinical Outcomes**
The goal of this session is to provide allied health professionals with a better awareness of the issues they bring to their care of ALS/MND patients, and a better understanding of how those issues affect their work. With this understanding, we can improve the level of care we give to our ALS/MND patients and families.

**Recommendations To The Field**
As professionals, we pride ourselves on being able to help others. However, it is necessary to raise our Personal Death Awareness so that we better cope with the emotions that inevitably arise when working with ALS/MND patients and their families. This will help the professional to raise her/his level of skill and compassion.

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# ALLIED PROFESSIONALS FORUM

JW Marriott Grande Lakes, Orlando, FL, USA | 10 December 2015

**Speaker**
Jennifer Armstrong
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**Biography**
Jennifer Armstrong, RN, MSN, MHA, is the lead nurse for the Northwestern Division of Neuromuscular Medicine in Chicago, IL. Jennifer joined the group in 2004, and has been involved with the Les Turner ALS Foundation, the International Alliance, and in the ALS/MND Community at-large helping to educate nurses and other allied health professionals. Jennifer graduated from Indiana University School of Nursing and completed her Master's of Science in Nurse and Master's of Health Administration in 2012.

INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

**Authors**
Jennifer Armstrong

**Title of Presentation**
What ALS/MND health professionals need to know about today's respiratory therapies

**Background**
Health professionals in ALS/MND Centers need to know how to address the respiratory needs of the persons living with ALS/MND throughout the disease process. Interventions should start with diagnosis and continue to be added throughout the progression of disease.

**Objective**
1. Describe challenges to ALS/MND health professionals helping with respiratory issues.
2. Discuss airway clearance device selection and timing of interventions.
3. Discuss care issues for people living with ALS/MND in their home on non-invasive or mechanical ventilation.

**Programme Description**
1. Describe challenges to ALS/MND health professionals helping with respiratory issues.
    a. How to assess respiratory symptoms, especially early in disease.
    b. How the ALS/MND health professional can impact disease progression by educating about respiratory issues.
2. Discuss airway clearance device selection and timing of interventions.
    a. When to initiate what devices
    b. Devices used for airway clearance
        i. Abdominal Binder
        ii. Resuscitator Bag
        iii. Nebulizer
        iv. Suction
        v. High Frequency Chest Wall Oscillation
        vi. Mechanical In/Ex-Sufflator
        vii. Non/Invasive Ventilation
3. Discuss care issues for people living with ALS/MND in their home on non-invasive or mechanical ventilation.
    a. Caring for home bound non-invasively ventilated patient
        i. Remote monitoring and therapies available and how to use them to optimize ventilation
    b. Caring for home bound mechanically ventilated patient
    c. Key issues related to the safety and emergency preparedness with patients

**Clinical Outcomes**
Heighten awareness of ALS/MND health professionals to key respiratory interventions to begin early in disease. Teach ALS/MND health professionals how to impact outcomes with monitoring via respiratory devices. Demonstrate online and real time features of devices to help optimize therapy.

**Recommendations To The Field**
This learning experience will explain to new and seasoned ALS/MND health professionals about respiratory interventions. More importantly, the experience will demonstrate current device features to help them with optimizing therapies to achieve highest quality of life.

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# ALLIED PROFESSIONALS FORUM

JW Marriott Grande Lakes, Orlando, FL, USA | 10 December 2015

**Speaker**
Julie Young
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**Biography**

Julie Young qualified from Coventry University in 2003 with a degree in Physiotherapy. She has specialised in respiratory physiotherapy since 2005 and has a wide range of experience with acute and chronic respiratory conditions.

Julie obtained a Postgraduate Certificate in Advanced Cardiorespiratory Physiotherapy from University College London in 2009 and is due to complete her MSc in Advanced Physiotherapy this year.
She has presented at a number of study days and has lectured on the Brookes undergraduate BSc Physiotherapy programme.

As service lead for the Oxford Sleep and Ventilation Service, Julie provides home ventilation for a variety of patients with ventilatory failure and has a particular interest in the management of cough in patients with neuromuscular weakness.

INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

**Authors**
Julie Young and Rachael Marsden

**Title of Presentation**
Improving the respiratory referral and assessment pathway

**Background**
Respiratory management is an essential component of the care of patients with ALS/MND and the UK NICE Guidelines (2010) recommend timely referral to respiratory services and provide detailed guidance on the decision making process.

Strong links exist between the Oxford MND Care Centre and the Oxford Sleep and Ventilation Service, providing good access to non-invasive ventilation and cough management. However, a delay was identified in the referral pathway to respiratory services whereby patients had to wait for overnight oximetry assessment that, in turn, delayed their assessment by the respiratory team.

At the ALS/MND Symposium Allied Professionals Forum in Brussels 2014 the two service leads had the idea of providing oximeters in ALS/MND clinic at the point of respiratory referral, therefore reducing the number of steps in the referral pathway.

**Objective**
To optimise the respiratory referral and assessment pathway by introducing provision of oximetry assessment in MND clinic.

**Programme Description**
Funding for three oximeters was gained from the MND Association and the new pathway was implemented in April 2015. The new pathway involved the provision of oximeters to patients in ALS/MND clinic alongside their referral to the Sleep and Ventilation Service. The patient was shown how to use the oximeter and asked to return it by post to the Sleep and Ventilation Service. The results were reported by a Respiratory Consultant and an appointment arranged if appropriate.

This differed from previous practice whereby, on receipt of referral by the Sleep and Ventilation Service, the patient was added to a waiting list for overnight oximetry. An oximeter was sent to the patient when available with written instructions and returned in the post.

**Clinical Outcomes**
An audit of the impact of the pathway on assessment times was performed for the first 3 months of the new pathway (n=6) compared to the previous 3 months (n=5). (We plan to collect data for 6 months pre and post). There was a reduction in time between ALS/MND clinic appointment and reporting of oximetry results from 30 to 11 days. This was achieved by removing the delay between referral and assessment, but also due to the more timely return of the device by the patient.

**Recommendations To The Field**
This case supports the need for joined up working between teams and highlights how small changes to processes and pathways can greatly improve the quality of care that we provide for those living with ALS/MND. It also demonstrates that the Allied Professionals Forum provides an invaluable environment to reflect on our practice and make changes that can make significant improvements to the patient care.

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# ALLIED PROFESSIONALS FORUM

JW Marriott Grande Lakes, Orlando, FL, USA | 10 December 2015

**Speaker**
Emily K. Plowman
eplowman@phhp.ufl.edu

**Biography**
Dr. Emily Plowman is an Associate Professor at the University of Florida in the departments of Speech, Language, Hearing Sciences, Physical Therapy and Neurology. She serves as the clinical director at the Center for Respiratory Rehabilitation and Research and is the founding director of the Neuromotor Speech and Swallowing Restoration laboratory. Emily is a certified Speech-Language Pathologist with a Doctorate Degree in Neurorehabilitation and a Post-Doctoral Fellowship in Neuroscience.

Dr. Plowman holds current funding from the National Institute of Health to conduct innovative research aimed at developing efficacious 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. She also provides clinical services at a multidisciplinary ALS/MND clinician and teaches graduate level courses in Dysphagia, Medical Speech-Language Pathology and Research Methodology.

Emily serves on the Northeast Amyotrophic Lateral Sclerosis Consortium (NEALS) Bulbar and Ventilation specialty Committees and is on the Board of Directors for the Dysphagia Research Society. She is an accomplished clinician and educator who lectures extensively both nationally and internationally and was 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.

INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

**Authors**
Emily K. Plowman

**Title of Presentation**
Updates in the evaluation and treatment of airway protection and dysphagia in ALS/MND

**Background**
Dysphagia, dystussia and aspiration are prevalent in ALS/MND and contribute to malnutrition, aspiration, pneumonia and death. These factors necessitate early detection and screening of at-risk patients to ensure maintenance of safe oral intake and pulmonary function. Further, treatments that improve and/or maintain cough, airway protection and swallowing kinematics in PALS/MND are currently lacking and warrant investigation.

**Objective**
*Study 1:* Determine the discriminant ability of voluntary cough airflow measures and a self-administered patient report (Eating Assessment Tool-10) in predicting the presence of penetration/aspiration in individuals with ALS. *Study 2:* Determine the Impact of Expiratory Muscle Strength Training (EMST) on respiratory, cough and swallowing function in individuals with ALS.

**Programme Description**
*Study 1:* 70 PALS/MND (El-Escorial criteria) completed voluntary cough spirometry testing, the EAT-10 survey and underwent a standardized videofluoroscopic swallowing evaluation (VFSE). A rater blinded to aspiration status derived six objective measures of voluntary cough airflow and scored the EAT-10 surveys. Two raters independently rated swallowing airway safety using the validated Penetration Aspiration Scale (PAS). A between groups ANOVA (safe vs. unsafe swallowers) was conducted and sensitivity, specificity, area under the curve (AUC) and likelihood ratios calculated. *Study 2:* 50 PALS/MND (El-Escorial criteria) participated in a blinded randomized sham control clinical trial. Patients underwent baseline testing of respiration, swallow and cough function and were then randomized to either the EMST or sham treatment conditions. Treatment was performed with an active trainer set at 50% of individualized maximum expiratory pressure (MEP) or using a sham trainer against atmospheric pressure, five-days per week, for eight-weeks. A post-treatment evaluation was administered. A mixed model ANOVA was performed with post-hoc testing.

**Clinical Outcomes**
*Study 1:* Cough Volume Acceleration, Peak Expiratory Flow Rate and Peak Expiratory Flow Rise Time were significant predictors of penetration/aspiration status in this group of PALS/MND (Sensitivity: 74-92%; Specificity: 74-78%). ALS/MND self-report of swallowing impairment using the validated EAT-10 survey was also able to discriminate between safe vs. unsafe swallowers with a cut value of 8 (sensitivity: 85.7%, specificity: 72%, NPV: 95.5%) with PALS/MND 3.05 times more likely to aspirate if they scores >8 on the EAT-10. *Study 2:* At this time all patients have been recruited and there are 4 patients completing treatment. At the completeion of the trial (July 1st) statistical analysis will be performed on the complete dataset. The interim data demonstrate that the active EMST group MEPs increased 28% pre vs. post intervention, while the sham group MEPS increased 4.9% pre vs. post intervention.

**Recommendations To The Field**
PALS/MND self-reports of swallowing impairment using the EAT-10 and expiratory measures of voluntary cough waveforms was able to differentiate safe vs. unsafe swallowers. These easy to administer screening tools could represent a quick and meaningful aide to dysphagia screening in busy ALS/MND clinics for identification and referral of dysphagic individuals. EMST may provide benefit in maintaining subglottic air pressure generation and airway protection during swallowing.

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# ALLIED PROFESSIONALS FORUM

JW Marriott Grande Lakes, Orlando, FL, USA | 10 December 2015

**Speaker**
Crystal Collinge
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**Biography**
Crystal has been practicing as a Speech Language Pathologist in the Calgary ALS/MND clinic for two and a half years. She participates in assessment and treatment of dysphagia and communication impairment.

In the ALS/MND clinic she has run several communication support group sessions to educate patients and caregivers regarding communication strategies and alternative communication modes and provide a supportive environment to practise communicating. She helped to organize an ALS/MND education day for professionals working in the central and southern Alberta area to encourage increased knowledge and collaborative practise.

Tiffany has been practicing as a Registered Dietitian (RD) for almost ten years. Her passion is nutrition counseling and supporting patients with empathy and compassion. In her position in the neurosciences clinics, Tiffany has collaborated with other members of the multidisciplinary team to create unique cooking/eating programs. Tiffany has been the RD offering nutrition support in the Calgary ALS/MND clinic for 3 years. She is honoured to be working with such a special population and aspires to make a positive difference in each of her patient's lives.

INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

**Authors**
Crystal Collinge, R.SLP, SLP(C) and Tiffany Lafleur, RD

**Title of Presentation**
Improving the eating experience for people with ALS/MND

**Background**
Sitting around a table with family and friends sharing a meal or a drink is a ritual in all cultures that encourages social exchanges and builds relationships. In ALS/MND patients, dysphagia and reduced appetite can lead to eating struggles that result in compromised nutritional status and changes in the overall experience of sharing a meal with peers. Changes in diet texture and strategies for improving nutritional intake are common interventions; however, support and education may be limited outside of the clinical setting leaving patients with a feeling of uncertainty and or isolation.

**Objective**
- Create an environment where patients feel supported and normalized in their eating struggles
- Demonstrate strategies and provide education to effectively modify food texture and improve nutritional intake.

**Programme Description**
A Speech-Language Pathologist (SLP) and a Registered Dietitian (RD) led four – one hour group sessions in the Wellness Kitchen on site at the Calgary ALS/MND clinic. Patients and their caregivers were invited to attend. Session themes included breakfast, soups, smoothies and supper. Demonstrations included modifying textures of food and liquid and providing strategies to increase calories and protein. Food and drink samples were offered and nutrition and dysphagia education was also provided. Handouts with recipes, tips and calorie/protein analysis were given and participants completed session evaluations.

**Clinical Outcomes**
Preliminary findings revealed that the overall patient experience was positive. Patients found the sessions informative and enjoyed the interactive atmosphere. One patient commented on the benefit of collaboration between patients at various stages of dysphagia. Patients took home practical suggestions and ideas to enhance their eating experience. The interactive nature of the program enabled patients to see and taste food items and feel normalized regardless of their swallow function. As a result, patients appeared more likely to change behaviours as compared to the simple instruction provided during a regular clinic visit.
Patient quotes:
“I am getting to the point where I no longer want to eat or drink in public. But you have created such a warm friendly atmosphere.” “I gained 5 lbs since the smoothie session.”

**Recommendations To The Field**
- Teaching skills in a more natural, home-like location
- Providing professional advice and expertise within a support group setting
- Demonstrating recommendations and tasting food and drinks
- Encouraging patients to share experiences
- Opportunity to normalize challenges with eating
- Proactively providing information using a sensitive delivery

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# ALLIED PROFESSIONALS FORUM

JW Marriott Grande Lakes, Orlando, FL, USA | 10 December 2015

**Speaker**
Karen Pearce
karen.pearce@mndassociation.org

**Biography**
Karen Pearce, MBA,MCSP, GradDipPhys, is the Director of Care (South) for the MND Association . She is a qualified physiotherapist and worked in various clinical and managerial roles in the NHS for 30 years.

She joined the MND Association in 2010 and leads on strategic development of the Association's Support Services for people with ALS/MND including wheelchair provision, communication aids, equipment loan services and support grants for people with ALS/MND and their carers. She is also responsible for delivery of regional care and influencing statutory service commissioning.

INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

**Authors**
Fiona Eldridge, Jenny Rolfe, Christine Orr, Karen Pearce

**Title of Presentation**
Anticipatory approaches to wheelchair provision

**Background**
It was found that people living with MND were often waiting a long time for wheelchair assessment and provision. This was partly due to the prescription required to meet clinical need being classed as a non-standard leading to increased costs and lead times. This impacted on independence, function and quality of life and resulted in higher costs to statutory services with repeated staff visits.

**Objective**
To develop a wheelchair pathway and prescription which was affordable to statutory wheelchair services that provides people living with MND the right equipment at the right time.

**Programme Description**
The project has three strands; a neuro powered wheelchair prescription, a pathway and specialist wheelchair therapists.
Extensive collaborative work between the MND Association, three leading wheelchair manufacturers, people living with MND and statutory services took place to develop the neuro powered wheelchair prescription. This prescription is designed to meet on-going changing clinical needs, and to work within the anticipatory model of care.
The project has developed a wheelchair provision pathway to streamline service delivery to meet the wheelchair needs of people living with MND.
The project has led to three specialist wheelchair therapists working with MND Specialist Care Centres. This adds value to the multi disciplinary team clinic and enables people with MND to be better informed about wheelchair availability and to be referred to their statutory provider earlier. The specialist therapists offer training and support to statutory service therapists about the powered neuro wheelchair prescription and the benefits of anticipatory provision.

**Clinical Outcomes**
This project has delivered a robust wheelchair prescription designed to meet the changing clinical needs of a person living with MND. A range of powered neuro wheelchairs are now available from three manufacturers. Several events, to secure support from statutory services, were held by the MND Association and the manufacturers to launch the prescriptions in 2014. A short film which explains the clinical reasons for the powered neuro wheelchairs was released in July 2014 and has received 1212 views. The project is being externally evaluated, with data, including impact on quality of life, will be available by December 2015.

**Recommendations To The Field**
There is international interest in the project and how the project concepts could be adopted in other countries. The combination of the three strands of the project has had a positive impact on wheelchair provision for people living with MND in England and the implementation of any or a combination of these could be applied internationally.

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# ALLIED PROFESSIONALS FORUM

JW Marriott Grande Lakes, Orlando, FL, USA | 10 December 2015

**Speaker**
Karol Connors
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**Biography**
Karol Connors is the Manger of Physiotherapy and Occupational Therapy at Calvary Health Care Bethlehem, Melbourne, which provides the Statewide Progressive Neurological Diseases Service for the state of Victoria, Australia.

INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

**Authors**
Karol Connors, Lisa Mahony, Susan Mathers, Prue Morgan, Maryanne McPhee, Sarah Solomon, Anna Smith

**Title of Presentation**
Assistive equipment use by people with ALS/MND in Australia

**Background**
People with ALS/MND (PALS/MND) benefit from access to adaptive equipment to address disability and improve social participation. This equipment ranges from small items such as adaptive cutlery or a foot splint, through to large expensive items such as motorised wheelchairs and electric beds. As the pattern of muscle weakness varies between phenotypes, it could be expected that equipment need also varies by phenotype. Equipment use is further complicated by the passage of time; equipment needs change and progress over the course of the disease. There are therefore many considerations for therapists attempting to predict and meet the equipment needs of PALS/MND.

**Objective**
This study aimed to examine the relationship between the type of equipment prescribed, the length of time since onset of symptoms and phenotype differences in equipment use by PALS/MND.

**Programme Description**
Prospective, longitudinal, observational consecutive cohort study in a multidisciplinary clinical setting, Melbourne, Australia. The following data was collected by treating Occupational Therapist, Physiotherapist and/or Speech Therapist at each clinic visit, or on inpatient admission: equipment in use, ALSFRS-R score, date of onset of symptoms and phenotype. Information was collected on the use of 56 items of equipment, grouped into eight categories: speech devices; transfer devices; mobility devices; power wheelchairs; orthoses; ADL equipment; assisted technology and home modification equipment.

**Clinical Outcomes**
Data was collected on 273 pw ALS/MND, mean age 67 years (sd 11.7), range 36-94 over the period March to December 2014. Phenotype distribution was as follows: ALS/MND Lumbar (33.0 %), ALS/MND Cervical (25.6%), ALS/MND Bulbar (22.7 %), PLS (8.4%), Flail Arm (6.6%), Flail Leg (1.8%) and Primary Muscular Atrophy (1.5%). The median length of time since symptom onset was 24 months, range 2–271 months. The number of equipment items per PALS/MND ranged from none to 20, (mean 5.3). Equipment use was mapped over time revealing differing trends between phenotypes. There were some unexpected results, such as pw Flail Arm phenotype twice as likely to be using an electric bed than those with Flail Leg phenotype.

**Recommendations To The Field**
This information can be used by therapists to help predict which people with ALS/MND will need certain items of equipment, and when. It will also help service providers estimate the types and amount of equipment needed to support PALS/MND, and potentially, costs associated with this.

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# ALLIED PROFESSIONALS FORUM

JW Marriott Grande Lakes, Orlando, FL, USA | 10 December 2015

**Speaker**
Jennifer Benson
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**Biography**
Jennifer Benson is a Clinical Specialist Speech and Language Therapist, employed by Northern Lincolnshire and Goole NHS Foundation Trust. She works with adults with a wide range of neurological conditions, and also adults with complex dysphagia. She works as part of an established Rehabilitation Medicine Service seeing people with MND in their own homes, and supporting them with their communication and swallowing through their entire journey, as part of a multidisciplinary team.

Ms. Benson obtained her first degree in English Language and Linguistics from the University of Durham, and went on to train as a Speech and Language Therapist on the MSc Language Pathology course at the University of Newcastle upon Tyne, qualifying in 1999. She has worked with adult patients with a range of neurological conditions since then, with a real interest in working with people with progressive neurological conditions.

“I have always had a passion for working with people with MND, and I have been fortunate to meet many inspirational people living with MND over the years, not least my current patients, who have willingly supported me in developing the voice banking support side of our service.”

INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

**Authors**
Jennifer Benson

**Title of Presentation**
Voice banking - just do it!

**Background**
Around 75% of patients with ALS/MND will lose their speech over the course of their condition and will require alternative or augmentative means of communication (AAC). Traditionally, AAC devices with voice output have used digitised, computerised voices, which sound very different to the patient's natural voice. Recent developments in technology have made the use of 'voice banking' much more accessible, enabling patients to record a sample of their own voice onto a system which will produce a synthesised version of their voice. This voice can then be used on the patients AAC system. Benefits include maintenance of the patient's own identity, which is linked to improved wellbeing. Relatives and friends are also helped by continuing to hear the voice of the person they love, rather than that of a computer. Recording early after diagnosis is beneficial to give optimum voice quality.

**Objective**
- To highlight the impact voice banking has on patients with ALS/MND and their relatives through discussion of real life experiences.
- To discuss the importance of the link between voice and identity, and how this can be considered when working with patients with ALS/MND and their families.
- To discuss some of the practicalities, and the ease with which voice banking can be used in everyday practice in a community setting.

**Programme Description**
Patients in the community with a diagnosis of ALS/MND, seen within the Rehabilitation Medicine Service, are offered support from the Community SLT to 'bank' their voices for use on AAC devices when needed. Initially offered to patients on the existing caseload who had maintained sufficient voice. Now offered to all newly diagnosed patients who have sufficient voice.

**Clinical Outcomes**
- To present patient and relatives experience of the voice banking process and outcomes.
- To discuss how use of voice banking improves psychological wellbeing for patients and relatives within the context of a devastating condition.
- To demonstrate from a busy clinician's perspective that it is possible to achieve this service.

**Recommendations To The Field**
- Voice banking should form a key part of an SLT's management plan with all suitable patients with ALS/MND.
- Recordings should be carried out as soon as possible, whilst voices are relatively intact, to achieve optimal outcome.
- SLTs should offer support with voice banking to make it a reality for patients with ALS/MND.

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# ALLIED PROFESSIONALS FORUM

JW Marriott Grande Lakes, Orlando, FL, USA | 10 December 2015

**Speaker**
Alisa Brownlee
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**Biography**
Alisa Brownlee, ATP, is the Manager of Assistive Technology Services for both the National ALS Association and the Greater Philadelphia Chapter. She is a 19 year staff member with the Association and has been RESNA Credentialed Assistive Technology Professional since 2000. Her specialty areas are communication, computer access, and electronic aids for daily living. Alisa speaks, blogs, writes articles and uses social media to increase awareness of ALS/MND and the use of assistive technology. She is a strong advocate for patient rights to access to communication and has lobbied elected officials, educated insurance companies and allied healthcare professionals on the importance of communication for people with ALS.

Alisa has previously served as a non-voting Board Member for RESNA and is current a member of the RESNA Professional Standards Board. She is also a Board Member of USSAAC.

INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

**Authors**
Alisa Brownlee

**Title of Presentation**
Using mainstream technology as a communication system for people with ALS/MND

**Background**
People with ALS/MND present the greatest challenge regarding communication issues. Approximately 75% of all people diagnosed with ALS/MND will need some form of communication assistance. While progression of speech disturbance varies in each person with ALS, most people will experience a severe communication disorder during the last few months of life. In a retrospective study of 100 hospice patients with ALS, 28% were anarthric (unable to speak) and 47% were severely dysarthric (slurred speech) at the time of their deaths. Only 25% could speak understandably during the terminal stage of the illness.

**Objective**
Learning Objectives:
- Describe 3 mainstream technology devices that can be used as an augmentative communication device
- List 3 communication apps applicable to people with ALS/MND
- Define 3 different access methods (besides hands) for people with ALS/MND to utilize to a mainstream technology device

**Programme Description**
AAC systems for people with ALS/MND range from low technology to complex electronic devices. Many PALS/MND are using mainstream technology like iPads/iPhones, Android tables/phones, laptops or other computers to not only speak for them but to also surf the internet, send email, access social media, make phone calls, etc.
This presentation will address how to use mainstream technology—both low and high tech and turn it into a communication system.

**Clinical Outcomes**
No one can force a PALS/MND to use an alternative form of communication. Many caregivers and professionals feel the need to help and offer AAC, but PALS/MND reject this intervention. There are many reasons PALS/MND refuse AAC, with the most prominent being the psychosocial loss of the ability to verbally communicate. Communication is associated with personhood and identity (Shadden et al., 2009). The loss of speech can be like the loss of humanity, and having to face this loss when confronted with a terminal illness is even more challenging. How each individual with ALS/MND reacts to the loss of communication will be unique, may change over time, and may influence the person's decisions about AAC specifically. Often PALS/MND will wait until no one can understand them before reaching out to communication professionals for assistance.

**Recommendations To The Field**
There is no one "right" way for PALS/MND to communicate. Many people with ALS/MND use multiple modalities of communication depending their communication environment (ie. in bed, in the bathroom). Healthcare professionals working with PALS/MND need to know the various options available and how to establish an immediate communication system with products you can purchase at any electronics store.

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