mnda
motor neurone disease association
international symposium on ALS/MND

INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

Allied Professionals Forum

6 December 2016 | Dublin, Ireland

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2016 Evaluations

Thank you for attending the 2016 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/D7Y8CH3** to complete an evaluation survey. The organising committee will consider attendees' responses as we plan and organise the APF programme for 2017 and beyond.

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

—*The APF Programme Committee*

14th Annual Allied Professionals Forum

Convention Centre Dublin | 6 December 2016

PROGRAMME

8.30	**Welcome and Opening Remarks**	Steve Bell & Sara Feldman	
8.50	About the International Alliance of ALS/MND Associations	Carol Birks	Australia
9.00	The ALS Assistive Technology Challenge: Winners	Lucie Bruijn	USA
9.20	Message Banking: Impact on Quality of Life of People with ALS/MND	Lesley Doyle	Ireland
9.40	Message Banking vs. Voice Banking: A Very Successful Proactive Model for People with ALS/MND	John M. Costello	USA
10.00	The Development of a Voice Banking Volunteer	Louise Rickenbach	UK
10.20	**Morning Tea**		
10.50	Cultivating Compassion: Caring for Families Living and Dying with ALS/MND	Ronald Hoffman	USA
11.10	Adopting a New Way of Working to Support and Provide Information for Families Where a Parent/Guardian Has ALS/MND	Karen Welsenaer	UK
11.30	The Carers' Alert Thermometer (CAT): Identifying ALS/MND Carers' Support Needs	Mary O'Brien	UK
11.50	Well-Being and Care Burden of Close Relatives to Persons with ALS-FTD	Brigit J. Hovmand	Denmark
12.10	**Lunch and Networking**		
13.30	What Do People Living with ALS/MND Think About Their Swallowing?	Dominika Lisiecka	Ireland
13.50	The Clinical Utility of a Self-Reported Swallowing Outcome Measure	Laurie Sterling	USA
14.10	First Contact Group: An Anticipatory Approach to Palliative Care	Colin Pearson	UK
14.30	Withdrawal of Mechanical Ventilation at Patient Request in ALS/MND	Alison Armstrong	UK
14.50	**Afternoon Tea**		
15.20	Mechanical Insufflation Exsufflation (M-IE) and Breath Stacking: The Patient's Experience	Rachel McConnell	Ireland
15.40	Eyedriveomatic	Karen Pearce	UK
16.00	I Can Do It: The Impact of a One-Day Training Intervention on Occupational Therapist and Speech Pathologist Confidence in Working with Assistive Technology for Clients with ALS/MND	Kristina Dodds	Australia
16.20	How You Can Use 3D Printing in Your Practice	Kevin Caves	USA
16.40	**Close**	Steve Bell & Sara Feldman	

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

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Speaker

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

INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

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 Rights of People with ALS/MND encourages members to stand up for the basic rights of people living with ALS/MND worldwide.

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Speaker

Lucie Bruijn
lucie@alsa-national.org

Biography

Lucie Bruijn, Ph.D. is the Chief Scientist of The ALS Association. Prior to that Dr. Bruijn led a team at Bristol-Myers-Squibb developing model systems for neurodegenerative disease. Dr. Bruijn holds a Master's degree in Neuroscience and a Ph.D. in Biochemistry, specializing in disease mechanisms of Alzheimer's disease, from the University of London, UK, and an MBA from Imperial College, London, UK. During her academic career she developed and characterized a SOD1 mouse model of ALS to study disease mechanisms. At The ALS Association, Dr. Bruijn leads a global ALS research effort with the goal to move treatment options from "bench to beside." She has made it a priority to collaborate with other national and international funding agencies, not-for-profit ALS organizations, and other foundations focusing on neurodegenerative research. She is involved in project development, encouraging partnerships with academia and biotech, and plays a key role in forging collaborations amongst investigators.

Authors

Lucie Bruijn, Maya Bronfeld, Sara Shnider, Shay Rishoni

Title of Presentation

The ALS Assistive Technology Challenge

Background

Continued ability to communicate has been identified by people living with ALS/MND (PALS) as one of the top priorities for maintaining quality of life. For patients who retain cognitive function, but have limited to no ability to communicate verbally, Augmentative and Alternative Communication (AAC) devices are transformative.

Objective

The ALS Assistive Technology challenge was designed to accelerate the development of novel technological solution for communication that will be innovative, effective, adaptable and accessible to PALS throughout the different stages of disease progression.

Programme Description

The Challenge is open to teams from academia and industry who can apply their skills to the development of communication devices for PALS. In the first phase of the program, grants of $50,000 were awarded on competitive bases for development of functional prototypes of promising novel communication systems that demonstrated a likely path to scale-up for widespread use. In the second phase, which is ongoing, participants will demonstrate their prototypes and compete over a $400,000 prize awarded for further development of their communication system. Projects submitted to the prize phase will be selected by a panel of experts from industry, business, clinical practice and patients, and prototypes will be directly assessed by PALS and their caregivers.

Clinical Outcomes

The first phase of the challenge attracted over 70 groups from industry and academia who submitted their communication solution. Development grants were awarded to four promising groups which presented solutions such as an automatic device repositioning system, low-cost communication device manipulated by facial gestures, augmented reality interface for communication and remote manipulation, and an auditory message bank recording and storage software. The second phase of the challenge is now open, recruiting teams that can present innovative solutions with demonstrated feasibility and capacity for large-scale and cost-effective production. All solutions are required to be adaptable for PALS at all stages of the disease.

Recommendations To The Field

This challenge uses a strong financial incentive to bring new players to the field of ALS/MND assisted communication in order to drive innovation and attract solvers from many fields. Prototype testing by PALS and caregivers and selection of the winning team will take place in parallel to the Annual Alliance Meeting. At the AFP meeting, the leading prototypes will be tested and the winning project will be presented, allowing for feedback and open discussion with the technology's end users: PALS, caregivers and ALS/MND clinicians.

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Speaker

Lesley Doyle
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Biography

Lesley Doyle is Senior Speech and Language Therapist in Neurology in Beaumont Hospital, Dublin, Ireland. Lesley is involved in several research projects in the field of MND and has presented research at a variety of study days and international conferences.

Authors
Lesley Doyle, Caroline Jagoe

Title of Presentation
Message Banking: Impact on Quality of Life of People with ALS/MND

Background
Message banking is the intervention whereby patients with progressive conditions record phrases that can later be used on Electronic Communication Devices. These messages, recorded in the patient's own voice, have an important role both in optimising communication, but also in maintaining a 'sense of self' and the individual's identity as a communicator (Costello, 2012). The ability to communicate in one's natural voice is a central aspect of expression of self and identity (Nathanson, 2016). Changes in speech can cause individuals to feel that they are not representing their true selves, or are perceived as having less interesting things to say (e.g. Wickenden, 2011). Message banking for people with progressive communication disorders is in its infancy but has the potential to enhance sense of self, sense of control and, through these factors, enhance quality of life.

Objective
To explore the impact of message banking on the quality of life of people with MND, as measured by the ALS Specific Quality of Life Scale and an analysis of responses to a questionnaire probing participants' expectations of the intervention.

Programme Description
This paper will present preliminary results from a pre-post multiple baseline study which is currently underway and will be completed by August 2016. The intervention sessions were based on the Group Plan devised by the researchers. The content of the group plan was developed based on the experience of a clinical pilot of Message Banking as an intervention for people with progressive communication disorders (Doyle & Jagoe, 2014). This case-series design allows for analysis of the impact of engaging in a group message banking intervention on Quality of Life in people with MND.

Clinical Outcomes
Maintaining communication and sense of identity is likely to be central to quality of life in people with MND. The findings of this study have clinical implications for how preparing clients for Alternative and Augmentative Communication (AAC) is managed in the early stages of MND.

Recommendations To The Field
1. We will explore how offering clients an optional intervention, which enhances their choice and control rather than purely responding to symptomatic changes, may influence quality of life.
2. A message banking toolkit is in development to support clinicians to provide message banking to clients with MND.
3. A group format may provide the benefit of lowering the resource-intensiveness of intervention while also providing a peer group for adult learning and support.

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Speaker

John M. Costello
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Biography

John Costello is the director of the Augmentative Communication Program and the ALS Augmentative Communication Program; a full-time clinic dedicated to the Augmentative Communication and Assistive Technology needs of people with ALS/MND at Boston Children's Hospital. In 1994 John created a model for message banking for patients in the ICU. This model has now been introduced and successfully used by many people with ALS/MND. In addition to message banking, various voice banking strategies are encouraged as part of a broad protocol focused on proactive augmentative communication assessment and intervention. John has lectured widely internationally on topics of augmentative communication, message banking and proactive intervention for people with ALS/MND.

Authors

John M. Costello

Title of Presentation

Message Banking vs. Voice Banking: A Very Successful Proactive Model for People with ALS/MND

Background

The augmentative communication program at Boston Children's Hospital has been a leading center for assessment, care and innovation in the field of augmentative communication for nearly 40 years. Grown out of a pediatric model first introduced in the intensive care unit, a thoughtful and well supported strategy for message banking, thus allowing one to preserve the expression of self, personality and control, has been introduced to people with ALS/MND. The success of this program led to the launch of a full time AAC program focused exclusively on augmentative communication assessment and implementation for people living with ALS/MND .

Objective

To introduce a successful model of MESSAGE banking that is technology agnostic and allows people with ALS/MND to capture sounds, words, phrases and full messages with their own personality, intonation, humor and emotion and then - when needed - incorporate those into the most appropriate augmentative communication technology. The most appropriate technology is then identified through a full assessment process. This strategy then allows banked messages to be co-mingled with synthetic VOICE banked or commercial synthetic speech.

Programme Description

This presentation will outline a successful model of message banking and differentiate it from voice banking. Case study and video will be used to demonstrate numerous successful uses of augmentative communication technology with message banking by people with ALS/MND. In addition, web based resources including a link that will support free processing and labeling of banked messages, will be shared with attendees.

Clinical Outcomes

To date, more than 100 people with ALS/MND have message banked, with many creating banks of 2000-4000 messages. These have been incorporated into varied technologies accessed both through direct selection including apps for the iPad as well as integrated technologies controlled with eye gaze, head mouse or other access strategies. Further, our program has partnered with engineers to create a free web-based software to support clinicians to download, label and store messages so they are ready if needed as the disease progresses.

Recommendations To The Field

A proactive model designed to support people with ALS/MND to message bank through a casual and low-key process that can be completed over time, in any location throughout the day and at the discretion of the person with ALS/MND is an effective strategy to support patient control and increased quality of life throughout the disease process. This model should be introduced to all people with ALS/MND and supported over the course of the disease as a standard practice of care.

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Speaker

Louise Rickenbach
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Biography

Louise Rickenbach is a Regional Care Development Adviser for the MND Association. She has a multifunctional role in the south of England, linking in with people affected by MND, volunteers, health and social care professionals and organisations.

Authors
Louise Rickenbach

Title of Presentation
The Development of a Voice Banking Volunteer

Background
Many people with MND will experience problems with their speech and voice. Technology is changing rapidly, particularly in Augmentative and Alternative communication (AAC). Recent developments, have meant that there is an increased opportunity for people to bank their own voice, which can potentially be synthesised and stored to be used in the future, via a communication device.

To do this effectively, it should be done when the person's quality of voice is still good. However, the process of recording one's voice is reported to be tiring and time consuming. It is also apparent that people with MND, might not have met a Speech and Language Therapist (SLT) at the ideal time to carry out the recordings. Due to this, many people seem to `miss the boat'.

The MND Association has experience in developing and training volunteers ,who can play a part in the lives of people affected by MND, for example Association Visitors.

Objective
The main aim is to facilitate the process of Voice Banking, in a timely but sensitive and supported manner. (Not everyone, early in the course of their disease, will be open to the potential risk of losing their voice in the future). Individuals who have carried out their own research or perhaps have had early contact with a SLT, have been accessing this technology, but many are missing the opportunity.

Programme Description
This is a pilot project, at an early stage. Linking in with MND clinics and professionals, potential participants for this project can be identified. With information provided in a sensitive way, people who would like to do voice banking, can then be put in touch with a trained volunteer, who will be able to visit them at home with the necessary equipment and knowledge, in order to do achieve good quality recordings and liaise with the company providing the service.

Clinical Outcomes
The main outcome will be that more people, from a diverse group, will have the opportunity to bank their own voice.
The volunteer role, training, supervision and cost implications, will be evaluated.
It is anticipated that the increased education and awareness in the area of the process, among people affected by MND and Professionals, will increase the uptake of voice banking.
It will be possible to assess how much involvement is needed by the clinical teams.

Recommendations To The Field
This project looks at the development of a new Volunteer Role within the MND Association. It will enable a person with MND, who might not have high technical skill levels, access to voice banking services.

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Speaker
Ronald Hoffman
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Biography
Since 1998, Ron Hoffman has served as founder and director of Compassionate Care ALS working with thousands of individuals, families and communities living with ALS/MND in the US and around the world. He facilitates and guides intimate discussions for those engaged in the complexities of living with and dying with this catastrophic illness. Ron's work helps examine the myriad of choices and possibilities that people confront including the process of death and dying and the questions that arise as together they create space for dialogue around their decisions.

Ron regularly leads trainings for hospice workers and health care professionals. He is a former board member of Men's Leadership Alliance of Boulder, Colorado and the Hospice and Palliative Care Federation of Massachusetts and the author of Sacred Bullet, Transforming Trauma to Grace While Tending the Terminally Ill, a book that sheds light on living with grace in the face of mortality.

Authors
Ronald Hoffman

Title of Presentation
Cultivating Compassion: Caring for Families Living and Dying with ALS

Background
Compassionate Care ALS serves the wide-ranging needs of families dealing with ALS/MND. We serve patients, caregivers and healthcare professionals, recognizing the breadth of the disease's impact and acknowledging that caregivers often need their own specific kind of support. Since 1998 we have worked with more than 1,400 ALS/MND patients. Our Cultivating Compassion Workshop Series which is presented regularly addresses a broad range of issues faced by ALS/MND patients, their caregivers, their families and healthcare professionals.

Objective
Participants will leave with new tools to share with those coping with end of life situations, including themselves.

Programme Description
In the US there is a lack of self-care support for healthcare staff and caregivers of ALS/MND patients as well as for the patients themselves. Most interventions are viewed through the lens of the traditional healthcare system. Ron Hoffman will speak about the CCALS relational model that helps patients with ALS/MND and their families to live with the illness, sit with their suffering, and discover their resilience through attending to the practical, the spiritual, social, physical and emotional challenges. He also will speak to how we teach healthcare professionals to be more present and aware when working with terminal patients.

The CCALS approach draws from nearly two decades of hands-on experience of striving to understand the overwhelming dynamics that ALS/MND families endure. During this presentation, we will address the relationship of our compassion-driven, community-based program and how it affects the patient experience with this illness and with facing end-of-life. Additionally, the audience will learn about the opportunity to partner with similar community programs to support all involved, from the story of the partnership between hospice and CCALS in enhancing the total care of patient and family. Lastly, practical skills will be shared on deepening one’s ability to listen to patients with ALS/MND struggling to communicate.

Clinical Outcomes
By reviewing the experience of living with ALS, its symptoms, challenges - physical, emotional, social, practical, existential - from a patient and family’s perspective, we will bring perspective to others including healthcare professionals to enable them to be more effective caregivers for those living with ALS/MND.

Recommendations To The Field
This presentation will bring new tools and techniques for listening to patients with ALS/MND. It will also help healthcare professionals understand the value of partnering with a non-clinician, community-based palliative care program in tending to patients with ALS/MND and their caregivers.

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Speaker

Karen Welsenaer
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Biography

Karen initially trained as a Registered General Nurse and a Registered Sick Children's Nurse. Worked in the NHS for 28 years providing direct patient care, unit management and production of care information and training materials. Set up child protection referral pathways whilst working as a Lead Nurse for children and young peoples services for NHS Direct. Previously set up a service of support for children and young people of drug and alcohol users in Northamptonshire and education for parents, other children and professionals.

Authors
Karen Welsenaer

Title of Presentation
Adopting a New Way of Working to Support and Provide Information for Families Where a Parent/Guardian Has ALS/MND

Background
Service provision has traditionally focused on the individual needs of a person with motor neurone disease and not considered the wider impact on a family where there are children.
Background: Current legislation and guidance governs joined up working using a family centred approach to provide care and services for families where it has been identified that someone needs care. The Motor Neurone Disease Association has traditionally focused on the individual needs of a person with motor neurone disease and a family centred approach would be a new way of working.

Objective
To identify children and young people living in families where someone close has motor neurone disease, living in England, Wales and Northern Ireland.
- To benchmark support for children pre and post bereavement.
- To develop a family centred approach to support a person with motor neurone disease who has children.
- To develop resource and support for staff, volunteers and professionals supporting families with children.
- To develop resources and support for children and families.

Programme Description
A scoping project identified opportunities to promote awareness of the needs of children, young people and young carers in contact with someone with motor neurone disease both within the Association and external agencies. It identified further processes and ideas to improve the outcomes for children and young people. Change will help the Association to work towards a long term goal of supporting families and improving pathways for a young person to access services. The Association has developed new resources for young people including a guide, web pages and a web app.

Clinical Outcomes
This way of working will:
- Improve communication of current provision to stakeholders.
- Support offered to children and young people due to earlier identification.
- Help children and young people to build resilience and achieve their full potential.
- People with motor neurone disease will feel reassured that the wellbeing of their children is being taken into consideration.

Recommendations To The Field
The adoption of a whole family centred approach will enable access to a range of services which will improve quality of life for all.

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Speaker

Mary O'Brien
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Biography

Mary O'Brien is a Professor of Palliative and Supportive care at Edge Hill University in the UK. Her role encompasses being an active researcher combined with teaching research methods and supervising research students. Mary's particular interests are end-of-life and palliative care research, including the needs of carers, focusing on non-malignant illness, particularly neurological conditions, including MND.

Authors

Mary O’Brien, Katherine Knighting, Barbara Jack, Hilary Fairfield, Neil Drinkwater

Title of Presentation

The Carers’ Alert Thermometer (CAT): Identifying ALS/MND Carers’ Support Needs

Background

The substantial burden and distress experienced by family carers of people living with ALS/MND (plwMND) is reported widely within the published literature. Consequently there have been calls for interventions to improve the care provided to carers. The Carers’ Alert Thermometer (CAT) is an evidence-based quick and easy to use alert tool completed collaboratively by carers and non-specialist health staff to identify the needs of carers of family members with cancer and advanced progressive illness in their last year of life. The CAT has 10 questions to identify the support needed by the carer to provide care and for the carer’s own health and well-being; a traffic light system indicates the level of need for each alert and a visual thermometer identifies the extent of the carer’s needs. A guidance section can be tailored to local services and there is an action plan to complete with review dates (for more details see https://www.edgehill.ac.uk/carers/).

Objective

We set out to modify the CAT and pilot it with family carers of plwMND to determine its usefulness in identifying their need for support.

Programme Description

A workshop was held with MND Association Visitors (AVs), Regional Care Development Advisers (RCDAs) and a Regional Delivery Manager (RDM) to review the CAT, provide training on its implementation and demonstrate resources including a DVD. Workshop participants piloted the CAT with family carers of plwMND during routine appointments over a four month period. Feedback on the utility of the CAT was obtained through self-completion of an online survey and telephone interview.

Clinical Outcomes

The AVs and RCDAs who trialled it found the CAT very useful in their discussions with family carers and intended to continue using it. It was particularly felt to be beneficial for monitoring changes in the caring role as the disease progresses.

Recommendations To The Field

Participants in the pilot found the CAT to be relevant and feasible. It is an easy to use tool to facilitate discussions with ALS/MND family carers regarding their own specific needs and how these may be addressed. Use of the CAT with carers supports the ALS/MND Association’s mission to ensure that support is there not just for the person diagnosed with ALS/MND, but for the relatives and friends who care for them too.

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Speaker
Birgit J. Hovmand
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Biography
Birgit J. Hovmand is as an occupational therapist who has been employed with National Rehabilitation Center for Neuromuscular Diseases (RCFM) for 20 years as an ALS/MND counselor. She previously worked in an ALS/MND hospital team. During the period from 1996-2002, Birgit J. Hovmand was one of the driving forces behind the national Danish ALS/MND counseling scheme. Over the past two years, her work has focused on psychosocial issues related to ALD-FTD and how the disease affects close relatives in terms of care burden and well-being.

Authors

Ole Gredal, Birgit J. Hovmand

Title of Presentation

Well-Being and Care Burden of Close Relatives to Persons with ALS-FTD

Background

Changes in personality in patients with ALS/MND are well-documented. In some cases, signs of FTD are prominent already in the early disease stages, and close relatives know without a doubt that the personality/cognition of the affected person has changed.

RCFM offers rehabilitation to the entire family. Spouses to persons affected with ALS/MND and personality changes or diagnosed with FTD report a heavier care burden and decreased well-being.

Objective

To investigate whether RCFM can reduce the care burden of close relatives by:
-identifying ALS/FTD problem areas in the family
-verbalizing daily problems such as changing roles, care burden and well-being
-informing about the causes and background for personality changes
-offering psychologist sessions and teaching strategies for coping with abnormal behavior.

Programme Description

The intervention begins with a home visit where we investigate the patient's cognitive and behavioral problems and the role, burden and well-being of the relative using questionnaires, tests and interviews. The interview may reveal problems associated with shame, sorrow, anger or frustration which have previously not been addressed. The relatives are asked to prioritize the five most critical problem areas which will subsequently be the focus of our intervention.

Clinical Outcomes

The study showed that ALS-FTD appeared in many different ways and that the relatives felt relieved by being able to address the problems. Their well-being vas affected by FTD and the care burden increased dramatically when reduced functional ability was added to mental changes. The intervention could not take away the burden from the relatives but they learned new strategies for living and coping with the affected person. We present the results from the first 15 ALS/MND patient/relative interventions at the symposium.

Recommendations To The Field

ALS-FTD is a progressive disease causing physical and mental changes. Focusing on the mental changes helps relatives understand the situation better and gives them a better understanding of their own capabilities in terms of help and care.The intervention calls for an individual design, and information should also address helpers, adult children and professional caregivers. RCFM is planning to set up a network for relatives to FTD. It is important that local professionals with expertise in dementia/FTD are involved in the intervention.

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Speaker
Dominika Lisiecka
sltclinic@gmail.com

Biography
Dominika Lisiecka, MSc, is currently a PhD candidate in the Department of Speech & Hearing Sciences, School of Clinical Therapies, University College Cork under the supervision of Dr. Helen Kelly and Prof Jeanne Jackson. Dominika (originally from Poland) has worked as a Speech & Language Therapist in County Kerry for over 10 years and has a particular interest in swallowing impairments and neurology. Her PhD research stems from her own clinical experience with people with Motor Neurone Disease (MND). Little is known about how people living with ALS/MND perceive and experience dysphagia. Dominika is aiming to address this gap by conducting a qualitative research project investigating the experiences of dysphagia in ALS/MND from the perspectives of both patients and their caregivers. Dominika has been awarded a prestigious Research Training Fellowship for Healthcare Professionals by the Health Research Board in May 2015 for the above project.

Authors
Dominika Lisiecka, Dr. Helen Kelly, Professor Jeanne Jackson

Title of Presentation
What Do People Living with ALS/MND Think About Their Swallowing?

Background
Motor Neurone Disease (MND) is a rare progressive neurodegenerative illness of unknown etiology, for which there is no cure. According to the Irish Motor Neurone Disease Association there are around 330 people currently living with ALS/MND in Ireland. Dysphagia often occurs as a consequence of ALS/MND and has a severe impact on persons affected from a medical, social and psychological perspective. A review of literature revealed that little is known about how people living with ALS/MND perceive and experience dysphagia. This knowledge is needed to ensure patient centred approach and to understand the experience of dysphagia in this population.

Objective
To explore the experiences of dysphagia in ALS/MND from patient and caregiver perspectives in order to explain:
-how they understand dysphagia;
-how dysphagia influence their lives;
-their coping strategies in relation to dysphagia;
-the experiences of SLT services received.

Program Description
10 adults with ALS/MND (AwMND) were included based on their cognitive status and level of dysphagia (FOIS 1-5). In addition 10 caregivers of AwMND were recruited. Data was collected primarily by multiple interviews (n=57) supported by observations. Interpretative Phenomenological Analysis was adopted to reveal the super-ordinate themes. The findings were interpreted from an SLT's perspective.

Clinical Outcomes
-There is a discrepancy between participants' perception of dysphagia and the real impairment.
-Admitting dysphagia seems to be a complex process for some participants.
-Participants who denied dysphagia (despite being formally diagnosed) developed own coping strategies (often subconsciously).
-Dysphagia coping strategies had a significant impact on the whole family and were often different for the patient and for the caregiver.
-Considering non-oral supplementation was an extremely traumatic time for some participants especially if getting contraindicate advice from professionals.
-Participants were generally happy with received SLT input, but had some suggestions to change the services.

Recommendations to the Field
-People living with ALS/MND may experience and approach dysphagia differently than other populations. This may be caused by the unique nature of ALS/MND and also by personal lived experiences.
-Be aware of the discrepancy between medical diagnosis of dysphagia and patient's perception of own swallow ability.
-Develop strategies to avoid giving contrary advice.
-Considering non-oral feeding may be extremely stressful time for some. That process should be carefully managed and guided.
-Consider offering individual appointments to caregivers only.

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Speaker

Laurie Sterling
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Biography

Laurie Sterling, MS, CCC-SLP, BCS-S is a senior speech pathologist at Houston Methodist Hospital in Houston, Texas. Laurie has been honored to serve as the speech pathologist for the MDA/ALS Clinic at The Methodist Neurological Institute for the last 15 years. Her interests include dysphagia and dysarthria in patients with neurodegenerative diseases. Laurie is also very involved in the American Speech-Language Hearing Association and sits on the board of the American Board of Swallowing and Swallowing Disorders.

Authors

Laurie Sterling SLP, Julia McCaffrey SLP, Heather Thompson SLP, Peggy Allred PT

Title of Presentation

The Clinical Utility of a Self-Reported Swallowing Outcome Measure

Background

Amyotrophic Lateral Sclerosis (ALS) is a progressive degenerative neurological disease affecting upper and lower motor neurons. It is estimated 85% of ALS/MND patients experience swallowing difficulties at some point in the disease process. The Eating Assessment Tool-10 (EAT-10) is a validated, self-rated, swallowing specific outcome measure developed to quantify patients' swallowing symptoms. The EAT-10 has been translated and validated in several languages. This tool was developed to document initial severity of swallowing disorder symptoms and response to treatment. Serial administration of the EAT-10 has been implemented in many ALS/MND clinics to document symptom severity and measure change throughout the course of the disease. There is progressive deterioration in ALS/MND . Does the EAT-10 reflect progressive dysphagia? When do we stop using the EAT-10?

Objective

-Determine the linear nature and serial consistency of EAT-10 scores in the ALS/MND population.
-Correlate EAT-10 scores with other commonly collected ALS/MND data points.
-Determine the utility of EAT-10 scores during different stages of ALS/MND.
-Discuss the benefits and shortcomings of this and other self-report scales in ALS/MND and strategies to best utilize the information for clinical decision-making.

Programme Description

Longitudinal data from 269 ALS/MND patients in multidisciplinary clinics at Houston Methodist Hospital (Houston, Texas) and Cedars-Sinai Medical Center (Los Angeles, California) were collected from 4/2014 to 2/2016. Data collection included demographics, serial EAT-10 scores, ALS-FRS scores, weight, BMI, and FVC measured at each clinic and assessed for change. We will examine the correlation of EAT-10 scores with site of onset, disease length, ALSFRS-R, FVC, PEG placement, weight and BMI.

Clinical Outcomes

Understanding limitations of self-reported swallowing measures is important when interpreting scores as they may not accurately reflect disability. Factors such as adaptation to disability, cognitive deficits, and patient underreporting of symptoms may play a role in EAT-10 score variation when compared to other clinical data. It is important to determine if the EAT-10 is applicable to the entire ALS/MND disease duration.

Recommendations To The Field

The utility of self-report scales in ALS/MND has been established for assessment of daily function (ALSFRS-R), quality of life (ALSQoL), and swallowing function (EAT-10). The limitations of self-report assessments should be considered when making clinical decisions based on these scores. Whereas they offer a unique patient perspective, we recommend they be taken into consideration in conjunction with objective clinical measures for clinical decision-making.

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Speaker

Colin Pearson
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Biography

Colin Pearson has worked for the Motor Neurone Disease Association for five years as one of its Regional Care Development Advisers in Cleveland, North and East Yorkshire.

Colin graduated from Teesside University in 2007 with a BA (Hons) in Social Work and worked for four years with people with complex physical disabilities including ALS/MND, Continuing Healthcare needs and the assessment of people requiring nursing care and cognitive impairment placements. Colin still maintains a continued interest in Social Policy in his work with the Motor Neurone Disease Association.

Prior to his career in social work, Colin spent 11 years in the United States teaching children and adolescents with mental health and learning disabilities at a residential school in Pennsylvania.

Authors
Colin Pearson, Anthony Hanratty

Title of Presentation
First Contact Group: An Anticipatory Approach to Palliative Care

Background
It has been found that traditional models of support including palliative care services are generally accessed by those living with ALS/MND at a late stage within the progression of the disease. Barriers to engagement cited are the fear of seeing someone worse than themselves, whilst engagement with hospices is avoided due to the stigma and misconception attached to hospices just being places to die. Consequently psychological factors result in decreased early monitoring, anticipatory support, involvement in support networks and uptake of appropriate services.

Objective
Development of a project to encourage and support those people living with ALS/MND to engage with palliative care support as soon as possible after diagnosis, thereby improving on-going care management, symptom control and quality of life.

Programme Description
The First Contact Group is an innovative partnership between the ALS/MND Association, Butterwick Hospice (Stockton) and Middlesbrough ALS/MND Care Centre.

Key to the project was getting those who were still working and living life as independently as possible to engage. A positive enticement lay in the provision of Complimentary Therapies, a relaxing therapy after a week at work. Butterwick Hospice were looking for innovative ways to compliment their traditional Day Care. Agreement was made to utilise their facilities and staff to accommodate a drop in session for ALS/MND patients, receive complimentary therapies, whilst utilising hospice services including family support, nursing support and benefits advice.

The Cleveland Branch of the MND Association funded the therapies with their ‘Association Visitors’ also attending to promote this additional form of support.

Clinical Outcomes
The initial trial was successful, with patients and carers dropping in, but also staying to socialise and interact with hospice staff and the ‘Association Visitors’. Attendees receive weekly support from the hospice nurse who liaises with the ALS/MND Care Centre Specialist Nurse facilitating improved monitoring and care co-ordination. Feedback illustrates the beneficial effect of both complimentary therapies and peer support as the group has grown as well as increased uptake of MND Association support, hospice / palliative care services, co-ordination of care and support for Carers.

Recommendations To The Field
The success of this project has resulted in replication at Dove House Hospice (Hull), and several other hospices are also considering this model. The concept and methodology of this project would support other hospices and services, both nationally and internationally, looking for innovative ways to increase earlier engagement with palliative care services.

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Speaker
Alison Armstrong
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Biography
Alison qualified as a registered nurse in 1993 and worked within neuro trauma intensive care for the 8 years that followed. She began her role within the remit of home ventilation in 2001. Since then, as part of a small specialist team, Alison's position has been entirely within the North-East Assisted Ventilation Service, which is a regional service providing support to patients on assisted ventilation in their own homes throughout the North of England. Alison is the host of the Specialists in Long-term Ventilation at Home (SiLVaH) group. This is a non-medical group, the focus of which is to promote the sharing of ideas which assists with the creation of new innovations, develop standardisation and service improvement in this specialist area of practise.

Alison She is currently studying towards her MSc in Practise Development, and her main interest is in assuring good life quality for this complex client group.

INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

Authors
Alison Armstrong and Dr. Ben Messer

Title of Presentation
Withdrawal of Mechanical Ventilation at Patient Request in ALS/MND

Background
Non-invasive ventilation (NIV) improves quality of life and survival in selected patients with respiratory failure due to Motor Neurone Disease (MND). A minority of patients request that assisted ventilation be withdrawn when they feel their disease progression is no longer tolerable. These patients are likely to suffer severe breathlessness once the ventilator is removed; therefore proactive management of the process is critical.

Objective
The primary aim of starting a treatment is to provide a health benefit to the patient. The same justification applies to continuing a treatment already started. In withdrawal of mechanical ventilation, the reason death occurs is because of the underlying disease

Programme Description
This case report describes how this process was managed:
-November 2012: ALS/MND diagnosis.
-January 2015: Symtoms - predominantly lower limb weakness with associated right upper limb weakness, morning headache, orthopnoea, reduced PFTs, well preserved bulbar function. NIV commenced.
-May 2015: Following increase in NIV dependency, patient requested discussion around withdrawal of NIV. This process was discussed with patient, family and members of the MDT. ADRT discussed and recorded. Still able to manage 15 to 30 minutes of ventilator-free breathing. Patient very clear about what level of disability he was prepared to tolerate; process of NIV withdrawal discussed; personnel to be involved agreed; all parties aware of who to be contacted when appropriate.

Clinical Outcomes
August 2015: Patient requested that the process begin. Involvement of McMillan team and palliative care nurse specialist who provided pre-emptive symptom control, as he was very (but not completely) NIV dependent at this stage. Home Ventilation consultant and nurse specialist managed the removal of ventilation. This all took place in patient's own home.

This patient had full control over when his treatment should be discontinued. As a result of advance planning, his death was peaceful and dignified, with his family around him.

Recommendations To The Field
Removal of mechanical ventilation can be effectively managed in the home setting. Clear and open communication and co-ordination between those involved is critical to the outcome. Consideration of the beliefs and values of all involved must be respected.

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Speaker

Rachel McConnell
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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. She is currently researching Mechanical Insufflation and Exsufflation and breath stacking in ALS/MND patients. Rachel's primary areas of interest include neurological rehabilitation and management of neuromuscular respiratory problems.

Authors

Rachel McConnell, Dr. Deirdre Murray, Dr. Dara Meldrum, Professor Orla Hardiman

Title of Presentation

Mechanical Insufflation Exsufflation (M-IE) and Breath Stacking: The Patient’s Experience

Background

The Multidisciplinary Team (MDT) at the Motor Neurone Disease (MND) clinic, at Beaumont Hospital, Dublin cares for the majority of Irish ALS (Amyotrophic Lateral Sclerosis)/MND patients. ALS/MND patients often present with neuromuscular respiratory weakness resulting in an impaired cough and an inability to clear secretions (Andersen et al., 2012). Physiotherapists in this setting prescribe airway clearance devices including Mechanical Insufflation-Exsufflation (MI-E) and breath stacking. There is minimal research to describe the patient’s experience with the use of M-IE and LVR although patient comfort is recommended as a key factor when choosing a device (Senent et al., 2011).

Objective

This study evaluated the patient’s experience after M-IE or breath stacking was prescribed:
-To assess M-IE and breath stacking usability
-To measure reported adherence
-To evaluate the effect of M-IE and LVR on cough and speech
-To evaluate the effect of M-IE and LVR on cough strength during a chest infection.

Programme Description

A questionnaire was completed by participants at the first clinic visit after the prescription of M-IE or breath stacking. The questionnaire was a 13 item self administered questionnaire. Participants were asked to rate their level of agreement to items that related to their experience with the use of the M-IE or breath stacking. Ten items were assessed on a five point Likert scale from strongly disagree to strongly agree. Two questions were multiple choices and one question was a yes/no answer. The questionnaire was developed by the research team based on clinical experience. Prior to data collection the questionnaire was piloted to ensure understanding and collection of appropriate data.

Clinical Outcomes

Fourteen participants were prescribed M-IE and breath stacking. M-IE was prescribed to 35.7% (n=5) and breath stacking was prescribed to 64.3% (n=9). The reported adherence of M-IE and breath stacking use was 92.9% (n=13). 76.9% (n=10) agreed that the devices were comfortable to use. Comfort was rated higher with breath stacking. 66.7% (n=8) agreed that the device increased cough strength and 36.7% (n=4) agreed that the device increased speech volume. Increase in cough strength and speech volume was rated higher with M-IE. One participant experienced a chest infection and agreed that M-IE made their cough stronger during this chest infection.

Recommendations To The Field

Reported adherence was high. Breath stacking was more comfortable than M-IE. M-IE increased cough strength and speech volume more than breath stacking. The participant’s experience with M-IE and breath stacking was positive.

Please complete the 2016 APF evaluation: **https://www.surveymonkey.com/r/D7Y8CH3**

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Speaker

Karen Pearce
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Biography

Karen qualified as a Physiotherapist and worked in the National Health Service in a variety of clinical and managerial roles for nearly 30 years before joining the MND Association in 2010. She leads on strategic development of 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.

Authors

Karen Pearce, MBA, MCSP, GradDipPhys

Title of Presentation

Eyedrivomatic

Background

There are up to 5,000 people with ALS/MND in the UK. A high proportion of these people will need a powered wheelchair, and a significant number of these people will ultimately have limited or no hand function meaning a reliance on care givers to propel the wheelchair. A high number of these people will also be reliant on AAC systems such as eyegaze. In the UK the health service often loans the wheelchair and AAC systems. Eye gaze technology is designed to operate a computer, not a wheelchair however an inventor with ALS/MND has designed a solution to this.

Objective

To design a system that would interface with the user's wheelchair mounted eye gaze system, and physically move the joystick without making any modifications to the loaned equipment, which would ultimately be returned, and could work across all wheelchair and eyegaze systems.

Programme Description

Patrick Joyce has developed a 'Brain Box' which interprets commands from the wheelchair mounted computer and controls servos in the electronic hand. The 'Electronic Hand' fits over the existing wheelchair joystick, receiving power & commands from the Brain Box and moves the wheelchair in the desired direction. Steve Evans has been one of the people to user test the product. Both Patrick & Steve have ALS/MND and are reliant on wheelchairs and eye gaze technology. They are keen to promote their invention to an international audience, probably through video.

Clinical Outcomes

Steve Evans is totally reliant on care givers. He now can independently move around his home, drive outside and interact with his young family. Pyscho-social benefits are yet to be researched and wheelchair therapists have noted the benefits and considered the risks of the system, which are easily overridden.

Recommendations To The Field

The invention won the 2015 Hackaday Prize. Patrick Joyce has developed the hardware and software systems as Open Source, with the intention from the beginning to enable all people to access, acknowledging the benefit for those with ALS/MND as well as spinal injuries etc. Therapists with a knowledge of the system can signpost to the website.

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Convention Centre Dublin | 6 December 2016

Speaker

Kristina Dodds
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Kristina Dodds

Biography

Kristina is the Education and Carer Support Coordinator at the Motor Neurone Disease Association of NSW, Australia (MND NSW). She has been in this role for six years. Kristina has a Masters in Adult Education and a background in disability, cancer care support and community development. She presented at the International Alliance of ALS/MND Associations Allied Professional Forums in Berlin in 2009 about ‘A better approach to end of life care: community mentors for caregivers’, and in Chicago in 2012 on ‘An innovative ALS/MND training program for frontline staff’

Authors
Kristina Dodds, Maree Hibbert, Penny Waterson, Gina Svolos

Title of Presentation
I Can Do It: The Impact of a One-Day Training Intervention on Occupational Therapist and Speech Pathologist Confidence in Working with Assistive Technology for Clients with ALS/MND

Background
"Early introduction of an appropriate communication device can have a positive effect on quality of life and levels of depression in people with MND" Korner et al (2013).
The state of New South Wales, Australia, covers a large geographical area and it is not possible or affordable for all people with ALS/MND who need augmentative and alternative communication (AAC) to access specialist AAC centres. The Motor Neurone Disease Association of NSW MND-ASC (assess, support, communicate) project commenced in 2012 to improve communication outcomes for people with ALS/MND. Findings from the MND-ASC environmental scan, research and consultations undertaken during 2012-2013 identified the need for a knowledge and capacity building initiative for 'everyday' therapists.

Objective
Enhance the skills, knowledge and confidence of 'everyday' speech pathologists and occupational therapists (SPOTs) so that people living with ALS/MND have evidence-based service delivery for communication difficulties, and improved communication outcomes and quality of life.

Programme Description
The pilot one-day CommSPOT workshop was conducted in 2015 for SPOTs. The learning objectives were for the participants to:
-hear from a range of speakers including assistive technology (AT) specialists and people living with ALS/MND;
-be introduced to the evidence for assessment and implementation for augmentative and alternative communication (AAC) for people with rapidly progressive neurological conditions including ALS/MND;
-learn about a 6-stage approach for providing assessment and support for people with ALS/MND who have communication and alternate access needs;
-explore, in discipline specific groups, assessment and implementation models focussing on person-centred outcomes;
-learn about everyday strategies and devices that commonly meet the needs of people living with ALS/MND.

Clinical Outcomes
More than 90% of workshop participants rated the workshop program as above average or excellent. Pre and post workshop participant surveys show (1) increased therapist knowledge of range of AAC strategies and options (2) increased confidence in assessment, implementation, monitoring and review (3) decreased and changed therapist identified future training and support needs.

Recommendations To The Field
Improving confidence of the 'everyday' occupational therapist and speech pathologist in working with assistive technology for clients with ALS/MND can improve quality of life for people living with ALS/MND and their carers, through early local access to AAC.

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Speaker
Kevin Caves

Biography
Kevin Caves is a Instructor in the Pratt School of Engineering at Duke University and a faculty member in the Departments of Surgery and Medicine at Duke University Medical Center. He coordinates Duke's Assistive Technology Clinic that provides assistive technology services to people with disabilities. In addition to teaching and working with people with disabilities, he conducts research in the area of rehabilitation engineering and assistive technology.

Authors

Kevin Caves, ME, ATP, RET

Title of Presentation

How You Can Use 3D Printing in Your Practice

Background

3D printers are inexpensive and becoming more available everywhere. With this technology designers can create widgets and even customized devices easily and inexpensively.

Objective

This presentation will discuss how 3D printed devices are being used to serve clients with ALS/MND and about where to find ideas for existing adaptive devices that can be created using 3D printing technologies. Participants will also learn about 3D printing services that they can access inexpensively and potentially for free.

Programme Description

The Duke Assistive Technology Clinic serves patients in the Duke ALS Clinic with the evaluation, recommendation, procurement, setup, training and support of assistive technologies, specifically computer access and augmentative communication. The Duke AT clinic serves a caseload of approximately 100 people with ALS/MND at any given time.

Clinical Outcomes

We are currently using two 3D printed devices extensively with our clients with ALS/MND. The first device is an enclosure for the activation button of an inexpensive wireless doorbell that makes it accessible as a call bell. The second is a 3D printed switch mount. Printing these devices has made them more accessible to our clients and significantly less expensive to procure than commercially available technologies.

Recommendations To The Field

We believe that 3D printed devices are going to become more available and accessible and it is in your clients' interests to learn how to access these tools and technologies.


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