



Allied Professionals Forum

6 December 2018 | Glasgow, Scotland, UK

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2018 Evaluations

Thank you for attending the 2018 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://surveyhero.com/c/a310d080> to complete an evaluation survey. The organising committee will consider attendees' responses as we plan and organise the APF programme for 2019 and beyond.

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

—*The APF Programme Committee*

16th Annual Allied Professionals Forum

Lomond Auditorium | Scottish Event Campus | 6 December 2018
Glasgow, Scotland, UK

Programme Agenda

8.30	Opening Remarks	Rachel Boothman & Sara Feldman	
8.40	Welcome Address	TBD	
8.50	About the International Alliance of ALS/MND Associations	Steve Bell	
9.00	CARE-MND	Judith Newton	UK
9.20	One size does not fit all - expanding our range of information formats to support families affected by ALS/MND	Emily Richardson	UK
9.40	MND Connect Helpline: A window to wider support	Adele O'Toole	UK
10.00	Hospice volunteers supporting those with ALS/MND and cognitive change	Marjolein Cleaver	UK
10.20	Morning Refreshments		
10.50	Gordon Aikman Scholarship Award - Breath Stacking Interim Results and Learning Strategies	Dianne Fraser	UK
11.10	Challenges of assessment and management of cough augmentation in ALS/MND	Charlotte Massey	UK
11.30	Multidisciplinary assessment and management of cough for airway clearance	Jodi Allen	UK
11.50	How dysphagia changes the perception of food in ALS/MND - the perspectives of people with ALS/MND and their caregivers	Dominika Lisiecka	Ireland
12.10	Lunch and Networking		
13.40	Advanced Care Planning in ALS/MND Patients: An Italian experience	Christian Lunetta	Italy
14.00	What do children need when a parent has ALS/MND? A review of existing psychological support interventions and suggestions for further developments	Rachel Tams	UK
14.20	Training in Non-invasive Ventilation: Incorporating discussions from diagnosis to End of Life Care	Jane Martin	UK
14.40	'A time to remember' A practical framework to support families who have been bereaved	Wendy Bennett	UK
15.00	Afternoon Tea		
15.20	Breaking the conspiracy of silence: A presentation for professionals on how to discuss sexuality and intimacy with ALS/MND patients and their partners.	Sandra de Moree	Netherlands
15.40	Music therapy in multidisciplinary ALS/MND rehabilitation: research and practice	Alisa Apreleva	Russia
16.00	Art Therapy for people with ALS/MND, group and virtual mode	Viviana Faierman	Argentina
16.20	Use of Cannabis Extract Spray (Sativex) in ALS/MND	Gill Craig	UK
16.40	Close	Rachel Boothman & Sara Feldman	

Co-Chairs: Rachel Boothman, MND Association; Sara Feldman, ALS Hope Foundation

Speaker

Steve Bell – Chairman of the International Alliance of ALS/MND Associations

Steve.bell@mndassociation.org

Biography

Steve Bell, MBA, GradDipPhys, FCMI, MCSP – Biography.

Steve qualified as a Chartered Physiotherapist in 1980 from the Sheffield school of Physiotherapy. After developing a specialism in working with adults with a learning disability he was appointed to develop community services for the South Manchester Health Authority.

Steve left clinical practice in 1990 to take up a post as a CEO of a charity providing residential care, day care and sheltered living for adults with Autism and Asperger's syndrome. During this time, he completed his MBA at Sheffield Hallam University, focusing on the change for Charities in moving from grant aid to the contract culture that we see today.

Steve moved to work for Goldsborough Home Care, a subsidiary of BUPA as Operations Director and then Director with responsibility for contracts and commissioning, covering the whole of England and Wales.

Steve joined the Motor Neurone Disease Association in 2002, as its first Regional Manager, covering the north of England. In 2009, Steve was appointed as Director of Care, with responsibility for the North of England, Wales and Northern Ireland. Steve is a Director and current Chairperson of the International Alliance of ALS/MND Associations.

Steve has a key interest in End of Life care and also cognitive impairment and Frontotemporal dementia for those living with MND.

Speaker

Judy Newton

Judith.newton@nhs.net

Biography

Judy Newton is the national lead /consultant nurse for MND. Appointed to this post in 2016 to standardise and deliver equity of care in Scotland.



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INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

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Authors

Judy Newton/Suvankar Pal

Title of Presentation

CARE-MND

Background

Clinical Audit Research Evaluation-Motor Neuron Disease (CARE-MND) is a unique platform integrating clinical care, research registry, audit and evaluation. This platform is used to assess patients, capture incidence of disease and perform audit of clinical care against NICE guidelines.

Objective

CARE-MND is an electronic platform of capturing in real time, clinical information, phenotyping and classification of disease on every person living with ALS/MND in Scotland.

Programme Description

In this presentation we would like to demonstrate the process of establishing a clinical care document, capturing of incident cases, and tracking of every person on a live database across Scotland .

This allows us to have valuable insight into care needs, service provision and understand the Scottish ALS/MND population as a whole.

Clinical Outcomes

CARE-MND has national approval to capture live audit of care set against the NICE guidelines as set out in the Scottish National Proforma. In addition we can accurately inform the number of living cases at any one time in any health board and track the disease journey of every individual case. We can establish at any time the number of people using NIV, tube insertion and provision of AAC in Scotland.

Recommendations To The Field

The development of a sophisticated database to capture disease incidence and prevalence whilst capturing every patients disease journey is unique.

Audits of care are produced and health boards can identify where service improvement is required driving up standards of clinical care in ALS/MND in Scotland.

Speaker

Emily Richardson

emily.richardson@mndassociation.org

Biography

Emily is Care Information Developer at the Motor Neurone Disease Association covering England, Wales and Northern Ireland. Her main responsibility is maintaining the development and revision cycle of the MND Association information sheet range for people living with and affected by MND.

Before joining the Association, Emily completed a research Master's degree in English language with a focus on phonology. In her spare time, Emily is a keen baker and enjoys gardening.



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Authors

Emily Richardson

Title of Presentation

One size does not fit all – expanding our range of information formats to support families affected by ALS/MND.

Background

We have a globally recognised information provision that supports families affected by ALS/MND across England, Wales and Northern Ireland. Despite this being the largest collection of specialist information for ALS/MND in the UK, there are still families we aren't reaching. We need to fill this gap.

Objective

Adding more content won't solve this problem and could actually overwhelm our audience. However, expanding the range of information formats we offer may enable us to reach these families and meet their varying needs. This will help them feel more confident in making informed decisions about care, accessing support, and opening important conversations with each other and with the professionals supporting them.

Programme Description

The presentation will discuss:

- the formats we already provide
- the information requirements of the whole family
- the scoping work and user engagement conducted to explore what our stakeholders needed
- the need for a wider range of formats.

Clinical Outcomes

Indicators from feedback and take up tell us that providing information in a range of formats enables more people to access it.

Our download figures have almost doubled since 2015, while the send out figures for printed resources have remained largely unchanged.

By broadening our formats, we become more inclusive. Pdf files are compatible with screen readers, audio visual information removes reading barriers, and video content can be accompanied by subtitles.

52% of people with MND/ALS in England, Wales and Northern Ireland use a computer or tablet device for communication support. Creating information that is compatible with these devices makes it easier to access.

"I'm finding it more difficult to turn pages, so online information is really helpful." – Chris, living with MND

We consistently see the two most sensitive sections of our End of Life guide downloaded significantly more than any other extracted section, and the same sections provided in print. By giving people a choice, we enable them to access information in spaces they feel comfortable.

Recommendations To The Field

Consider the information needs of the families you're supporting. This includes their varying levels of understanding and preferred way of accessing information. Are you providing them with information they can access, understand and apply?

Be willing to allow your stakeholders' behaviour to influence and determine the way you work. We need to adapt to, and embrace, the changing way people are accessing information.



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Speaker

Adele O'Toole

adele.otoole@mndassociation.org

Biography

Adele is a MND Connect Adviser for the Motor Neurone Disease (MND) Association offering telephone and email support to people living in England, Wales and Northern Ireland. She has worked on the helpline for over 3 years. Adele works as part of a team of 5 to ensure that people living with MND, their families, carers and health professionals receive the reliable and accurate information about MND.

Adele completed her undergraduate degree in Psychology and a Master's degree in Health Psychology. Adele's career has involved working within the public and private sectors and before joining the MND Association she worked as an associate practitioner within a Speech and Language Therapy Department. Adele is a keen cyclist and enjoys making art and crafts in her spare time.

Authors

Adele O'Toole

Title of Presentation

MND Connect Helpline: A window to wider support

Background

The Helpline was created in 1999 to provide comprehensive information and support services across England, Wales and Northern Ireland. We provide support for people with MND, Carers, Family Members (including children), Health and Social Care Professionals, Staff and Volunteers. We will however offer help to anyone who contacts us and we do occasionally receive calls/emails from other countries.

The helpline offers information and support on all aspects of motor neurone disease (MND), including symptom management, clinical research and signposting to other organisations.

The helpline provides a daytime and evening telephone services as well as email support & a thread on the MND Association online forum.

Objective

Our goal is to provide emotional support as well as reliable and accurate practical information regarding all aspects of motor neurone disease.

Programme Description

The presentation will focus on:

- Changes to the helpline over the years – how its evolved and developed
- Advisers having a holistic view & knowledge of all aspects of MND
- Support we offer to all callers, both practical and emotional
- How we can support health professionals to help them support their patients
- Working to an accredited standard
- Recent developments – call recording, language line
- Future projects – webchat, call queueing

Clinical Outcomes

For the person with MND and their carers the helpline provides an opportunity to have honest and open conversations. We listen & guide people to both internal and external services to ensure people are linked into appropriate support & receiving the highest level of care.

For health and social care professionals we answer all questions on MND and talk about the support we offer as an association including our funding and equipment loan provision. We use a collaborative approach to best support the paMND.

The following feedback and comments have been received.

“We have had contact with a number of different people at the Association including MND Connect, providing excellent advice with a common theme of always here to help” Leslie

“Its basically MND Connect that we turn to for everything and that’s how we find everything out” Martin

Recommendations To The Field

Everyone involved in the care of someone with MND knows about the helpline and how to access its services, to ensure that the needs of the person with MND and their family are being well supported.



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Speaker

Marjolein Cleaver

marjoleincleaver@loros.co.uk

Biography

Marjolein heads up the EVOLVE project at LOROS Hospice, Leicester. She trained as an occupational therapist and has a keen interest in working with people with dementia. Prior to her training she spent many years working in the Voluntary and Community Sector setting up and running community projects, locally and internationally.

Authors

Marjolein Cleaver

Title of Presentation

Hospice volunteers supporting those with ALS/MND and cognitive change

Background

Following a high number of referrals of patients with the dual diagnosis of ALS/MND and frontotemporal dementia a bid was written to obtain extra funding to support these patients and their carers as existing services did not adequately meet their need. The EVOLVE project was made possible through funding from Hospice UK to provide rehabilitative palliative care over a period of 18 months.

Objective

To recruit and train volunteers, with a background in healthcare, to support patients with complex needs. Specially trained volunteers support patients with a dual diagnosis of MND, or other neurological condition, and cognitive change to work towards their own goals during regular home visits. At the same time these visits provide respite for carers who are encouraged to use this time to attend to their own priorities.

Programme Description

Following referral from the MDT at the hospice the project lead carries out a home assessment to discuss the service, carry out an environmental risk assessment and set goals. They then identify and introduce a volunteer to visit weekly or fortnightly to provide a social visit to work towards those goals. The carer is made aware they can use this time for respite. Regular follow ups with carer and long arm supervision for volunteer are provided. With the support from the research team, a project evaluation is also being carried out.

Clinical Outcomes

Preliminary findings have been as follows. The calibre of volunteers recruited for the project has been very high with a high level of experience in caring. This has provided former carers with a role which they have enjoyed carrying out. Goal setting with patients has proved difficult due to the cognitive changes patients experience, however, meaningful relationships were built up and social advantages were seen as significant. Carers seem to have benefitted most from this project through having a dedicated person who was able to learn the patient's specific needs and provide them with practical and emotional support. Recommendations from the final report, available from August 2018, will be included in the presentation.

Recommendations To The Field

Specifically trained volunteers can support people with complex conditions, when appropriately supported by qualified staff, to engage in meaningful occupations. This enhances client centered care as the volunteers provide an additional support network to the patient and their carer and are able to bridge the gap between healthcare services and families. Carers of those with neurological conditions benefit from having a dedicated person who understands the changing needs of their loved one and can provide them with some regular respite from caring responsibilities.



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Speaker

Dianne Fraser

dianne.fraser@nhs.net

Biography

An Occupational Therapist by profession Dianne has worked as a Clinical Specialist for Motor Neurone Disease for 18 years in the north of Scotland. She has recently been awarded the Gordon Aikman Scholarship to further the work she has been completing since 2012 on breath stacking. This award will offer an opportunity to map best practice and bring this and learning strategies together in the form of a practical package for patients and professionals.

Authors

Dianne Fraser

Title of Presentation

Gordon Aikman Scholarship Award – Breath Stacking: Interim Results and Learning Strategies

Background

UK NICE MND Guidelines site Breath Stacking (BS) and use of a Lung Volume Recruitment Bag (LVB) as a treatment technique for MND/ALS patients. The British Medical Journal Best practice in MND Guide recommends BS. (Ref 1, 2) It can aid secretion clearance, reduce rigidity of the chest wall, and can increase voice volume for up to 30 minutes. The LVB costs £32 per unit has been studied alongside a Cough Assist Machine (£3,100 to purchase) and found to be as effective, unless a chest infection was present. (Ref 3, 4) However very few patients are offered this technique.

Objective

To complete a Joanna Briggs Systematic review, mapping current evidence and grey literature

To question why this technique is not being widely used

To respond by producing a practical package of solutions for professionals and patients

Programme Description

Interim results will be reported.

Successful strategies/models used to populate breath stacking into everyday practice in Scotland between 2012 and 2018 will be discussed.

Clinical Outcomes

All appropriate patients in Scotland should be offered this therapeutic intervention.

The finalised package will be web based and freely available.

Other neurological conditions may benefit by increasing their knowledge of this technique.

Recommendations To The Field

Flexibility of training models has produced sustainable and dynamic learning.



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Speaker

Charlotte Massey

charlotte.massey3@nhs.net

Biography

Charlotte Massey is a Physiotherapist based at the National Hospital for Neurology and Neurosurgery. She provides specialist neurological and respiratory intervention to patients with neurological and neuromuscular impairments as part of a multi-disciplinary team. The team specialise in provision of cough augmentation for neuromuscular patients and there is always consideration of both bulbar and respiratory impacts of this. She has completed research work in the field of neuromuscular disease including a natural history study in myotonic dystrophy and is currently completing a project assessing activity levels in neuromuscular disease.

Authors

Charlotte Massey and Jodi Allen

Title of Presentation

Challenges of assessment and management of cough augmentation in ALS/MND

Background

Respiratory insufficiency and complications are the main cause of morbidity and mortality in patients with Motor Neurone Disease (MND). Implementing cough augmentation and swallowing strategies at the appropriate time can have a profound impact on quality of life by reducing risk of chest infections and unnecessary hospital admissions.

Objective

To understand the clinical challenges associated with providing cough augmentation in ALS/MND.

Programme Description

Retrospective review of case notes and data collection on all patients admitted to the National Hospital for Neurology and Neurosurgery (NHNN) between December 2017 and March 2018 (n=16). Data points included MND subtype, time to first cough assessment, Forced Vital Capacity (FVC), Peak Cough Flow (PCF), form of cough augmentation provided and reasons for failure.

Clinical Outcomes

18% of patients assessed had PCF > 270 and were deemed not to need MI:E /LVR. Instead they were taught breath stacking and manually assisted cough strategies. Of the 82% of patients PCF < 270, all were deemed potentially appropriate for MI:E / LVR provision. Following joint SLT/PT assessment, 53% were successfully initiated on MI:E (75%) or LVR (25%). 31% were unable to tolerate any form of cough augmentation.

Reasons for failure of MI:E or LVR included uncontrolled sialorrhoea (80%), pseudobulbar presentation (60%), unmanaged dysphagia (40%), bulbar collapse (40%), and cognitive impairment (20%). FVC, PCF and time to first PT assessment did not differ between those successfully initiated and those in whom MI:E/LVR failed.

Recommendations To The Field

At point of referral for cough augmentation in MND physicians and therapists need to be aware of the possible barriers to successful initiation. Identifying and addressing modifiable risk factors (sialorrhoea, dysphagia) and identifying cognitive impairment precluding MI:E /LVR initiation allows specialist therapists to target their finite resource to the most appropriate population. We recommend, and stress the importance of joint PT/SLT assessments in these patients, as well as close working with other MDT colleagues, in order to identify those patients most likely to benefit from MI:E /LVR without incurring undue risk.



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Speaker

Jodi Allen

jodi.allen@nhs.net

Biography

Jodi Allen is a Speech and Language Therapist based at The National Hospital for Neurology and Neurosurgery in London. She provides a highly specialist service to patients living with neurological and neuromuscular disease as part of a multidisciplinary team. Her clinical remit includes diagnostic motor speech examinations and specialist assessment and management of dysphagia. She has a particular interest in the respiratory and neuromuscular interface in the treatment and management of patients with dysphagia and advocates for early, prophylactic interventions to optimise function and avoid unnecessary complications. Jodi completed an NIHR-funded Masters of Clinical Research in January 2017 which sort to identify tools to support early diagnosis of dysphagia in neuromuscular disease. She aims to continue with this work in future.

Authors

Jodi Allen and Charlotte Massey

Title of Presentation

Multidisciplinary assessment and management of cough for airway clearance

Background

Assessment and management of cough for airway clearance typically falls under the remit of respiratory physiotherapy. Bulbar impairment and dysphagia are common in motor neurone disease (MND) and can present with symptoms similar to those associated with weak cough and difficulty clearing secretions. If bulbar impairment is not fully considered in assessment of cough, management may be poorly tailored, leading to patient discomfort and sub-optimal clinical outcomes. We propose a multidisciplinary approach to assessment and management of cough to tailor management programmes and improve outcomes for patients.

Objective

To establish whether a joint Speech and Language Therapy (SLT) and Physiotherapy (PT) approach to cough assessment for airway clearance alters the clinical management of patients with ALS/MND.

Programme Description

Patients referred to physiotherapy for airway clearance were jointly assessed by SLT and PT over a five month period. Assessment domains included: clinical respiratory history, inspiratory and expiratory muscle strength, bulbar impairment, dysphagia, voluntary and reflexive cough, oral and pharyngeal secretions, cognitive status and mobility.

Primary issues impacting airway clearance were identified post assessment and addressed in a hierarchical order, tailored to individual circumstances, clinical risk and patient wishes.

For example;

- 1) An individual presenting with a poor peak cough flow (200l/min) but a clearing reflexive cough on a background of unmanaged dysphagia and no chest infections would likely be referred for formal SLT assessment to optimise dysphagia management prior to any initiation of cough augmentation.
- 2) An individual presenting with weak volitional cough (160l/min) and a poorly-clearing reflexive cough on a background of well-managed dysphagia but excess oral secretions would likely be referred for pharmacological management prior to cough augmentation with the physiotherapist.

Clinical Outcomes

Over half (53%) of patients initially referred to physiotherapy had primary needs associated with unmanaged dysphagia and/or oral secretion management. These patients were referred either for SLT assessment and management of dysphagia and/or for pharmacological management of secretions with a view to return for repeat assessment once these issues had been addressed. Of those requiring initiation of cough assist, joint evaluation using nasendoscopy was beneficial.

Recommendations To The Field

Deterioration in cough and bulbar function are common in MND. Assessment of cough and airway clearance without consideration of bulbar function may result in poorly tailored management programmes. A recommendation is made for joint SLT-PT assessment to ensure primary issues are addressed in a safe and clinically effective manner. At the point of MI-E initiation, joint assessments are also recommended in order to optimise pressures and tolerance.



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Speaker

Dominika Lisiecka

dominika.lisiecka@ul.ie

Biography

Dominika is a Senior Speech & Language Therapist working in Ireland for the past 15 years. Her particular interest is in adults neurology and dysphagia. Dominika's PhD examined the experiences of dysphagia in MND. This PhD was awarded prestigious Health Research Board Research Fellowship in 2015. Currently Dominika lectures in adults neurology at the University of Limerick in addition to working clinically.

Authors

Dr. Dominika Lisiecka, Dr. Helen Kelly, Prof. Jeanne Jackson

Title of Presentation

How dysphagia changes the perception of food in ALS/MND - the perspectives of people with ALS/MND and their Caregivers.

Background

Although dysphagia affects the majority of people with ALS (PALS), relatively small number of studies examined the every-day experiences of dysphagia in this population. In addition, no comparative studies were identified which investigated PALS - caregiver dyads to reveal any differences in their perceptions of dysphagia. Yet, dysphagia-related services are often provided for PALS and their caregivers simultaneously. We aimed to address the above gaps. Interestingly, our study identified that dysphagia in ALS/MND changes the relationship and the meaning of food for both PALS and their caregivers. These changes were distinctive for the two groups.

Objective

To investigate any variations between the experiences of PALS and their caregivers in relation to dysphagia. To investigate the consequences of dysphagia, particular how dysphagia influences PALS' and their caregivers' relationship with food.

Programme Description

Multiple, qualitative, individual interviews (n=59) with 10 PALS and 10 caregivers from Ireland.
Data analysis: Stage 1: Interpretative Phenomenological Analysis - individual for each participant. Stage 2: comparative thematic analysis of PALS vs. caregivers' data.
Inclusion criteria for Caregivers: normal cognition, involvement in dysphagia management at home.
Inclusion criteria for PALS: normal cognition, communication at sentence level (verbal or not), diagnosis of dysphagia, self-reporting dysphagia.

Clinical Outcomes

There is a discrepancy between PALS and their caregivers' perception of dysphagia and perception of dysphagia-associated risk.
The caregivers recognise signs of dysphagia sooner than PALS.
Although dysphagia has strong emotional impact on both groups, it appeared to affect the caregivers earlier than PALS.
Dysphagia affected the relationship with food in both groups, but at a different times.
There appears to be a relation between one's relationship with food and readiness to accept non-oral feeding.

Recommendations To The Field

Dysphagia can affected PALS differently to their caregivers. Both groups can have different expectations from health-services. Dysphagia alters the relationship and the meaning of food in both groups, but in a very different way.
Inquiring about PALS' relationship with food can guide their decision making process in relation to non-oral feeding.



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Speaker

Rachel Tams

rachel.tams@ouh.nhs.uk

Biography

Dr Tams and Dr Daisley are Consultant Clinical Neuropsychologists based at the Oxford Centre for Enablement in Oxford working with people with MND and their families. Both have extensive experience over many years of delivering psychological interventions to people with neurological conditions and their families. Dr Daisley established the first NHS service to specifically support the children of parents with neurological illness and injury. More recently Dr Tams and Dr Daisley were awarded a prize for innovation from the MS Trust for their work on resilience building in families affected by neurological illness. They are part of OxINMHAR (the Oxford Institute of Nursing, Midwifery, and Allied Health Research) which is part of the Oxford Academic Health Science Centre (a partnership between Oxford Brookes University, University of Oxford, Oxford University Hospitals NHS Foundation Trust and Oxford Health NHS Foundation Trust). This is one of only six Department of Health accredited centres of excellence and focuses on translating research to evidence based care and innovation for patient benefit.

Authors

Dr Rachel Tams and Dr Audrey Daisley

Title of Presentation

What do children need when a parent has ALS/MND? A review of existing psychological support interventions and suggestions for further developments

Background

The impact of progressive neurological illnesses on adult family members has been well documented in the research and clinical literature, but much less is known about how children are affected when a close family relative has a neurological condition. While it is recognised that this group of children face many adjustment challenges, and may be vulnerable to a range of psychological difficulties which require input, there are few reports of targeted interventions for children.

Due to rare nature of ALS/MND, the condition-specific literature base is even more limited. However as this illness presents children with a unique set of adjustment challenges the authors feel this is an important oversight and requires urgent further study.

Objective

In this presentation we will 1) discuss what is already known from the literature about how children respond to ALS/MND in a close family member, 2) highlight the gaps in service provision and 3) describe the small number of interventions that have been developed in ALS/MND field, to help children manage the challenges they face.

Programme Description

The authors will argue that this is an area that requires considerably more research, particularly in the development and evaluation of child-specific and whole family support interventions to ensure that those affected by ALS/MND are able to develop the emotional strength to live as well as possible within the challenges they face. In particular they will discuss families differing needs over the course of the illness – from diagnosis through to longer term support after the death of the relative. The presenters will share their own experiences in this area, and the lived experiences of families they have worked with, outlining some of the obstacles but also the immense opportunities and possibilities faced in the development of such work.

Clinical Outcomes

They will conclude by proposing a strengths-based resilience focused approach to supporting children and families living with ALS/MND. They highlight the importance of building resilience in children – shifting away from the all too dominant focus on problems to one that concentrates on solutions and possibilities, in order to build capacity in children and families to thrive despite facing the challenge of ALS/MND.

Recommendations To The Field

The presenters will recommend that addressing the emotional support needs of family members including children of people with ALS/MND are incorporated into routine care.



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Speaker

Christian Lunetta

christian.lunetta@centrocliniconemo.it

Biography

Dr. Christian Lunetta (MD) is a neurologist and responsible for care and research of ALS at NEMO Clinical Center. He is a member of ITALSGEN, a consortium devoted to performing genetic studies in ALS patients, a member of EURALS group devoted to performing epidemiological studies in ALS patients, and Medical Director of the Italian ALS Association (AISLA). He has served as a principal investigator and co-investigator in several clinical trials in ALS patients. His scientific production includes 95 papers in journals indexed in Pubmed (H Index (Google Scholar): 22; i-10 index: 42) and many presentations at national and International meetings.

Authors

Christian Lunetta*, Stefania Bastianello, Daniela Cattaneo, Alessandro Fabbri, Massimo Mauro, Mario Sabatelli

Title of Presentation

Advanced Care Planning (ACP) in ALS/MND Patients: An Italian experience

Background

Although ALS/MND is a neurodegenerative disease with a poor prognosis, different studies showed that fewer than 40% of patients with ALS (PALS) have recorded their attitudes and wishes regarding life-sustaining treatment and supports. The direct consequences of the absence of advanced directive for future medical treatment, are often sub-optimal medical decision-making during a crisis, unwanted treatment and moral distress for those who must make surrogate healthcare decisions. Recently, in Italy it was approved a specific law for Advanced Care Planning (Article 5, Law n.219 of 22 December 2017) that represents an important step in the work of sharing and thought started since 2014 by the Italian ALS Association (AISLA) with the publication of the first consensus document on the therapeutic choices of PALS.

A fundamental aspect of this law is that it is the expression of a path of dialogue and information, sharing between health personnel, family and PALS, in a context of mutual respect and trusting care relationship, aimed at achieving a full awareness of PALS in the therapeutic choices.

Objective

To validate a form devoted for ACP in ALS as a tool to improve the care of the disease.

Programme Description

The form was made by a group of professionals of AISLA with experience in ACP. It was used in the context of multidisciplinary care program of 4 ALS Italian Centers. The preliminary results showed that the form was perceived by the PALS and health professionals as an useful tool to ensure the fundamental right of the person with a severe disease to decide about the treatments that he or she wishes to undergo. This experience confirms that therapeutic choices in PALS must necessarily represent the result of a relationship of care based on constant dialogue between the patient and the multidisciplinary team, in which the principles of appropriateness, proportionality and consensuality constitute unavoidable references.

In fact, the actions resulting from the expressed therapeutic choices do not determine acts contrary to the current legislation such as instigation or determination to suicide, as these choices are health processes for which informed consent is required for treatment.

Clinical Outcomes

Evaluation of "perception" by the patient, caregiver and health personnel. Further analysis under construction.

Recommendations To The Field

Promote the dissemination of the experience of AISLA in relation to the ACP in all settings: home, hospital, residential, both among health workers and among PALS, through structured and traceable pathways.



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INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

ALLIED PROFESSIONALS FORUM

Lomond Auditorium | Scottish Event Campus | 6 December 2018

Speaker

Jane Martin

ally.lycett@rbch.nhs.uk

Biography

Jane Martin is a Clinical Nurse Specialist in the care of pw MND, she has chaired the Dorset Local Interest Group for MND and has recently received an award from the MNDA for excellence in care, as well as an Extra Mile award.

Ally Lycett is a senior physiotherapist who has worked with pw MND for over 10 years.

Both Jane and Ally work with the East Dorset MND service which is part of the Specialist Palliative Care Service in Christchurch, Dorset, UK. This service is joint funded by the NHS and the local Dorset charity Macmillan Caring Locally.

Authors

Jane Martin and Ally Lycett

Title of Presentation

Training in Non-invasive Ventilation: Incorporating discussions from diagnosis to End of Life Care

Background

From 2010 we saw an increase in patients under our specialist palliative care service using Non-Invasive Ventilation. Hospice staff lacked confidence for discussions and decision making re NIV initiation and practical care. After staff feedback and team reflections we found our staff were unprepared, even distressed, at NIV withdrawal with some unclear regarding the ethics and legality. Qualitative evidence supports these findings.

Objective

We wanted to design a training programme that would:

- educate all our staff regarding law and ethics,
- help staff become confident to discuss NIV and help patients make decisions, to screen and refer the right people at the right time,
- to train staff to manage the equipment and interfaces, especially out of hours, and lower the risk complications.
- to educate re NIV withdrawal and facilitate reflection on difficult cases

Programme Description

From November 2013:

- we reflected on 5 cases of NIV withdrawal
- we attended national and local training and gained competencies in spirometry and NIV
- we completed literature searches on respiratory screening and qualitative studies.
- we developed a respiratory screening tool and a local withdrawal pathway
- we edited a Respiratory Care Pathway for Dorset, in collaboration with the MND Local Interest Group
- we wrote staff competencies and 3 hour training session, which was delivered to all specialist palliative care trained staff

Clinical Outcomes

Staff were asked to rate their ability to recognise S + S of respiratory failure in MND - 93% rated themselves good or excellent after training.

When asked to rate their practical confidence - 88% rated themselves good or excellent after training.

The best results were in the area of legal and ethical frameworks - where 97% of staff rated themselves good or excellent after the training.

Recommendations To The Field

Multi-disciplinary team care and non-invasive ventilation have both been shown to prolong life in pw MND. This involves a mix of skills including advance care planning, discussions and complex decision making, respiratory screening, referral and practical NIV management. Confident management at end of life including withdrawal involves planning that can start before referral. Training is essential for staff competence and confidence. Hospice based multi-disciplinary palliative care teams are ideally placed to provide all of these services and can help the right persons select NIV at the right time for the right length of time.



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INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

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Lomond Auditorium | Scottish Event Campus | 6 December 2018

Speaker

Wendy Bennett

wendy.bennett@lthtr.nhs.uk

Biography

Wendy Bennett qualified in 1991 and has pursued an active career in Neurosciences based at Lancashire Teaching Hospitals Foundation Trust in Preston. Initially working within Neurosurgery, she moved to Neuromedicine in 1995 and has specialised in Motor Neurone Disease since 2005. In her current role, Wendy works part time as a specialist nurse in the Lancashire and South Cumbria MND Care and Research Centre, taking an active role in research and service development.

Authors

Wendy Bennett

Title of Presentation

'A time to remember' A practical framework to support families who have been bereaved

Background

The NHS and MND Association expedite resources and support for people living with MND and their families. Whitehead et al (2011) reports support received for both patient and carer was vital to help reduce carer burden. However carers reported often feeling lonely and unsupported and didn't feel they had enough time to come to terms with their partner's imminent death due to the increasing demands of the disease. Aoun et al (2012) found MND family carers had little regard for their personal needs. These families can enter bereavement often physically and emotionally exhausted without the care networks upon which they have become dependent. This paper demonstrates how the MND team in Lancashire and South Cumbria, UK, set up a programme to show bereaved families they have not been forgotten, following the death of their relative.

Objective

To develop a framework of bereavement support for supporting a family during the first 12 months of bereavement.

Programme Description

The MND team always sent sympathy cards upon bereavement, Honeyman (2005) and Vacha-Haase (2013) highlighted the value of sending cards up to the first anniversary death. This approach has been adopted. In 2014 the MND team arranged the first Memorial service for bereaved families. The programme included a service in the hospital chapel with poems and messages read out for each of the bereaved. Due to the success of the first year, the Memorial has now become an annual service with increasing attendees yearly. 58 people attended the first year, increasing to 115 in 2017.

Clinical Outcomes

Families report that they appreciate the time spent by the service to remember their loved one. Familiarity with the professional helps them appreciate their empathy with the family's bereavement experience. This service is a continuation of the holistic care offered to those living with MND. The positive comments and increased numbers of people attending the memorial service suggest we are responding to an unmet need in our service.

Recommendations To The Field

Care of the bereaved, by those working in Care Centres is often limited by professional workload. However, receiving cards and an invitation to a yearly memorial service are reminders of support to reduce the feeling of isolation and abandonment people experience after the death of their relative. These initiatives add value to the care of people with MND and their families and are recommended as a gesture of holistic support to families still coming to terms with their loss.



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INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

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Lomond Auditorium | Scottish Event Campus | 6 December 2018

Speaker

Sandra de Moree

s.demoree@amc.uva.nl

Biography

Sandra de Morée, licensed clinical health psychologist and psychotherapist, departments of Medical Psychology, Rehabilitation (MND team), and Sexology, Academic Medical Centre of Amsterdam, the Netherlands.

Authors

Sandra de Moree, MSc

Title of Presentation

“Breaking the conspiracy of silence” - A presentation for professionals on how to discuss sexuality and intimacy with Motor Neuron Disease (MND) patients and their partners.

Background

People diagnosed with ALS/MND are faced with progressive loss of physical functioning and a shortened life expectancy. Clearly, physical deterioration and physical impairment like salivation, appearance changes due to muscle loss, fatigue, care dependency and medical aids (e.g. ventilation) can have a significant impact on sexuality and intimacy of the patient and his or her partner in the course of the illness process. This does not mean that they have lost the need for intimacy and sexual pleasure and may experience a need for advice or counseling. The topic of sexuality however is however rarely addressed in clinical encounters, for a variety of reasons. On the side of the health care professional (HCP) lack of knowledge, time constraints, personal attitudes, low confidence and insufficient ‘soft’ skills can be barriers to recognizing the need for and opening up the discussion around sexuality with ALS/MND patients and partners; patients may feel uncomfortable or in doubt whether it is appropriate to talk about sex. Assumptions from both HCPs and patients, like: “they didn’t mention it, so they don’t want to talk about it; or “this is not the time and the place to talk about it“ can easily lead to a ‘conspiracy of silence’. Breaking this conspiracy can contribute to the quality of care for ALS/MND patients and their life quality.

Objective

To enhance professionals’ confidence and ability to detect and talk about sexual needs and intimacy in ALS/MND patients and their partners, and arrange adequate referral if indicated.

Programme Description

In this presentation the following topics are addressed:

- 1) Why is it relevant to discuss sexuality and intimacy with patients with ALS/MND and their partners?
- 2) What barriers are encountered by HCP in discussing this topic?
- 3) What do we know about sexual problems experienced by patients diagnosed with ALS/PSMA en PLS?
- 4) How to identify and discuss problems with sex and intimacy in the context of ALS/MND Care Tools and the PLISSIT model as a practical framework for clinicians.

Clinical Outcomes

Discussing sexuality and intimacy with ALS/MND patients and their partners can contribute to the quality of care for ALS/MND patients and their life quality.

Recommendations To The Field

As patient advocates health care providers can play an important mediating role in helping to find alternatives and resources related to sex and intimacy issues that maybe unknown to individuals and couples with ALS/MND.



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INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

ALLIED PROFESSIONALS FORUM

Lomond Auditorium | Scottish Event Campus | 6 December 2018

Speaker

Alisa Apreleva

apreleva@gmail.com

Biography

Alisa Apreleva, MT-BC, NMT, Founding director at music therapy advocacy initiative MuzTerapevt.Ru (Russia), International advisor for ALS Foundation "Live Now", PhD researcher at Anglia Ruskin University (Cambridge, UK).

Dr. Lev Brylev, MD, Head of neurology department at Moscow City Hospital #12, Medical director at ALS Foundation "Live Now" (Moscow, Russia).

Authors

Alisa Apreleva, MT-BC, NMT, Lev Brylev, MD

Title of Presentation

Music therapy in multidisciplinary ALS/MND rehabilitation: Research and Practice

Background

Music therapy (MT) is the clinical use of music and its elements to accomplish individualized health goals within a therapeutic relationship. Music therapists have theoretical and practical knowledge of music, human psychology and physiology, and work with MDT to provide evidence-based, problem-oriented treatment. There is evidence that MT may be beneficial for psychological wellbeing of PALS during NIV use, may improve QoL, increase communication and decrease physical symptoms of the disease for people living with ALS (PALS), may be effective for managing behavioural and psychiatric symptoms of people with FTD, may have a beneficial effect on heart rate, respiratory rate, and anxiety in mechanically ventilated patients. MT has been shown effective to treat cognitive, sensory, and motor dysfunctions caused by human neurologic diseases. Still, MT is rarely available to PALS prior to the end-of-life stage when benefits of the intervention are limited.

Objective

Until the cure is found, more rehabilitation options for PALS need to be considered. MT may enable PALS to reach their fullest potential. It may also be an accessible and cost-effective way to decrease caregiver burden in CALS, including children.

Programme Description

Two music therapists are employed at ALS Centre Moscow and are regularly referred by the MDT to patients at various stages of the disease progression. Home-based MT interventions are tailored to individual clinical needs, preferences and capabilities of PALS, providing opportunities for psycho-emotional support and counseling, relaxation, verbal and nonverbal communication, pain management, relationship dynamics improvement, socialization, behavioural and cognitive symptoms management, and, with proper precautions, bulbar and respiratory functions support and moderate physical exercise.

Clinical Outcomes

Empirical clinical evidence, feedback from PALS and CALS and increasing demand for the service at ALS Centre Moscow suggests that MT may be a motivating and effective way to manage non-physical and physical ALS/MND symptoms, to aid treatment planning and compliance, and to support caregivers. Our practice and research also suggest that structured, individualized breathing and vocal exercises have a potential to sustain bulbar and respiratory functions for PALS.

Recommendations To The Field

Empirical clinical evidence, feedback from PALS and CALS and increasing demand for the service at ALS Centre Moscow suggests that MT may be a motivating and effective way to manage non-physical and physical ALS/MND symptoms, to aid treatment planning and compliance, and to support caregivers. Our practice and research also suggest that structured, individualized breathing and vocal exercises have a potential to sustain bulbar and respiratory functions for PALS.



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INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

ALLIED PROFESSIONALS FORUM

Lomond Auditorium | Scottish Event Campus | 6 December 2018

Speaker

Viviana Faierman

pabloaquino@asociacionela.org.ar

Biography

Viviana Faierman is a sensitive, curious, 51 years old woman, whose life was enriched by art since she was a child. When she was young, she worked as a Systems Analyst in a company, but she was not happy doing that. After thinking deeply about her life and her future, she decided that Art was her passion, and that through the art languages she could help people. She studied and graduated in Fine Arts, Art Therapy, and Counseling. She attended numerous courses, workshops and conferences. She worked with children with cancer, disabled people, and persons in rehabilitation from addictions. She assists older adults in geriatrics houses. At this moment, she continues studying Transpersonal Psychology, and she works with people suffering from ALS/MND. She is a woman committed to the aid and welfare of suffering people, which brings her the meaning of life.

Authors

Viviana Faierman

Title of Presentation

Art Therapy for people with ALS/MND, group and virtual mode

Background

This Art Therapy project, designed by the ALS Association of Argentina, and coordinated by Viviana Faierman (Art Therapist and Counselor), offers people with ALS/MND a safe healing space that helps them regain self-control of their lives, and face their circumstances in a more positive way. This is possible by trusting the fact that every person has a vital force that drives them to be the best they can be in a specific moment, even in the most adverse conditions. This project contemplates mobility difficulties, also taking place in virtual mode. It is an ongoing project since March 2018.

Objective

This Art Therapy project, designed by the ALS Association of Argentina, and coordinated by Viviana Faierman (Art Therapist and Counselor), offers people with ALS/MND a safe healing space that helps them regain self-control of their lives, and face their circumstances in a more positive way. This is possible by trusting the fact that every person has a vital force that drives them to be the best they can be in a specific moment, even in the most adverse conditions. This project contemplates mobility difficulties, also taking place in virtual mode. It is an ongoing project since March 2018.

Programme Description

People with ALS/MND are overwhelmed by feelings and concerns; their lives aren't and won't be the same. Losing control, anxiety, anger, distress, sadness; fear of the unknown, fear of death. Often these people cannot express these feelings. In other cases, they lack words, or these are not enough to describe their inner world. This is where Art Therapy helps them, as it is a discipline that uses art as means of expression and allows, through art language, to speak without words. Through the creative process, people find meanings; this provides clarity and a better acknowledgement of their own emotions. The group space enriches their experience, since each member provides their perspective and their natural skills, which nourishes each of the group's participants and allows them to discover other forms of behavior. Thanks to the virtual mode, there are no boundaries, barriers or distances. Every single person affected by ALS/MND can join this shared and safe space where they can help themselves and also help others with their own experiences.

Clinical Outcomes

People are connecting with memories they had forgotten, with possibilities they believed lost, and with the joy of playing and experiencing as if they were children, which gives them satisfaction and desires of overcoming. Besides, the fact of sharing their works and putting them in consideration of others, gives them a new look and a new meaning to their lives.

Recommendations To The Field

It's not necessary to be talented or an artist to begin art therapy. An artistic activity by itself promotes well-being, accompanied by professionals who help the person make changes that improve quality of life.



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INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

ALLIED PROFESSIONALS FORUM

Lomond Auditorium | Scottish Event Campus | 6 December 2018

Speaker

Gill Craig

gillian.craig3@nhs.net

Biography

Work as a Specialist Nurse MND across NHS Tayside. Has specialised career over 20 years in cancer and palliative care. Transferred interest to MND in April 2016 when the Scottish Government doubled numbers of MND Specialist Nurses from Gordon Aikman's Campaign. Specific interest in providing and facilitating holistic care to patients and families living with MND, ensuring excellent symptom control, palliative care and advance care planning are embedded in practice from diagnosis.

Authors

Gill Craig

Title of Presentation

Use of Cannabis Extract Spray (Sativex) in ALS/MND

Background

In some forms of ALS/MND spasticity is a major feature and can have a significant impact on quality of life. Patients often complain of stiff limbs, difficulty in initiating movement, painful spasms and involuntary movements. Laryngeal spasm, a distressing acute symptom defined as the sudden sensation of the inability to breathe is associated with bulbar onset ALS/MND. At least 80% of these patients will develop symptomatic speech and swallowing dysfunction. In my current practice I find these symptoms complex and complicated to manage due to numerous factors. The aim of treatment is to maintain muscle length and range of movement to prevent soft tissue shortening without reducing function. This is addressed by a MDT approach, non-pharmacological treatments and drug treatment. Despite this approach patients symptoms remain troublesome, uncontrolled and ultimately cause huge distress and anxiety. Three patients in my area are using this with tremendous results and optimum symptom control however others are being denied access to this and continue in constant pain and physical and emotional distress. Despite fighting for this their requests are being denied leading to an inequity of service.

Objective

To explore the use of Sativex Oromucosal Spray and why it remains unlicensed in ALS/MND

Programme Description

Cannabis is already a recognised treatment for MS and there is every indication that it may be equally beneficial in the treatment of ALS/MND. However, legal access to medicinal cannabis within the UK is limited to the pharmaceutical cannabis based medicine Sativex. This can only be prescribed in MS sufferers and it is at the doctors discretion, so differing GPs can effect access. Unfortunately, many doctors are reluctant to prescribe Sativex because of ignorance and misunderstandings over the legality and benefits of cannabis as a medical treatment. This needs to be changed and legalised and available to prescribe in ALS/MND.

Clinical Outcomes

Demonstrate the benefits of Sativex spray in patients with ALS/MND

Demonstrate the unsatisfactory anti-spasmodic therapies and impact on QOL

Recommendations To The Field

Licencing of Sativex in ALS/MND



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