



ALLIED PROFESSIONALS' FORUM
Maritim Hotel, Berlin
7 December 2009

SPEAKER: NICOLE YARAB, RN, BA

BIOGRAPHY:

Nicole received her Bachelor of Arts in Sociology from Emory University in 1994. She attended and graduated from the Dekalb College School of Nursing and received her registered nursing license in 1997. From 1997-1998 she worked as a staff nurse on the neuroscience unit at Emory University Hospital. In 1998, she took a position as a clinical research nurse in the stroke division of the Emory Neurology department. For the next 5 years, she worked in a dual role as both clinical coordinator for the WASID Clinical Coordinating Center and as the Emory study coordinator for the WASID Clinical Coordinating Center and as the Emory study coordinator. WASID (Warfarin-Aspirin Symptomatic Intracranial Disease) was an NIH-funded (National Institutes of Health) multicenter stroke trial, based in the Neurology department of the Emory University School of Medicine. In 2004, at the end of the trial, she joined the department's neuromuscular division as the ALS nurse clinician. She is the team leader for the Emory ALS Clinic and she manages and coordinates the care of over 250 patients with ALS/MND. Nicole has participated in several ALS Advocacy events in Washington, D.C, and has served on the Patient Services and Operations Committee for the ALS Association of Georgia She regularly speaks to local hospice organizations, patients and providers at ALS educational symposiums at the local and national levels.

AUTHOR: NICOLE LESSARD YARAB, RN, BA

TITLE OF PRESENTATION: INVOLVING VOLUNTEERS IN MULTIDISCIPLINARY ALS CLINIC

ABSTRACT:

Background:

All ALS centers strive to provide optimal care for their patients and caregivers, but face various challenges to achieving that goal. Multidisciplinary ALS clinics provide a broad range of services in a “one-stop” setting. However, scheduling, space, time-management and staffing are not always ideal. Large referral centers often have busy ALS clinics resulting in undesirable downtime for patients during a half to all-day appointment. Patients and caregivers are left hungry and tired. Integrating volunteers into the ALS Clinic program can provide potential solutions to some of these challenges.

Objective

- Participants will describe the role of the volunteer at ALS Clinic.
- Participants will identify 2 areas for volunteer involvement.
- Participants will define the framework needed to create and implement a volunteer program at their center.

Programme description

- I. ALS Clinic
 - a. “Lay” volunteers
 - i. Offer refreshments during appointment
 - ii. Photograph patients
 - iii. Converse with patients and caregivers during downtime
 - iv. Offer to share personal story and experiences
 - v. Offer a hug or a friendly ear
 - b. Vendor volunteers
 - i. Assist staff with administrative and operational tasks
 1. Copying
 2. Faxing
 3. Escort patients to clinic rooms
 4. Perform sling scale weights
 5. Assist with loaner equipment needs
- II. Fundraising activities
 - a. 5K run/walk
 - b. Bike ride
 - c. Golf tournament

Clinical outcomes

- Increased patient and caregiver satisfaction
- Increased staff satisfaction
- Rewarding and therapeutic experience for volunteers
 - New support system created for volunteers with personal connection to ALS
 - Provide support and share knowledge with patients and caregivers
- Increase efficiency of ALS Clinic operations
- Creates a safe, caring, not just “clinical” environment
- Rewarding experience for staff

Recommendations to the field

- **Invite participation of previous patients' family members as volunteers**
- **Involve vendors as volunteers**
- **Identify a lead volunteer to coordinate volunteer scheduling and training**
- **Create criteria for volunteering at your center**
 - **Connection with ALS community**
 - **Dedication to optimizing care of the ALS patient and caregiver**
 - **Complete volunteer training**
 - **Follow institutional guidelines for volunteers**
 - **Professional conduct and dress code**
 - **Respectful, positive attitude**
- **Check with your institution for their volunteer guidelines**
 - **Privacy training**
 - **ID badges**
 - **Confidentiality statement**
 - **Liability Waiver**
- **Recognize the volunteer's new role**
 - **Behind the scenes- seeing the professional side of the clinic**
 - **Can be an emotional experience**



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SPEAKER: DEBBIE PICKERILL

BIOGRAPHY:

Debbie trained as an occupational therapist in London, qualifying in 1985. Since qualifying, she has worked in a range of specialities, including community mental health and neurological outpatients. Currently working within an Occupational Therapy Neurology Outpatient Team based in a district hospital.

Debbie has developed a special interest in motor neurone disease and palliative care and is an active contributor to the development and streamlining of services.

She has just completed a post graduate diploma in neuro-rehabilitation at Brunel University.

AUTHOR: DEBBIE PICKERILL

TITLE OF PRESENTATION: THE DEVELOPMENT AND IMPLEMENTATION OF A MULTI-AGENCY, MULTIDISCIPLINARY CARE NETWORK FOR PEOPLE LIVING WITH MOTOR NEURONE DISEASE IN EAST AND NORTH HERTFORDSHIRE, UK

ABSTRACT:

Background:

The East and North Hertfordshire MND Network was formed in 2006 by a group of health and social care professionals and representatives from the MND Association (UK), following publication of the National Service Framework for Long Term Conditions. This stipulates that, "...care planning requires an integrated multidisciplinary team of people who have the appropriate training, expertise and skills and who are able to cross refer to provide co-ordinated care."

A need was identified for timely and integrated cross agency multidisciplinary intervention, although service development in the locality would be without additional resources

Objective

1. Develop a monthly cross agency multidisciplinary network meeting, providing a forum and single point of contact for:
 - Discussion of complex cases
 - Sharing of expertise/best practice
 - Accessing and providing training and development
 - Supporting health and social care professionals,
2. To prevent crises and hospital admission through co-ordinated, cross agency multidisciplinary communication and service provision, utilising limited resources more effectively.
3. Raise awareness of and improve timely access to local and regional services/resources.
4. Facilitate seamless, holistic care for people living with MND, carers and families, from diagnosis to bereavement.
5. To audit the Network.

Programme description

The group formed in 2006, with attendees from all professions across health, social and palliative care and the MND Association. The group worked towards the aforementioned objectives and wrote terms of reference and the operational policy. The monthly network meeting was formed and quarterly training sessions were planned. Presentations were delivered to palliative care stakeholders and allied health professionals across Hertfordshire. In 2008, an audit of the Network was completed.

Recommendations to the field:

- 1. Monthly meetings are necessary, due to the rapidly progressive nature of MND.**
- 2. Training raises awareness of the condition, the network and local services.**
- 3. Early referral and open access to the group is essential.**
- 4. Cases should remain open to health and social care professionals throughout the disease pathway.**



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SPEAKER: MARYANNE MCPHEE

BIOGRAPHY:

Maryanne McPhee is currently the manager of the dynamic Speech Pathology department at Calvary Health Care Bethlehem.

Maryanne worked in the United Kingdom for two and a half years in the early 1990s and it was here her interest in progressive neurological diseases and palliative care developed.

She has been working at Calvary Health Care Bethlehem for over twelve years and has extensive experience in palliative care, especially providing assessment and management for people with progressive neurological diseases.

She recently completed her Post Graduate Diploma in Palliative Care and is continuing her studies in this area – specialising in Progressive Neurological Diseases. She is also the co-author of the chapter on Communication in David Oliver's new book "Palliative care in ALS".

Maryanne is also involved in a project looking at the model of care and state-wide services for people with Motor Neuron Disease.

AUTHORS: MARYANNE MCPHEE DR SUSAN MATHERS

TITLE OF PRESENTATION: COLLABORATIVE CARE IN MOTOR NEURONE DISEASE IN VICTORIA, AUSTRALIA

ABSTRACT:

Background:

This paper will report on a recent project which described how the individual needs of a person with Motor Neurone Disease (MND) can be better met in the future. The project team comprised Calvary Health Care Bethlehem (CHCB), the Victorian Respiratory Support Service (VRSS), and the Motor Neurone Disease Association of Victoria (MND Victoria). With the support of the Department of Human Services (Victorian Government Department) and a steering committee, the project team gathered information about current service delivery and unmet needs from patients, families, and a wide range of health and community care providers across the state of Victoria.

Objective

To determine the main tenets underpinning the best model of care for people living with MND in Victoria.

Programme description

When addressing an uncommon and rapidly progressive illness like MND, any model of care needs to ensure *timely* and *equitable access* to information, services and treatment. It must be able to adapt to the problems of distance, disability and the availability of the right expertise. The current model provides or facilitates some services to most people with MND across the state, and specialist MND clinical services to more than two-thirds. It does not fully address equity of access, particularly for people living in regional and rural Victoria, or for people no longer able to travel. It does not fully integrate services provided by specialist teams, local providers and community services. There are some systemic barriers and resource issues that inhibit good continuity of care.

The literature supports a continuous model of care using multidisciplinary team-based paradigms in the field of chronic neurological care. Interfacing neurological, rehabilitation, and palliative care skills enhances clinical care in MND

Clinical outcomes

The project found that people with MND, whenever possible, want to remain in their own homes and to be part of their local communities. With the right care and services, they can be enabled to lead as comfortable and independent lives as possible. It is the task of clinicians and social services to provide and coordinate the resources for that support.

Recommendations to the field

The Victorian Motor Neurone Disease Program (VMNDP) proposes a stronger collaboration between local and specialist providers to provide care closer to home, and a mechanism to augment the skills of health professionals and carers to assist them to care for people with MND responsively. The VMNDP will provide a clear pathway to deliver care and to support decision-making for people with MND and their families. The model will develop skilled regional teams, regional multidisciplinary clinics, shared care options and outreach tools to enhance care delivery and coordination of care over distance.



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SPEAKER: MIEKO OGINO

BIOGRAPHY:

After graduating from Kitasato University (Department of Medicine) in Japan in 1985, Mieko Ogino began her career as a clinical neurologist at Department of Neurology of Kitasato University Hospital and was concurrently involved with the neuroimmunological research. She studied under Prof. Latov at the department of neurology at Columbia University in USA as a post-graduate research fellow from 1991 to 1994. Upon her return to Japan she built up her medical career at a nursing home for the disabled from 1995 to 1998. She was appointed as Assistant Professor at the Department of Neurology of Kitasato University in 2000. As ALS specialist, she is in charge of the ALS Clinic at Kitasato University East Hospital.

Dr. Ogino is a board certified neurologist of the Japanese Society of Neurology. Her other academic achievements include the CBEL diploma from Center for Biomedical Ethics and Law of Tokyo University in 2005, and Master of Medical Administration (MMA) from the Graduate School of Tokyo University of Medicine and Dentistry in 2008.

AUTHOR: MIEKO OGINO

TITLE OF PRESENTATION: DILEMMA AND INTEGRITY OF MEDICAL PROFESSIONALS

ABSTRACT:

The result of the survey we conducted in March, 2009 shows that ALS physicians in Japan are isolated in practice and divided among themselves over the issues of morphine prescription and withdrawal right of the permanent ventilation. The questionnaire containing 30 questions about the issues was sent out to the 4,500 board certified neurologist membership of the Japanese Society of Neurology. By the end of April 1,470 anonymous responses were returned. It aims to survey in what environment the ALS physicians practice medicine in Japan where prescribing morphine to ALS patients is not prevalent, and where the withdrawal of the permanent ventilation is illegal. One of the reasons why permanent ventilation is encouraged in Japan is often pointed out as a form of the ultimate palliative care in the circumstances where morphine prescription remains ambivalent, which we disagree. In this paper we will discuss only the portion of the withdrawal right based on the survey result.

21% of the respondents were asked by their patients to turn off the ventilation, and 6% of them accommodated with the patient's wish. 77% of them declined and explained they could not do so. 18% of them flatly declined. While 23% of the respondents oppose the withdrawal right, 46% support the right with the condition of explicitness of own decision by patient and/or his/her family member(s) .

20% of the respondents commented on their own, aside from answering to the set of questions, to share their thoughts, and to demonstrate sincere and faithful compassion to their patients who genuinely wish to have their ventilation withdrawn.

In this presentation we will touch upon two episodes happened in Japan in 2004 and 2008. The former is about our own patient who wanted his ventilator off out of fear of going into TLS. His mother accommodated with her son's wish and was indicted. The latter is in connection with a permanently ventilated patient who made a request with his hospital to have his ventilator withdrawn upon going into TLS. The hospital assembled an ethical committee and concluded that the patient's request should be honored. However, the hospital management disapproved in order to protect their physician from being indicted.

By discussing the dilemma openly with the overseas audience, it is our hope to educate ourselves as to how we can push forward the issue of patient's right and our professional integrity.



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SPEAKER: GERALDINE FOLEY

BIOGRAPHY:

Geraldine Foley is a Clinical Specialist Occupational Therapist at Beaumont Hospital, Dublin. Geraldine obtained an honours degree in occupational therapy from Trinity College Dublin in 1997. She worked at the National Rehabilitation Hospital, Dublin between 1997 and 2000 and has worked at Beaumont Hospital since 2001. Geraldine completed a Masters in occupational therapy with Trinity College Dublin in 2005. Her Masters thesis on quality of life in MND was published in *Amyotrophic Lateral Sclerosis* in 2007. She has also published a number of opinion papers in the *British Journal of Occupational Therapy* on motor neurone disease for occupational therapists and on occupational therapy and rehabilitation in progressive neurology.

Deirdre Murray is a Clinical Specialist Physiotherapist at Beaumont Hospital, Dublin. Deirdre graduated from University College Dublin in 2001 having obtained a BSc. (Physiotherapy). She worked as a physiotherapist in Cork University Hospital from 2001-2003 followed by a period at the Epworth Multidisciplinary Hospital, Melbourne in 2003. Since 2004 Deirdre has worked as part of the neurology multidisciplinary team at Beaumont Hospital. Deirdre's areas of interest include neuromuscular disorders, multiple sclerosis and vestibular stimulation. She has been working towards a PhD since 2005 investigating activity levels and exercise in prior polio patients.

Roisin Moloney is a Senior Physiotherapist at Beaumont Hospital, Dublin. She graduated with a BSc in (Physiotherapy) from Trinity College Dublin in 2003. Roisin worked as a physiotherapist in the Adelaide Meath & Children's Hospital, Dublin from 2003-2005 followed by the Mater Hospital, Brisbane, Australia in 2006. She has worked in Beaumont Hospital since 2007 as a member of the neurology multidisciplinary team. Roisin's area of interest include motor neurone disease, multiple sclerosis, and somatoform disorders.

AUTHORS: GERALDINE FOLEY, DEIRDRE MURRAY, ROISIN MOLONEY

TITLE OF PRESENTATION: OCCUPATIONAL THERAPY AND PHYSIOTHERAPY AT AN IRISH TERTIARY ALS CENTRE: AN AUDIT TO REVIEW CARE LINKS WITH COMMUNITY CARE SERVICES

ABSTRACT:

Background:

The EFNS task force on management of ALS state that specialist multidisciplinary clinics should provide secondary or tertiary services to ALS patients and they should liaise closely with primary care services¹. In the Republic of Ireland, hospital and community allied health professional services for neurology care are under-resourced and fragmented¹.

Objective

1. To audit services and standards of care provided to ALS patients by OT and PT in an Irish tertiary care centre. 2. To evaluate correspondence between hospital and community services.

Programme description

A retrospective audit was conducted by OT and PT over a 4 month period (Jan-April 09) to review the number of in- and outpatients seen at our tertiary ALS centre. PT and OT were benchmarked against practice guidelines. Correspondence between community and tertiary services was reviewed.

Clinical outcomes

OT: Thirty-eight patients were seen at clinic with 6 seen more than once. Sixteen patients were seen as inpatients of which five were also seen at clinic. 37% of patients were already known to community OT (COT) services. Written referrals or updates were sent to COT on all but one of the patients seen either at clinic or from inpatient admission. No correspondence was received from COT on patients prior to attending the clinic. Correspondence (written / verbal) was returned from COT on 57% of patients.

PT: Twenty-four patients were seen at clinic, with 13 seen more than once. Twenty patients were seen as inpatients of which 2 were also seen at clinic. Community PT (CPT) services were already in place in 33% of cases. Written contact where indicated was made in 76% of cases and phone contact in 5%. Correspondence was returned from CPT on 8% of patients.

Of note, both OT and PT identified uncertainty amongst patients about the nature and type of services received in the community.

¹ EFNS task force on management of amyotrophic lateral sclerosis (2005). Guidelines for diagnosing and clinical care of patients and relatives. An evidence-based review with good practice points. *European Journal of Neurology*, 12, 921-938

¹ Neurology Steering Group (2007). *Neurosciences in Ireland. Strategic review of neurology and clinical neurophysiology services. Report to the National Hospital's Office.* Unpublished report.

OT and PT input at Beaumont hospital meet practice guidelines regarding access to specialised services in a tertiary care setting. Communication between the hospital setting and community services was fragmented and patients' difficulty in accessing COT and CPT services was identified. Results of this audit highlight difficulties in OT and PT service delivery for ALS patients in Ireland¹.

Recommendations to the field

Our clinic outlines the potential benefit of using a 'patient management passport' to facilitate communication between hospital and community settings. Investigation of patients' understanding of services may assist service providers in meeting care needs.



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SPEAKER: MARYANNE MCPHEE

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She has been working at Calvary Health Care Bethlehem for over twelve years and has extensive experience in palliative care, especially providing assessment and management for people with progressive neurological diseases.

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Maryanne is also involved in a project looking at the model of care and state-wide services for people with Motor Neuron Disease.

AUTHORS: MARYANNE MCPHEE (CHIEF SPEECH PATHOLOGIST), LISA POINTON (SENIOR CLINICIAN)

TITLE OF PRESENTATION: COMMUNICATION OPTIONS FOR PEOPLE WITH ALS/MND: FAST AND FLEXIBLE

ABSTRACT:

Background:

People with progressive neurological conditions experience many challenges in their ability to actively participate in their life roles at home and within the community. Alternative access and communication options can allow people to continue to undertake work and home responsibilities and provide a means of maintaining connectedness through spoken and written communication.

Objective

This paper will discuss the development of the joint Communication Technology Clinic, the benefits and challenges experienced by both services, and the impact of technology advances on the lives of people with progressive conditions.

Programme description

In late 2006, Calvary Health Care Bethlehem (CHCB) and ComTEC Yooralla developed a monthly joint assessment clinic for people with progressive neurological conditions who were investigating technology to support communication and/ or computer access needs. The Speech Pathology and Occupational Therapy departments of CHCB have specialist knowledge in the treatment and management of people with a wide range of progressive neurological conditions. ComTEC is an assistive technology service of a statewide disability service and comprises Speech Pathologists, Occupational Therapists and IT support.

Clinical outcomes

- Gain an understanding and begin to map the phenotypes of MND to the timing and type of AAC.
- Opportunity to jointly trial Assistive Technology options for clients with complex access and communication needs
- Opportunity to collaboratively begin to build knowledge and experience of the application of Eye Gaze systems for people with MND/ALS

38 patients with MND/ ALS have undergone individualised assessments, prescribed appropriate alternative and augmentative communication devices and provided with training and ongoing support and management by the team. 31% have utilised eyegaze technology and a summary of clinical learnings will be presented

Recommendations to the field

The development of the Comtec clinic has resulted in more efficient and specialised management of the communication needs of our patients.

- Clinicians need to work collaboratively with AAC specialists to ensure access to all AAC options
- AAC Options need to be presented in a timely manner with due consideration given to the progressive nature of MND/ ALS
- Ongoing monitoring and support is crucial to the successful implementation of AAC in this population



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SPEAKER: SARA FELDMAN, MA, PT, ATP

BIOGRAPHY:

Sara is the physical therapist for the MDA/ALS Center of Hope at Drexel University College of Medicine. She graduated from Temple University with a BS in Physical Therapy in 1987 and from University of Pennsylvania with a Masters in Environmental Science in 1997. After working in rehabilitation until 1993, she started at Hahnemann University Hospital in the acute neuro-trauma department. As part of this rotation, she covered the ALS clinic, and by 1994 became the permanent physical therapist for the clinic. She enjoys her work with the multidisciplinary team at the center where in addition to her role as the physical therapist, she is the Clinical Evaluator for ongoing clinical trials and the Assistive Technology Professional.

Jennifer King is currently a PhD student at Albany University in New York continuing to work with the Wadsworth Center on the BCI. She was a graduate student in biomedical engineering at Drexel University until she graduated in June. She was a key connection between the people with ALS using the BCI and the engineers developing the system.

Please contact Sara with any questions after the program at sfeldman@drexelmed.edu

AUTHORS: SARA FELDMAN JENNIFER KING

TITLE OF PRESENTATION: THE P300 SPELLER: USING A BRAIN COMPUTER INTERFACE FOR COMMUNICATION

ABSTRACT:

Background:

Amyotrophic lateral sclerosis (ALS) is characterized by progressive weakness resulting in a state of profound disability. The rise of new technologies allows these individuals alternate ways to communicate. Brain Computer Interfaces (BCIs) are currently the final step in alternative communication and possibly the only option available to locked-in individuals. BCI2000 is a general BCI system which can be used for data acquisition, stimulus presentation, and brain monitoring applications. In particular, the P300 Speller application can be used to communicate words and phrases through an onscreen keyboard accessed by electroencephalographic (EEG) activity.

Objective

The objective of this lecture is to provide allied health professionals with information regarding the BCI2000 as it is used in the P300 Speller application.

Programme description

Individuals are seen at our center quarterly. The speech language pathologist documents their communication needs and methods and throughout the course of their illness, issues related to communication are addressed. As appropriate, options from low technology communication boards to high technology eye-gaze systems are presented. If interested, the individuals are able to try the P300 Speller and participate in BCI research projects. One goal of running the program this way is to determine if the individual is capable of using the BCI effectively prior to the point of being locked-in.

Clinical outcomes

Although the P300 Speller is currently only available as a research tool, BCI systems are becoming apparent in popular media. Individuals with ALS are turning to our multidisciplinary clinic with questions about BCIs. To address this we have developed a screening program which allows us to determine the individual's ability to use the system. We are also conducting research with the BCI specifically focusing on creating a system that is more user-friendly for the individual, the caregiver and the clinician. Through this applied clinical research, we are moving the BCI2000 closer to home use

Recommendations to the field

Communication for individuals with ALS is not only important to express needs but also to participate in everyday conversations. Once an individual becomes locked-in, they lose the ability to communicate. However, with a greater understanding of the brain and alternative methods of communication it may be possible for individuals with end-stage ALS to continue to communicate. Through the use of clinical applied research, the increasingly sophisticated BCI technology that is evolving in the laboratory can be translated into a useful and functional communication tool.



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SPEAKER: SARAH LAVENDER

BIOGRAPHY:

Following Sarah's training as an Occupational Therapist at St Loyes College, Exeter in 1985, she worked at Orsett Hospital, Grays, Essex on a basic Grade Rotation post in general physical conditions. Sarah moved to Kingston upon Thames, Surrey as a Senior II OT in 1987 on Orthopaedics before getting married and moving to Kent.

She was employed with Social Services from 1988 for 2 years carrying out Disabled Facilities Grant work before working as the Wheelchair Therapist at the Disablement Services Centre, Medway Hospital, Kent.

Sarah then had a career break to bring up her 3 children before returning to work in 2000 at the Wisdom Hospice, Rochester, Kent, where she now works as part of the multidisciplinary team with people with specialist palliative care needs. She is a member of the MND Clinical Team, lead by Dr David Oliver, and Sarah is involved with all the MND/ALS patients whether they are at home, in the day hospice or on the hospice in-patient unit.

AUTHORS: SARAH LAVENDER DR DAVID OLIVER

**TITLE OF PRESENTATION: PROVIDING EQUIPMENT FOR PEOPLE WITH MND
- THINKING OUTSIDE THE BOX!**

ABSTRACT:

Background:

The MND Clinical Team in Medway and Swale is a multidisciplinary team providing support and care for people with MND at home. There are often problems in providing equipment in a speedily and appropriate manner, with many challenges of bureaucracy and waiting lists.

Objective

The Occupational Therapist within the MND Team has looked for ways of ensuring that equipment is provided in the most effective way that is acceptable and appropriate for the person with MND and their family.

Programme description

The Occupational Therapist works closely within the multidisciplinary MND Clinical Team and has developed close relationships with local equipment providers and the technicians involved in the installation of equipment, including:

- Liaison with other agencies
- Direct contact with a Motor Neurone Disease Association both at National level and the local branch
- Attendance at the MND Clinical Team meetings on a monthly basis
- Assessment of all the needs and issues

Taking time with patients and their families to listen to their particular needs and wishes and trying to help facilitate their needs.

Clinical outcomes

The OT aims to be involved in the discussion with patients and people with MND and their families as soon after diagnosis as possible to look at their particular needs and to build up a relationship so that further equipment can be provided as the disease progresses. Regular reassessment of the person's needs allows a rapport to be built up with the OT so that equipment can be suggested and provided in a speedy and timely manner. This may include not only the aids for daily living but hobbies, mobility, holidays and particular wishes of the person with MND. This also allows an increased acceptance and consideration of the use of equipment as the disease progresses.

Recommendations to the field

The OT needs to be involved early in the disease process and work closely with people with MND and their families as the disease progresses. There are a wide range of resources that need to be used and there is a very important role of the OT's liaising with many different services. Primarily the most important aim of any assessment and provision of equipment is by careful listening to the person and their family and planning for their particular needs and wishes. At all stages it is important to think more widely – to think outside the box!



International Alliance of
ALS/MND Associations

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SPEAKER: BERNIE CORR

BIOGRAPHY:

Bernie Corr is the ALS/MND Clinical Nurse Specialist in Beaumont Hospital, Dublin, Ireland. Bernie qualified as a Sick Children's Registered Nurse in the National Children Hospital, Dublin. She qualified as a Registered General Nurse in the Meath Hospital, Dublin. Her special area of interest is end-of-life care in ALS/MND. Bernie was recently awarded the Junior Clinician Scientist Award for Nursing and Midwifery, this award was funded by the Health Research Board to enable Clinical Nurse Specialists to conduct research leading to a postgraduate Masters. Bernie is currently conducting her research in collaboration with Beaumont Hospital and the Royal College of Surgeons in Ireland.

AUTHOR: BERNIE CORR

TITLE OF PRESENTATION: END OF LIFE DECISIONS AND ADVANCE CARE DIRECTIVES IN MOTOR NEURONE DISEASE, EVIDENCE BASED GUIDELINES FOR BEST PRACTICE.

ABSTRACT:

Background:

The clinical management of ALS/MND is palliative from the time of diagnosis, and is focused on symptom control and adjustment to the progressive loss of neurological function with the certainty of early death. Formal guidelines regarding advance care planning, end-of-life decisions and advance care directives in neurodegenerative disease are currently unavailable in Ireland.

Objective

- To identify the attitudes, understandings and experiences of patients with ALS/MND, their carers and their health-care providers to end-of-life decisions and advance care directives.
- To determine if the views of patients, carers and their health-care providers concur.
- To explore the relationship and impact of self reported quality of life, on patients with ALS/MND concerning end-of-life decisions and advance care directives.
- To make recommendations for the formulation of advance care directives and end-of-life decisions in the ALS/MND population in Ireland.

Programme description

Hermeneutic Phenomenology was chosen as an appropriate methodology for this study as it illuminates the meaning and understanding of the lived experience of contemplating end-of-life decisions and advance care directives for patients, their carers and their healthcare professionals. Participants included, patients', their carers, Consultant Neurologists, Palliative Care Consultants and nurses. All participants had experience pertaining to the phenomena under investigation.

Clinical outcomes

This project has provided valuable insight into the attitudes, understandings and experiences of Irish patients with ALS/MND, their carers and their health-care professionals towards end-of-life decisions and advance care directives. It has identified areas where attitudes of patients, carers and health professionals are not concordant. The project has identified a number of evidence-based guidelines that are pertinent to the formulation of advance care directives and advance care planning.

Recommendations to the field

There are many ethical dilemmas to be considered in caring for patients with ALS/MND, especially regarding nutrition and respiration. It is essential that these issues are discussed in a timely and appropriate manner. Increasing our understanding of the attitudes, experiences and difficulties for patients, their carers and their health-care professionals in discussing end-of-life issues will ultimately improve practice. It is imperative that we avoid a "tick box" scenario to end-of-life management, individualised advance care plans need to be devised. As health-care providers we have an obligation to create an appropriate atmosphere that encourages patients and their carers to discuss their legitimate issues and fears regarding end-of-life decisions and advance care directives.



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SPEAKER: KRISTINA DODDS

BIOGRAPHY:

Kristina Dodds has been the Program Manager for HOME Hospice since July 2007. Previous to this position, Kristina worked with The Cancer Council NSW for 8 years, in the Volunteer Program Unit, as Projects Coordinator and State Manager. In 2001 she represented the Volunteer Program Managers from all the state Cancer Councils across Australia and presented a paper to the International Cancer Care conference in Brighton, UK, on the principles of volunteering in cancer organisations. Kristina has also had many years experience working in the disability sector in training and development. She holds a BA DipEd, a Masters of Education (in adult education) and a Diploma of Volunteer Management Practices.

Josephine Fowler joined the Motor Neurone Disease Association of NSW Family Support Team in March 2006. She is currently working as a Regional Advisor for Northern Sydney / Central Coast area. Her employment history is varied. Jo has worked for many years as a nurse educator, a midwife and a community health worker, both interstate and abroad. Jo has qualifications in general nursing, cardiac care, midwifery, nurse education, women's health and health promotion. She has a Diploma in Teaching (Nursing) and a Bachelor of Arts Degree.

AUTHORS: KRISTINA DOODS JOSEPHINE FOWLER

**TITLE OF PRESENTATION: END OF LIFE AND BEYOND: A CAREGIVER
PATHWAY OF SUPPORT**

ABSTRACT:

Background:

Health facilities are largely unable to meet all the complex and changing needs of people with MND at the end-of -life. Home-based palliative care is often difficult to access and is largely restricted to the last few weeks or even days of life. 80% of people would prefer to die at home but only 20% do.

The Home Hospice Community Mentoring Program was established 28 years ago. Volunteer Community Mentors, who themselves have cared for a family member at home, are matched with MND caregivers. Mentors provide practical support by giving open ended psychosocial support and coordinating the goodwill of friends and family. Currently 62% of caregivers supported by a Home Hospice Community Mentor have had their family member die at home. In December 2008 a partnership between Home Hospice and MND NSW was formed to address issues relating to caring for a person with MND at home.

Objective

Implement a new care pathway of palliative care support for MND caregivers; facilitate caregiver role through ongoing psychosocial support by volunteer Mentors (up to one year after bereavement); present sustainable alternatives to death in health facilities; alter people's perceptions and experiences around death; engage the community to reduce caregiver burn out and value-add to services available.

Programme description

A new care pathway of palliative care support for MND caregivers has been established through collaboration between Home Hospice and MND NSW. Both Home Hospice and MND NSW share a belief that education and support throughout the journey of terminal illness can empower caregivers and their families to make informed decisions about their care, including where they choose to be cared for. Ongoing evaluation will measure the success of the program.

Clinical outcomes

This Pilot program is a work in progress. Between March and May 2009, 34 of a total of 51 carers were offered the opportunity to link with Home Hospice. To date, almost half (n=16) agreed to participate. Reasons for non-participation include carer perception that they do not currently need a Community Mentor; unwillingness to discuss end-of-life issues; and feeling that they have enough support.

Recommendations to the field

Shared goals make it possible for two separate organisations to work collaboratively not only to enhance caregiver psychosocial support, but also to replicate this care model to engage wider communities to care for their dying at home. Shared services and the utilisation of volunteer Community Mentors achieve economies of scale.



ALLIED PROFESSIONALS' FORUM
Maritim Hotel, Berlin
7 December 2009

SPEAKER: PAULINE CALLAGHER

BIOGRAPHY:

Pauline qualified as a registered general nurse in 1989 and has focused her career in acute neurology and neurosurgery. In January 2005 she was appointed as the coordinator of the Preston MND Care and Research Centre, based in the regional neuroscience unit at Lancashire Teaching Hospitals NHS Foundation Trust (LTHTR). The coordinator role involves providing support, information and advice for patients, their carers and families as well as involved health and social care professionals. The Centre covers the catchment area of Lancashire and South Cumbria; all people living with MND diagnosed by a neurologist are referred into the Centre for nurse led monitoring, assessment and coordination of care. The Centre is committed to providing access to high quality research to patients, including drug trials.

Since commencing her position as care centre coordinator Pauline has been involved in the introduction of the use of the preferred priorities of care document, (PPC), development of a fast track service for diagnosis of MND; introduction of 3 monthly nurse-led clinics in all the six hospices within the catchment area, the introduction of a monthly multi-disciplinary team clinic based at the Royal Preston Hospital and the introduction of a fast track MND specialist nurse-led referral system to a respiratory physician with a special interest in MND.

**AUTHORS: CALLAGHER P, MITCHELL, JD, ADDISON JONES R, BENNETT W,
GARDHAM J.**

**TITLE OF PRESENTATION: HOW PATIENTS WITH ALS MAKING ADVANCED
DECISION, CAN INFLUENCE OUTCOMES IN WHERE
THEIR END OF LIFE CARE IS RECEIVED.**

ABSTRACT:

Background:

The preferred priorities of care document (PPC) gives the terminally ill patient an opportunity to think, talk about and write down preferences and priorities for end of life care.

Objective

Our aim was to establish if patients had specified a choice of where their care would be received at their end of life that this had been achieved and if not what had happened to prevent this.

Programme description

It is suggested that in the UK between about 80-90% of those with a terminal illness expressed a preference for death at home but 60% die in hospital.

Comparisons were made between three groups of patients with ALS, those who completed a PPC, those who had made discussions with the MND specialist nurse with regard to their PPC but had not formally recorded their wishes and those who did not wish or had not had the opportunity to complete a PPC. Data recorded included their preferred place of terminal care

Clinical outcomes

Of the 44 people who chose to complete preferred priorities of care, 39 stated they would prefer to die at home 25 died achieved their death at home, 3 in a hospice, 9 in hospital, 2 in nursing homes. 2 patients wished to die in a hospice as their second choice and this was achieved. 2 chose to die in hospital and 1 in a nursing home.

Of the 45 patients who did not complete a PPC 18 died at home, 16 in hospital, 8 in a nursing home and 2 in hospice.

14 patients had had discussions about PPC but had not made decisions on place of terminal care. 6 of these died in hospital, 5 at home, 2 in a nursing home and 1 in hospice.

Main reasons for not achieving their PPC included carers being unable to cope or sudden change in the medical condition.

Recommendations to the field

The results of our audit suggest that patients have a higher chance of achieving their preferred place of end of life care if their wishes have been recorded on a PPC. Further investigations should be made to establish causes of breakdown in care leading to hospital admission in the last few days or hours of life and how these admissions can be prevented. However, PPC offers an opportunity to discuss difficult issues that may not otherwise be addressed thus minimising inappropriate interventions and admissions.



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SPEAKER: CAROL BIRKS

BIOGRAPHY:

Carol trained and worked as a registered nurse in London before emigrating to Australia in 1983. She worked part time in a variety of specialties including oncology, aged care and research, whilst also caring for her three daughters, before focussing on palliative care nursing. She graduated from the Australian Catholic University with a Graduate Diploma in Nursing (Palliative care) in 1996.

Carol has been working with MND Associations and people living with 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 as national executive director with MND Australia which is the peak body for motor neurone disease in Australia.

AUTHOR: CAROL BIRKS DR MONIKA WILSON

TITLE OF PRESENTATION: PROMOTING CONFIDENT CARING AND HOME BASED CARE FOR PEOPLE LIVING WITH MND

ABSTRACT:

Background:

Support services available to people living with MND vary considerably throughout Australia. MND Australia has identified the need to promote equitable services and partnerships to address unmet need nationally. In 2008 MND Australia received funding from the Australian Government Local Palliative Care Grants to conduct the Confident Caring Pilot Program in Queensland.

Objective

- To work collaboratively to support home based care for people living with MND
- To implement education programs in Queensland based on those established in NSW
- To support the MNDQ workforce to provide quality family support
- To assist caregivers, health professionals, service providers and volunteers to feel more confident in their caring role
- To maximize the involvement of palliative care professionals and volunteers in the care and support of people living with MND

Programme description

Existing MNDNSW programs were reviewed and then further developed to meet the needs of the Queensland population. Programs were implemented to provide quality, and where possible evidence based, education sessions to four specific client groups:

1. People recently diagnosed with MND and their family and friends
2. Family caregivers in three regions
3. Health and community care providers including palliative care services involved in the care and support of people living with MND
4. Palliative Care volunteers

Clinical outcomes

Programs were delivered over a 12 month period. The project confirmed the current unmet need in Queensland, the value of MND specific information, education and peer support to these groups and the need for all programs to continue. The significant lessons learnt through the project will assist MNDQ to develop the national family support model of care. The project was successful in increasing health care professionals, volunteers and family caregiver's confidence. One palliative care registrar noted, "*I feel more confident now in discussing end of life issues with patients with MND*".

Recommendations to the field

- There is no need to reinvent the wheel – share resources and create partnerships
- It takes time to establish interest and trust in new programs
- Flexibility is key when delivering services to MND populations
- MND specific education and peer support helps to increase confidence
- Funded pilot projects have been vital in MND association program development



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SPEAKER: MERAIDA POLAK, RN

BIOGRAPHY:

Meraida is a graduate of the University of Florida College of Nursing. She was the nurse manager of neuroscience unit at Emory University Hospital from 1976-1988. In 1988 she became the neuromuscular research nurse in the department of Neurology in the Emory University School of Medicine. She has practiced exclusively with ALS patients since 1992. Since that time she has started and managed a multidisciplinary clinic and coordinated more than 10 clinical trials in ALS. She has co-authored chapters on ALS in neuroscience nursing textbooks and Core Curriculum for Neuroscience Nurses. Meraida speaks frequently in the US and internationally on a variety of topics related to ALS patients.

In 2004 she was a co-investigator in a preliminary study to survey healthy individuals who were at risk to develop familial ALS. These results led to the start of the Pre-familial ALS study (Pre-fALS) in 2007

AUTHORS: MERAIDA POLAK DIANE McKENNA- YASEK

**TITLE OF PRESENTATION: RISK FOR DEVELOPING FAMILIAL ALS:
WHAT FAMILY MEMBERS KNOW AND WHAT THEY
WANT TO KNOW**

ABSTRACT:

Background:

In all ALS Centers a small percentage of patients have familial disease. Family members sometimes express but often have unspoken questions about their own possibility of risk. Healthcare providers in specialty ALS clinics can use additional information about what to tell family members and how to tell them.

Objective

- **Participants will describe the differences in usefulness of genetic testing in families that are SOD positive, negative and families whose SOD status is unknown.**
- **Participants will define the defense mechanism of denial and describe how it is useful in protecting individuals from fear and anxiety.**
- **Participants will identify the steps to take in obtaining genetic testing for family members including how to locate qualified genetic counselors world wide.**

Programme description

- I. Common myths and erroneous information**
- II. How to learn family status of SOD-1 mutation**
- III. Examples of opening statements when talking to people at risk**
- IV. Discussion of methods of coping with risk**
 - a. Becoming an activist**
 - b. Denial**
 - c. Choosing to learn genetic status**
- V. Options for people at risk**
 - a. Clinical testing**
 - b. Research testing**
 - c. Declining testing**
- VI. Genetic counseling**
 - a. North America**
 - b. Europe**

Clinical outcomes

Healthy individuals at risk for developing familial ALS will identify their family status as:

- SOD positive**
- SOD negative**
- SOD status unknown.**

Healthy individuals at risk for developing ALS will understand how to clarify their family status if unknown and understand what they should take into consideration when

Recommendations to the field

- **Do not assume that community based health care professionals have accurate information about the risk of familial ALS.**
- **Do not assume that family members, even those who have participated in counseling or education, have accurate understanding of their risk.**
- **Individuals deal with the knowledge of their risk in different ways. Recognize that denial is a very effective defense mechanism and should be respected.**

In the future there may be treatments to prevent or delay the onset of familial ALS. Therefore, identification of SOD-1 mutation status has potential benefit to the family



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SPEAKER: SUSAN GRONKA

BIOGRAPHY:

Sue Gronka is the Clinical Coordinator for the Pre-fALS study and the Project Manager for the ALS Research Collaborative Group at Emory University in Atlanta, Georgia. She graduated from Thomas Jefferson University in Philadelphia, Pennsylvania with a Bachelor's degree in Nursing. She has 20 years of clinical research experience in oncology and neurology, in particularly neurodegenerative genetic diseases. She helped establish the Emory University Ataxia Center in 2001. Most recently, she joined a research team as the lead coordinator investigating familial ALS with the goals of defining the pre-symptomatic stages of the disease. She is pleased to be able to present some of the most recent findings from the Pre-fALS study.

**AUTHORS: SUE GRONKA¹, CHRISTINE STANISLAW², JOANNE WUU³,
AND MICHAEL BENATAR⁴**

**TITLE OF PRESENTATION: PRE-SYMPTOMATIC TESTING FOR FAMILIAL ALS-
THE PRE-fALS EXPERIENCE**

ABSTRACT:

Background:

Recognition that mutations in SOD1, TDP-43, and FUS genes are responsible for ~25-30% of familial ALS (fALS) cases makes it possible to perform pre-symptomatic genetic testing in healthy individuals from fALS pedigrees (“at-risk individuals”). The presence of a mutant gene carries a very high lifetime risk of developing disease. In the absence of any prophylactic/therapeutic interventions, there has been little motivation for at-risk individuals to undergo genetic testing. To this end, two years ago we initiated the Pre-fALS study, a longitudinal observational study with the goals of defining the pre-symptomatic stages of the disease and learning more about issues that surround pre-symptomatic testing.

Objective

To (1) determine the feasibility of performing pre-symptomatic testing for ALS susceptibility genes in at-risk individuals, who can choose whether or not to learn the results; (2) examine attitudes towards participation in such research; (3) develop strategies to support at-risk individuals undergoing genetic testing.

Programme description

Pre-fALS involves recruitment, genetic testing, and clinical evaluation of at-risk individuals (currently SOD1 only; to be expanded to TDP-43 and FUS as well). A pre-screening process eliminates individuals with active psychiatric problems. Eligible subjects decide whether or not to learn the results of genetic testing. Those who elect disclosure of results are randomized to in-person or telephone counseling, which is performed by the same genetic counselor. Counseling occurs prior to genetic testing and then at time of disclosure of results. An online support group has been formed that comprises prior study participants. The psychosocial impact of undergoing pre-symptomatic genetic testing is evaluated using a qualitative structured interview.

Clinical outcomes

To date family members from 37 of the 61 fALS families with a known SOD1 mutation have been consented to participate in Pre-fALS. Ten individuals have decided to undergo testing without learning their results. Twenty-eight have decided to learn their genetic results; 14 were randomized to receive in-person counseling and 14 to telephone counseling. No subject has withdrawn from the study.

Recommendations to the field

Pre-symptomatic testing is feasible and can be done safely given appropriate consideration of autonomy, confidentiality, and psychosocial well being. Pre-fALS offers healthy individuals from fALS pedigrees the opportunity and motivation to undergo pre-symptomatic testing to help improve our understanding of ALS. Pre-fALS also permits early diagnosis in at-risk individuals and thereby their prospect of receiving experimental and established therapies early in the disease course when therapeutic potential is likely the greatest.

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ALLIED PROFESSIONALS' FORUM
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7 December 2009

SPEAKER: KATHY MITCHELL R.N

BIOGRAPHY:

Graduate of Toronto General Hospital and McGill University Montreal Canada
Worked as a staff nurse at the Montreal Neurological Institute
Professor of Nursing-Toronto General Hospital
Professor Ottawa Civic Hospital School of Nursing

Kathy has worked with ALS patients and families in the clinical setting and community with nursing students.

The complexity of care required by ALS/MND families requires the ongoing support of the interprofessional team.

In developing countries, the opportunity to give family centred care is often limited by the health care system and the scope of practice of health care workers. Her goal is to work with the International Alliance of ALS/MND to support patient autonomy, and to improve health care professional education by presenting seminars with the country.

By encouraging the ALS/MND team to increase public awareness and political advocacy we can improve the quality of care and quality of life for the people we care for.

Kathy has worked as a volunteer to achieve these goals in Turkey, Serbia, Croatia, Peru and Montenegro.

She is appreciative of funding support from the Canadian International Development Agency (CIDA), the ALS Hope Foundation, The International Alliance of ALS/MND and ALS Canada.

Kathy believes that we need to be the change we seek in the world-

Kathy Mitchell R.N
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AUTHOR: PROFESSOR KATHY MITCHELL R.N. B.N.

TITLE OF PRESENTATION: INTERPROFESSIONAL PRACTICE-LOCAL KNOWLEDGE/GLOBAL IMPACT

ABSTRACT:

Background:

As a member of the International Alliance of ALS/MND I have had the opportunity to work in developing countries –Turkey, the Balkans and Peru to present educational programs to health care professionals. I have been able to access funding from the Canadian International Development Agency-CIDA for the last five years as well as from the ALS/MND Alliance. The impact of this volunteer initiative has delivered education programs to over 1000 health care professionals. My colleagues have also visited South America, Iceland, and Mongolia.

Objective

1. To inform members of the ALS/MND interprofessional community of the work done in developing countries.
2. To invite those with expertise to consider registering as members of a Human Resource Bank.
3. To use the Internet to create connections and provide expertise to health professionals in developing countries.

Programme description

This session will include PowerPoint and a short lecture.

Clinical outcomes

1. The quality of care for families and patients with ALS/MND will improve when health care professionals in developing countries have access to information and knowledge from those working in first world countries.
2. The potential for clinical exchange and support will create synergy in the global ALS/MND interprofessional community.

Recommendations to the field

1. Many health care professionals are interested in the possibility of volunteering to work with developing ALS/MND groups.
2. By presenting the work done by various health care professionals which reflect international differences and similarities in care management we can create a data base from which to create connections via the Internet and/ or through exchange visits.

