



Allied Health Professionals Agenda
November 30, December 1 & 2, 2022

November 30		
ALS/MND Connect		
10:00 AM – 12:00 PM	ALS/MND Connect	Phil Green, Eugene Brandon, Dr. Caroline Ingre, Dr. Angela Genge & Dr. Colleen O’Connell
12:30 – 1:45 PM	Luncheon & Keynote: The Right to a Quality of Life, Dr. Colleen O’Connell Honoring 30 Years and Celebrating PALS & CALS	
Welcome		
2:00 – 3:25 PM	Welcome & About the Alliance	Calaneet Balas
	Welcome from the Program Chairs	Sara Feldman Rachael Marsden
	PALS Address	
	March of Faces	
	Panel: History and evolution of multi-disciplinary care	Dr. David Taylor, Dr. Orla Hardiman, Dr. Terry Heiman-Patterson, Sara Feldman & Rachael Marsden
3:25 – 3:45 PM	Coffee Break	
Activities of Daily Living		
3:45 – 5:15 PM	Welcome back	
	One year later, an update on My ALS Decision Tool™ and information guides	Anne Marie Doyle
	"Positive Tiredness": A Concept to challenge fatigue management for people with ALS/MND	Helen Carey
	Using and creating educational resources for families	David Meissner & Kim Hughes
	The wheelchair alliance	Nick Goldup
5:30 PM	ALS/MND Walk	
6:00 PM	Cytokinetics Reception	

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December 1		
7:30 – 8:00 AM	Virtual Networking	
Care Management		
8:00 – 10:10 AM	Welcome back	
	Establishing a neuro-palliative care clinic in the hospital setting: lessons learnt for ALS care	Gargi S Kumar
	Augmentative and alternative communication (ACC): the AISLA model for evaluating and providing devices in Italy.	Prof. Massimiliano Filosto
	ALS Canada support group model	Kim Barry
	How to break the news in ALS/MND	Dr. Angela Genge, Dr. Melinda Kavanaugh, Dr. Colleen O’Connell & Cathy Cummings
10:10 – 10:30 AM	Coffee Break	
Mental Health, Psychosocial & Emotional Support Models of Care		
10:30 AM -12:40 PM	Welcome back	
	Developing a web resource on experiences of inherited MND for patients, families and healthcare professionals	Jade Howard
	Making sense: An online meaning centred psychological intervention for individuals with MND	Sandra De Moree
	Mitigating stressors through building systems of support for children and young adults impacted by ALS	Lily Cola
	E-Learning on palliative and end-of-life care in ALS for all caregivers accompanying ALS patients in Belgium	Liesbet Casier
	My ALS/MND patient mentioned wanting to die, now what? A brief guide to conversations about death, dying, and suicide screening for non-mental health	Amber Johnstone
	Voice Banking - what is the current status of the technology and where do we go from here to help ensure it meets the needs of people with MND/ALS?	Richard Cave Nick Goldup

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12:40 – 2:00 PM	Poster Luncheon & Networking	
1:30 – 2:00 PM	Virtual Networking	
Assistive Technology / Improving Technology		
2:00 – 3:10 PM	Welcome back	
	DuoRhythmo: a collaborative accessible digital musical interface for PALS and CALS	Ivanyl Balazs & Truls Tjemsland
	Guidelines for Healthcare Professionals Working with Individuals with Complex Communication Needs	Lisa Bruening
	What we learned about making videogames more enjoyable to play for people living with MND: insights from a scoping review	Ben O’Mara, Kirsten Harley, Matthew Harrison & Natasha Dwyer
3:10 – 3:30 PM	Coffee Break	
Multi-Disciplinary Care		
3:30 – 5:20 PM	Welcome back	
	Building Local Mental Health Support Through Education and Collaboration	Melissa Enfinger
	Eating with Dignity: Exploring how eating can be improved for people with Amyotrophic Lateral Sclerosis	Gudlaug Gisladóttir
	Neck Weakness in MND/ALS: An Investigation of the impact of neck weakness on walking ability.	Stephanie Zhao
	BowALS: understanding changing bowel habit in amyotrophic lateral sclerosis	Jan Clarke
	Let's Talk about Sex and ALS	Joanna Nunez
5:20 -5:50 PM	Virtual Networking	
7:00 PM	Dine Around	

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December 2		
Research		
8:00 – 9:50 AM	Welcome back	
	Gendered meaning making of caregiving among spouses of persons with ALS: implications for care.	Manjusha Warriar G, Dr. Priya Treesa Thomas & Nalini Atchayaram
	Strengthening the Paradigm of Science and Patient Collaboration	Allison Bulat
	A qualitative evaluation of the revised Amyotrophic Lateral Sclerosis Functional Rating Scale (ALSFRS-R) by the patient community	Danielle Boyce
	Abstract, research staff satellite meeting	Tommy Bunte, Corey Straub, Mathias Couillard, Vanessa Bertone, Juliette Foucher & Romy Verschoor
	Roundtable Outcomes	Cathy Cummings
9:50 – 10:20 AM	Coffee Break	
Speech Therapy & Communication		
10:20 AM – 12:00 PM	Welcome back	
	Allied Health Professional Award	
	MND professionals' community of practice	Jennifer Bedford
	The ALS Association's rapid access communication kit distribution program	Alisa Brownlee
	Your voice, your choice – Speech language pathologist navigation of the ever-evolving process of voice banking for people with Motor Neurone Disease.	Rachel Robinson
	Looking forward to 2023	Florence Maeder
Packed Lunch		

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