

Welcome to:
Sussex MND Network
Study day

Tuesday 12th November 2024

Welcome!

- Parking- make sure you have registered:
<https://www.sussex.ac.uk/sef/services/transport/campus-parking/event-parking> (conference name: SUSSEX MND NETWORK)
- WiFi
- Evaluation:
<https://www.smartsurvey.co.uk/s/sussexnetwork2024/>



Professionals networking session

Please share what setting you work in and locality.

1. Please share any developments you have made or plan to make for pw MND? E.g. Support offer, new equipment/ another source of support or funding, an audit, pathway development, a helpful CPD or course.
2. What areas would you like to change/improve?
3. What MND specific learning opportunities do you already have access to?
4. Would you like to have further opportunities to mix with your professional colleagues? If so, how might this work? Please make notes to hand in.

Sign up to join a discipline specific group

<https://forms.office.com/e/YWT0S15gTK>









Sussex MND Network 2024-28

- Overview
 - Funding model
 - Objectives 2024-28



Objectives 2024-2028

- 1. Patients will have access to nutritional care & support which adheres to best practice and NICE guideline standards.**
- 2. Patients & carers will have access to screening and support for cognitive, behavioural and psychological change.**
- 3. Patients will be offered information about the genetics of MND and have access to testing if wished.**
- 4. Patients will have access to support for secretion management which adheres to MND best practice & NICE guidelines.**
- 5. To provide more equal opportunity for access to hospice care across the Sussex region.**

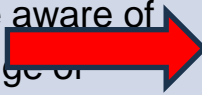
Nutrition: All patients will have access to nutritional care & support which adheres to best practice and NICE guideline standards.	Objective	Activity	Output	Outcome
Y1	<p>1. To agree and define standards of nutritional care.</p>    	<p>1.1. Scoping exercise to establish current practice amongst healthcare professionals involved in nutritional care.</p> <p>1.2 Undertake focus groups with key teams</p> <p>1.3 Evaluate nutritional care through local audits.</p> <p>1.4 Work with key partners including MND Assoc to influence equitable service provision in all localities.</p>  	<p>1. Community teams work together to develop a standard level of care across the board.</p> <p>2. Development of an MND Nutrition Care Pathway that has agreed nutrition standards for people with MND across the whole region.</p> <p>3. Produce a comparison of local care vs national practice.</p>	<p>1. patients will have access to timely and appropriate nutrition support throughout their disease progression.</p> <p>2. >90% patients in MND clinic will be weighed at first appt and subsequent rvs</p> <p>3. All MDTs will have clearly defined nutrition pathway for their local services.</p>

	Objective	Activity	Output	Outcome	Barriers
Year 2	1. To improve professionals' knowledge of nutritional care through the development and delivery of training.	2.1 Conduct a survey to evaluate training needs of teams 2.2 Signpost teams to existing training resources. 2.3. Development and delivery of training session where gaps identified above (e.g. having conversations, withdrawal of feeding).	2.1 Improved knowledge of MND and nutritional care amongst community MDTs as measured by snapshot survey	Community teams are better informed & equipped to manage nutritional; care of pw MND. Collect feedback to measure level of knowledge post events.	Network capacity to deliver training



All patients will have access to screening and support for cognitive, behavioural and psychological change.	Objective	Activity	Output	Outcome	Barrier
Y1	<p>To offer screening, behaviour and cognitive change to all patients within 4/12 of diagnosis.</p>  	<ol style="list-style-type: none"> 1. Establish a working group. 2. Clarify appropriate screening tools. 3. Pilot a cognitive/behaviour testing pathway in two teams (1 in East & 1 in west) 	<ol style="list-style-type: none"> 1. Evaluate pathway feasibility. 2. Finalise pathway. 3. Feedback to other teams (e.g. using case examples in a forum /support group.) 4. Assessment & treatment pathways defined. 	<ol style="list-style-type: none"> 1. Teams have knowledge of cognitive & behaviour change in MND. 2. Range of assessment tools agreed. 3. Screening offered to 90% of patients. 4. Onward referral pathways clarified. 5. Evidence collected for specialist MND psychology service. 	<p>Teams don't have capacity to engage in project.</p>

<p>Y2</p>	<p>All patients offered appropriate support for cognitive & behaviour change.</p>	<p>1. At least 1 Sussex team to participate in MiND toolkit full study.</p> <p>2. Develop links with SPFT & specialist cognitive clinic.</p>	<p>1. MiND toolkit results.</p> <p>2. Clarified specialist referral pathways</p> <p>3. Audit the support that is offered.</p>	<p>1. Teams skilled in supporting PABMND in behaviour change.</p> <p>2. 90% of patients & carers are offered appropriate support</p>	<p>MiND toolkit study delayed.</p> <p>Teams don't have capacity to engage in project.</p>
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Secretions	Objective	Activity	Output	Outcome	Barrier
Y1 All patients will have access to support for secretion management which adheres to MND best practice & NICE guidelines.	1. Relevant professionals within teams are aware of range of options for secretion management. 	1.1 Establish working group. 1.2 Develop secretion toolkit. 1.3 RT to work on national secretion toolkit with other care centre/networks.	1.1 Secretion toolkit produced. 1.2 Local secretion workshop to share toolkit. 1.3 Present to national forum (e.g. CCN day/ COP).	1.2 Resources shared with teams. 1.2 Teams fully informed of range of options available across region, (as measured by snapshot survey).	Team engagement
	2. People with MND in Hastings & Rother locality will have access to nebulisers at no cost to them	2.1 To highlight inequity to local providers & ICB	2.1 Service agreement to supply units.	2.1 Nebulisers available as needed	Funding not agreed.

Development groups sign up

Nutrition:

<https://forms.office.com/e/c39zuYPzcg>



Cognition and behaviour:

<https://forms.office.com/e/dX8k1wtKq6>



Secretion toolkit:

<https://forms.office.com/e/Am6uD5hDLy>



Withdrawal of ventilation: discussion panel

Panel members:

- Dr Isae Kilonzo- Consultant in Palliative medicine, St Michael's Hospice
- Faye Bravant-In patient team leader, St Peter & St James Hospice
- Justin Anderson- Association Visitor, MND Association
- Paula Perera- Former carer of person with MND & Association Visitor

Final actions

1. Complete evaluations:

<https://www.smartsurvey.co.uk/s/sussexnetwork2024/>

2. Hand in badges

3. Sign up to our mailing list:

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Thank you for coming!