

Moving forward with Motor Neurone Disease: evaluating the impact of a local motor neurone disease group in a regional community setting

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Background:

Motor neurone disease (MND) is a complex and progressive neurological disorder, requiring extensive multidisciplinary team input.

Geographical isolation often creates difficulty for rural and regional dwelling consumers living with MND to access specialist health care.

Commencing in April 2018, monthly education and support group sessions delivered by multi-disciplinary allied health and nursing clinicians combined education, mindfulness activities and opportunities for consumers and family/carers to speak directly to each health professional about particular concerns.

Education sessions included information on symptoms associated with progression of the disease, and treatment and support options available.

Aims:

- Increase consumer and family/carers' knowledge of MND, and the treatment and support options available.
- Decrease the feeling of social isolation.
- Improve overall quality of life.

Goal:

- To support consumers and family/carers' development of knowledge and confidence to proactively prepare for their health journey.

Data collection:

Attendees completed a patient reported outcome questionnaire that asked eight (8) questions using a 1-10 scale.

Data Analysis:

Analysis of the data set was conducted in SPSS.

Key outcomes – participants reported:

- Increased understanding of MND.
- Increased confidence to contact services for support throughout their healthcare journey.
- Increased confidence in making informed health decisions.
- Feeling better prepared for their healthcare journey.
- Finding value in meeting other community members who were experiencing similar healthcare journeys.
- Pharmacy (medication use and handling/ gastrostomy administration techniques), and Social Work / Psychology (adjustment, copying and planning for the future) were the topics consumers felt most unclear about before attending the group.

Future Directions:

- In 2019, consumers and families living with other progressive neurological disorders (eg. progressive supranuclear palsy) will be invited to attend the regional community group.
- New community members will be asked to complete a pre and post outcome questionnaire, which will allow a statistical analysis to be completed to evaluate the impact of the group.
- Results will be shared across health services in order to showcase and promote the benefit a community group can provide consumers and families living with progressive neurological conditions.

Results

	How useful was the information in helping understand your condition?	How confident are you about making contact with services for support?	Do you feel better prepared for your health journey?	How valuable was it to speak directly to each health professional?	How valuable was it to meet other group members?	What topics were you most unclear about?	Have the education sessions addressed your questions?	How confident are you to make informed decisions about your health?
N	Valid 5	5	4	5	4	5	4	5
	Missing 0	0	1	0	1	0	1	0
Mean	9.80	9.80	9.50	9.80	10.00		9.75	9.80
Std. Deviation	.447	.447	1.000	.447	.000		.500	.447

