

# NEUROLOGICAL PALLIATIVE CARE SPECIAL INTEREST FORUM DECEMBER 2019

## Issue 4

Welcome to the fourth newsletter of the APM Neurological Palliative Care SIF.

I hope you find the newsletter of interest. If anyone comes across any useful information or articles which you would like to be included in future newsletters, please do let me know.

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Consultant in Palliative  
Medicine, Severn Hospice  
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### SAVE THE DATE:

#### Study days and learning for 2020

- 17<sup>th</sup> September, NeuroSIF study day - Models of Care and Joint Working @ Severn Hospice, Shrewsbury. More details to follow in the new year.
- 11<sup>th</sup> & 12<sup>th</sup> March, Sheffield university campus – Palliative care masterclass <https://neurologyacademy.org/courses/palliative-care/>
- 24<sup>th</sup> March, South East MND Network Conference Surrey
- 26<sup>th</sup> March, SITran MND Study Day Sheffield
- 25<sup>th</sup> March, End of Life Masterclass Cheadle
- 3<sup>rd</sup> July, Kings and St Christopher's Joint Annual MND Conference

Further information about all of these study days is available on the MNDA website [www.mndassociation.org/professionals/professional-education-and-development/education-events/](http://www.mndassociation.org/professionals/professional-education-and-development/education-events/)



Association for  
Palliative Medicine  
Of Great Britain and Ireland

Parkinson's: managing palliative and end of life care - online course (Excellence Network)

<https://www.parkinsons.org.uk/professionals/events-and-learning/parkinsons-managing-palliative-and-end-life-care-online>

### Have you seen this?

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#### *RightCare Progressive Neurological Conditions Toolkit*

*People with progressive neurological conditions are experiencing delays in diagnosis and treatment, fragmented and uncoordinated services, limited availability of neurospecialist rehab and reablement and a lack of psycho-social support. This toolkit will provide you with expert practical advice and guidance on how to address the key challenges when commissioning services and treating people with progressive neurological conditions. August 2019*

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<https://www.england.nhs.uk/rightcare/wp-content/uploads/sites/40/2019/08/progressive-neuro-toolkit.pdf>

## ONLINE RESOURCES:

'myTube' is an educational website about tube feeding in MND/ALS developed within the NHS in the UK, by Sheffield MND Care Centre and SITraN, with support from the MND Association.

<https://mytube.mymnd.org.uk/fitting/>

## UPDATES FROM COLLEAGUES:

### Collaboration between neurology and palliative care – a European survey

Professor David Oliver, University of Kent; Dr Nilay Heggul, Cicely Saunders Institute, London; Professor Gian D Borasio, University of Lausanne; Professor Raymond Voltz, Uniklinikum, Cologne; Dr Simone Veronese, FARO, Turin; Professor Marianne de Visser, Amsterdam University Medical Centre, Amsterdam

| Introduction   | Results  | Results   |                  |           |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
|--|--|-----------|------------------|-----------|--------|-----|-----|-------|-----|-----|-----------------|-----|-----|------------------------|-----|-----|---------------|-----|-----|----------------|-----|-----|---------------------|-----|-----|--------------|-----|-----|--|-----------|--|-----------|--|------------------|------|------------------|------|-----------------|-----|-----|-----|-----|-----|-----|-----|-----|-----|----|-----|-----|-----|-----|--------|-----|-----|-----|-----|----|-----|-----|-----|-----|----------|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|----|-----|-----|-----|-----|-----|-----|-----|-----|-----|------------|-----|-----|-----|-----|--|-----------|-----------|---------|-----|-----|--------------|-----|-----|-------------|-----|-----|----------|-----|-----|-----------------|-----|-----|--|--|-----------|-----------|--|-----|--|----------------------|--|-----|-------------------------|--|-----|------------------|-----|-----|------------------|-----|-----|--------------------|-----|-----|--|-----------|-----------|-------------------|-----|-----|----------------------|-----|-----|-------------------------|-----|-----|--|-----------|-----------|--------------------------|-----|-----|-------------------|-----|-----|--|-----------|-----------|--|-----|-----|
| <p>There is increasing discussion of the role of palliative care for people with chronic progressive neurological disease. In 2016 the European Association for Palliative Care (EAPC) and the European Academy of Neurology (EAN) produced a Consensus Statement on palliative care<sup>1</sup>. As part of the collaboration between the EAPC Reference Group on Neurology and the EAN Specialty Panel on Palliative Care a survey of this collaboration was proposed, based on an earlier UK study-OPTCARE-Neuro.</p> <p><small>1. Oliver DJ, Borasio GD, Caraceni A, de Visser M, Grisold W, Lorenzi S, Veronese S, Voltz R. A consensus review on the development of palliative care for patients with chronic and progressive neurological disease. Eur J Neurol 2016;23: 30-38.</small></p> <p><b>Methods</b></p> <ul style="list-style-type: none"> <li>On-line questionnaires were developed for neurologists and palliative care specialists asking for details of their involvement with people with chronic progressive neurological disease and the level of collaboration with other services. This was advertised, with a link to the questionnaire, through the EAPC and EAN, and other national learned societies.</li> <li>557 people responded to the questionnaire           <ul style="list-style-type: none"> <li>179 Palliative care professional completed from 12 countries</li> <li>120 Neurologists completed from 22 countries</li> </ul> </li> </ul> <p><b>Further contact:</b><br/>D.J.Oliver@kent.ac.uk</p> | <p>Several themes could be seen:</p> <p><b>Team members:</b></p> <table border="1"> <thead> <tr> <th></th> <th>Pall care</th> <th>Neurology</th> </tr> </thead> <tbody> <tr><td>Doctor</td><td>90%</td><td>94%</td></tr> <tr><td>Nurse</td><td>98%</td><td>99%</td></tr> <tr><td>Physiotherapist</td><td>77%</td><td>79%</td></tr> <tr><td>Occupational Therapist</td><td>27%</td><td>43%</td></tr> <tr><td>Social worker</td><td>73%</td><td>53%</td></tr> <tr><td>Spiritual care</td><td>61%</td><td>43%</td></tr> <tr><td>Speech and language</td><td>18%</td><td>68%</td></tr> <tr><td>Psychologist</td><td>90%</td><td>79%</td></tr> </tbody> </table> <p><b>Collaboration according to disease</b></p> <table border="1"> <thead> <tr> <th rowspan="2"></th> <th colspan="2">Pall care</th> <th colspan="2">Neurology</th> </tr> <tr> <th>Strong +moderate</th> <th>None</th> <th>Strong +moderate</th> <th>None</th> </tr> </thead> <tbody> <tr><td>Cerebral tumour</td><td>68%</td><td>13%</td><td>63%</td><td>20%</td></tr> <tr><td>ALS</td><td>63%</td><td>14%</td><td>70%</td><td>10%</td></tr> <tr><td>MS</td><td>34%</td><td>31%</td><td>37%</td><td>30%</td></tr> <tr><td>Stroke</td><td>34%</td><td>31%</td><td>36%</td><td>31%</td></tr> <tr><td>PD</td><td>30%</td><td>27%</td><td>27%</td><td>38%</td></tr> <tr><td>Dementia</td><td>30%</td><td>24%</td><td>39%</td><td>25%</td></tr> <tr><td>MSA</td><td>20%</td><td>45%</td><td>32%</td><td>42%</td></tr> <tr><td>PSP</td><td>17%</td><td>49%</td><td>31%</td><td>41%</td></tr> <tr><td>HD</td><td>14%</td><td>62%</td><td>36%</td><td>35%</td></tr> <tr><td>CBD</td><td>14%</td><td>62%</td><td>26%</td><td>42%</td></tr> <tr><td>Myopathies</td><td>10%</td><td>68%</td><td>26%</td><td>40%</td></tr> </tbody> </table> <p><b>Collaboration:</b></p> <table border="1"> <thead> <tr> <th></th> <th>Pall care</th> <th>Neurology</th> </tr> </thead> <tbody> <tr><td>Clinics</td><td>29%</td><td>24%</td></tr> <tr><td>MDT meetings</td><td>25%</td><td>29%</td></tr> <tr><td>Ward rounds</td><td>15%</td><td>13%</td></tr> <tr><td>Meetings</td><td>20%</td><td>21%</td></tr> <tr><td>Telephone calls</td><td>50%</td><td>50%</td></tr> </tbody> </table> |           | Pall care        | Neurology | Doctor | 90% | 94% | Nurse | 98% | 99% | Physiotherapist | 77% | 79% | Occupational Therapist | 27% | 43% | Social worker | 73% | 53% | Spiritual care | 61% | 43% | Speech and language | 18% | 68% | Psychologist | 90% | 79% |  | Pall care |  | Neurology |  | Strong +moderate | None | Strong +moderate | None | Cerebral tumour | 68% | 13% | 63% | 20% | ALS | 63% | 14% | 70% | 10% | MS | 34% | 31% | 37% | 30% | Stroke | 34% | 31% | 36% | 31% | PD | 30% | 27% | 27% | 38% | Dementia | 30% | 24% | 39% | 25% | MSA | 20% | 45% | 32% | 42% | PSP | 17% | 49% | 31% | 41% | HD | 14% | 62% | 36% | 35% | CBD | 14% | 62% | 26% | 42% | Myopathies | 10% | 68% | 26% | 40% |  | Pall care | Neurology | Clinics | 29% | 24% | MDT meetings | 25% | 29% | Ward rounds | 15% | 13% | Meetings | 20% | 21% | Telephone calls | 50% | 50% | <p><b>Barriers to collaboration:</b></p> <table border="1"> <thead> <tr> <th></th> <th>Pall care</th> <th>Neurology</th> </tr> </thead> <tbody> <tr><td>Neurology not referring Palliative care team</td><td>43%</td><td></td></tr> <tr><td>not seeing neuro pts</td><td></td><td>14%</td></tr> <tr><td>No palliative care team</td><td></td><td>28%</td></tr> <tr><td>Financial issues</td><td>21%</td><td>43%</td></tr> <tr><td>Patients refusal</td><td>15%</td><td>10%</td></tr> <tr><td>GP wanting to care</td><td>17%</td><td>13%</td></tr> </tbody> </table> <p><b>Common areas of involvement</b></p> <table border="1"> <thead> <tr> <th></th> <th>Pall care</th> <th>Neurology</th> </tr> </thead> <tbody> <tr><td>Physical symptoms</td><td>94%</td><td>74%</td></tr> <tr><td>Psychological issues</td><td>96%</td><td>77%</td></tr> <tr><td>Complex decision making</td><td>96%</td><td>76%</td></tr> </tbody> </table> <p><b>Expertise in providing palliative care in neurology</b></p> <table border="1"> <thead> <tr> <th></th> <th>Pall care</th> <th>Neurology</th> </tr> </thead> <tbody> <tr><td>None/ limited / somewhat</td><td>44%</td><td>57%</td></tr> <tr><td>Expert/ very good</td><td>18%</td><td>16%</td></tr> </tbody> </table> <p><b>Does palliative care help in neurology?</b></p> <table border="1"> <thead> <tr> <th></th> <th>Pall care</th> <th>Neurology</th> </tr> </thead> <tbody> <tr><td></td><td>93%</td><td>74%</td></tr> </tbody> </table> <p><b>Conclusion</b></p> <p>There is evidence of good collaboration between palliative care and neurology - this may not truly reflect all services, as those with close links were more likely to respond.</p> <p>The collaboration is commoner for ALS and brain tumours and less likely with HD, CBD or myopathies.</p> <p>Team involvement varies with less psychosocial and spiritual support in neurology and less OT and speech and language support in palliative care.</p> <p>The barriers to collaboration were often lack of availability and financial, rather than refusal for patients and families.</p> <p>There is a need for continued education of all concerned as expertise was variable. Closer consideration of how the barriers may be reduced.</p> |  | Pall care | Neurology | Neurology not referring Palliative care team | 43% |  | not seeing neuro pts |  | 14% | No palliative care team |  | 28% | Financial issues | 21% | 43% | Patients refusal | 15% | 10% | GP wanting to care | 17% | 13% |  | Pall care | Neurology | Physical symptoms | 94% | 74% | Psychological issues | 96% | 77% | Complex decision making | 96% | 76% |  | Pall care | Neurology | None/ limited / somewhat | 44% | 57% | Expert/ very good | 18% | 16% |  | Pall care | Neurology |  | 93% | 74% |
|  | Pall care  | Neurology |                  |           |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
| Doctor   | 90%  | 94%       |                  |           |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
| Nurse  | 98%  | 99%       |                  |           |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
| Physiotherapist  | 77%  | 79%       |                  |           |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
| Occupational Therapist   | 27%  | 43%       |                  |           |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
| Social worker  | 73%  | 53%       |                  |           |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
| Spiritual care   | 61%  | 43%       |                  |           |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
| Speech and language  | 18%  | 68%       |                  |           |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
| Psychologist   | 90%  | 79%       |                  |           |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
|  | Pall care  |           | Neurology        |           |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
|  | Strong +moderate   | None      | Strong +moderate | None      |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
| Cerebral tumour  | 68%  | 13%       | 63%              | 20%       |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
| ALS  | 63%  | 14%       | 70%              | 10%       |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
| MS   | 34%  | 31%       | 37%              | 30%       |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
| Stroke   | 34%  | 31%       | 36%              | 31%       |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
| PD   | 30%  | 27%       | 27%              | 38%       |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
| Dementia   | 30%  | 24%       | 39%              | 25%       |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
| MSA  | 20%  | 45%       | 32%              | 42%       |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
| PSP  | 17%  | 49%       | 31%              | 41%       |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
| HD   | 14%  | 62%       | 36%              | 35%       |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
| CBD  | 14%  | 62%       | 26%              | 42%       |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
| Myopathies   | 10%  | 68%       | 26%              | 40%       |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
|  | Pall care  | Neurology |                  |           |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
| Clinics  | 29%  | 24%       |                  |           |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
| MDT meetings   | 25%  | 29%       |                  |           |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
| Ward rounds  | 15%  | 13%       |                  |           |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
| Meetings   | 20%  | 21%       |                  |           |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
| Telephone calls  | 50%  | 50%       |                  |           |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
|  | Pall care  | Neurology |                  |           |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
| Neurology not referring Palliative care team   | 43%  |           |                  |           |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
| not seeing neuro pts   |  | 14%       |                  |           |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
| No palliative care team  |  | 28%       |                  |           |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
| Financial issues   | 21%  | 43%       |                  |           |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
| Patients refusal   | 15%  | 10%       |                  |           |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
| GP wanting to care   | 17%  | 13%       |                  |           |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
|  | Pall care  | Neurology |                  |           |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
| Physical symptoms  | 94%  | 74%       |                  |           |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
| Psychological issues   | 96%  | 77%       |                  |           |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
| Complex decision making  | 96%  | 76%       |                  |           |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
|  | Pall care  | Neurology |                  |           |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
| None/ limited / somewhat   | 44%  | 57%       |                  |           |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
| Expert/ very good  | 18%  | 16%       |                  |           |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
|  | Pall care  | Neurology |                  |           |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |
|  | 93%  | 74%       |                  |           |        |     |     |       |     |     |                 |     |     |                        |     |     |               |     |     |                |     |     |                     |     |     |              |     |     |  |           |  |           |  |                  |      |                  |      |                 |     |     |     |     |     |     |     |     |     |    |     |     |     |     |        |     |     |     |     |    |     |     |     |     |          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |    |     |     |     |     |     |     |     |     |     |            |     |     |     |     |  |           |           |         |     |     |              |     |     |             |     |     |          |     |     |                 |     |     |  |  |           |           |  |     |  |                      |  |     |                         |  |     |                  |     |     |                  |     |     |                    |     |     |  |           |           |                   |     |     |                      |     |     |                         |     |     |  |           |           |                          |     |     |                   |     |     |  |           |           |  |     |     |

## Summary of a service evaluation of hospice admissions for patients with Motor Neurone Disease and Duchenne's Muscular Dystrophy and barriers to their transition and admission.

Dr Rachel Taylor (Palliative Medicine Specialty Trainee)

78 responses from 191 hospices. 98.7 % admitted MND patients and 93.6% would admit DMD patients; however 51.3% had not had any referrals for DMD. Barriers were identified as challenges rather than barriers. The top four for each group were:

| MND                                 | DMD   |
|-------------------------------------|---|
| Staffing levels and high dependency | Patients remaining under children's services/difficulty with transition |
| NIV                                 | Difficulties managing their needs                                       |
| Bed availability                    | Not being referred  |
| Difficulty managing their needs     | No respite in adult hospices  |

93.6% of hospices would admit patients on NIV, but most of them often found this challenging and wouldn't start NIV or amend the settings; only 23% had formal training on NIV.

### Conclusions

While it's difficult to provide answers for wider service issues like staffing and bed availability, we need to be providing increased services for transitioning DMD patients into adult care. Commonly hospices were worried about the complexity of care that these patients require, including familiarity with equipment and use of NIV. Going forward, it is necessary to work with children's services to develop learning packages for adult hospices to feel more comfortable with these admissions.

### Impact of implementing a multidisciplinary MND clinic on hospital stays in the last year of life

Faris Hussain 5<sup>th</sup> Year Medical Student (Cardiff University) and Siwan Seaman (Consultant in Palliative Medicine, Marie Curie Hospice, Cardiff and the Vale)

A retrospective comparison of MND patients across three South Wales Health Boards who died in 2012 with those who died in 2018. Following the establishment of the South Wales MND Care Network the MND clinics became multiprofessional from 2013 onwards and by the end of 2014 each clinic across the network had a Palliative Care physician as a core member.

Individuals who died in both study years were identified from the network database and subsequently their paper records and electronic portals used to gather data. A total of 31 patients who died in 2012 and 45 patients who died in 2018 were included in the analysis. The mean number of bed days for patients who died in 2012 was 33.19 days (range 0-230), with a mean number of 2.26 admissions (range 0-6). For 2018 deaths, the mean number of bed days was 23.91 (range 0-106) with a mean of 1.91 admissions (range 0-7).

The average number of admissions and days spent as in-patients in the last year of life decreased for patients dying in 2018 compared with those who died in 2012, although the reduction was not statistically significant, supporting the role for MDT-run clinics. Next steps are to extend the project to include patients from across the South Wales MND network to provide a larger sample powered to demonstrate whether the impact results in a statistically significant reduction.

## RECENT ARTICLES OF INTEREST

### **Advance care planning in progressive neurological diseases: lessons from ALS**

Antje A. Seeber, A. Jeannette Pols, Albert Hijdra, Hepke F. Grupstra, Dick L. Willems & Marianne de Visser . BMC Palliative Care volume 18, Article number: 50 (2019)

<https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-019-0433-6>

Twenty-eight Dutch patients participated, varying in age, gender, disease onset and severity of physical decline. ACP started directly when the diagnosis was given, by means of a general outlook on the future with progressive disability and immediate introduction to a customized multidisciplinary team. During follow-up ACP was realized by regular appointments in which monitoring of the patient's status and clear communication strategies formed the basis of tailor-made discussions on treatment options. Patients accepted this policy as careful professional guidance.

#### **Conclusions**

ACP is a professional communication process throughout the *whole* course of progressive disease. It is feasible to integrate ACP into follow-up of patients with ALS and PMA from diagnosis onwards. Supported by recent literature, we argue that such a well-structured approach would also enhance the quality of care and life of patients with other chronic progressive neurological diseases.

### **Measuring quality of life in palliative care for Parkinson's disease: A clinimetric comparison**

Samantha K.Holden, <sup>a</sup>Claire E.Koljack<sup>a</sup>Lindsay P.Prizer<sup>b</sup>Stefan H.Sillau<sup>a</sup>Janis M.Miyasaki<sup>c</sup>Benzi M.Kluger<sup>a</sup>. Parkinsonism & Related Disorders Volume 65, August 2019, Pages 172-177

<https://doi.org/10.1016/j.parkreldis.2019.06.018>

Quality of life (QOL) assessments allow for more complete evaluation of patients' lived experiences in relation to chronic conditions, such as Parkinson's disease (PD). In palliative care, such instruments are vital to ensure QOL issues are catalogued and addressed for patients. However, little is known regarding the psychometric properties of quality of life scales for use in palliative care for PD, specifically.

210 participants with parkinsonian disorders, who participated in a larger palliative intervention clinical trial, completed four quality of life scales (PDQ-39, PROMIS-29, QOL-AD, and McGill QOL) at baseline and post-intervention. Psychometric properties, including internal consistency and concurrent validity, were examined. Factor analyses were performed to evaluate relationships between scale items. Minimal clinically important differences (MCID) and responsiveness were calculated for each scale.

#### **Conclusions**

The PDQ-39, PROMIS-29, QOL-AD, and McGill QOL are all valid for use in PD palliative care, though subdomains of the scales in this population may differ slightly from those initially defined. We recommend the use of PDQ-39 and PROMIS-29 as outcome measures in clinical trials for palliative care in PD, though the QOL-AD may be superior for tracking disease progression.

**Please see our updated Terms of Reference for the group on the APM website**