

Date and Time: *Wednesday 24 September 2014, 10:00-16:00*

Minutes: Draft

Guideline Development Group Meeting 5

Place: *NCGC, 180 Great Portland Street, London, W1W 5QZ*

Present:

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| David Oliver | Consultant in palliative medicine and medical director, Wisdom Hospice |
| Liz Avital | Associate director, NCGC |
| Julie Neilson | Senior research fellow, NCGC |
| Caroline Farmer | Research fellow, NCGC |
| Alexander Haines | Health economist, NCGC |
| Katie Broomfield | Document editor/process assistant, NCGC |
| Jean Waters | Patient/carer member |
| Sandra Smith | Patient/carer member |
| Roch Mayer | Patient/carer member |
| Steven Bloch | Lecturer & faculty of brain sciences graduate tutor, London |
| Julie Brignall-Morley | Community matron in neurological conditions, Yorkshire |
| Jennifer Rolfe | MND specialist occupational therapist, Oxford |
| Liz Brown | Principal physiotherapist in emergency, cardiothoracic and specialised medicine, Staffordshire |
| Chris McDermott | Consultant neurologist, Sheffield |
| Annette Edwards | Consultant in palliative care medicine, Leeds |
| Rachael Marsden | MND care centre coordinator and advanced nurse practitioner, Oxford |
| Rachel Starer | General practitioner, Oxford |
| Robert Angus (co-optee) | Respiratory physician, Liverpool |

In attendance:

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|---------------|---------------------------------------|--|
| NICE Staff: | | |
| Caroline Keir | Guideline commissioning manager, NICE | |

Apologies:

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| Katie Jones | Senior project manager, NCGC | |
| Aleksander Radunovic | Consultant neurologist, London | |

Notes

1. Welcome, declarations of interest and GDG4 minutes

The chair welcomed the group to the fifth meeting of this GDG. The following declarations of interest were made, for which no action was required:

DO

- Gave a lecture to the MND Association of Australia Conference. Received £1,000 for travel from MND Association of Australia, and £1,000 for travel from MND Association of Victoria.
- Advised the Motor Neurone Disease Association to update a leaflet on death and dying but declined invitation to update it.

RA

- In receipt of a grant from the small business research initiative through NHS England to look at remote monitoring of ventilation and respiratory symptoms.

RMa

- Advising on a casualty storyline on MND.

CB

- Giving a lecture, as part of her role there, for Keele University on the management of respiratory complications for neuromuscular disease.

JW

- Speaking at a GSK seminar on MND in October. Her contribution is as a patient living with MND. Will receive an honorarium for attending.
- Taking part in the NHS England programme looking at re-designing the provision of wheelchair services across the country. Has been asked to comment on the draft wheelchair service specification, for which no honorarium will be received.

SS

- Giving a lecture at Manchester University on being a carer for people with MND.

JR

- Has been asked by the MNDA to review their guidance on wheelchair provision. Is ensuring that the guidance is clinically accurate.
- Recruiting MND patients onto a TONIC quality of life study (funded by MNDA).
- Has been asked to comment on the NHS England programme looking at re-designing provision of wheelchair services across the country.

CMD

- Has been asked to comment on the MNDA review document of advice on how to care for people with MND.
- Has been asked to write an article for a GP magazine on MND. He offered not to receive the honorarium.

2. NIV update

CK and LA gave an update on the inclusion of CG105.

3. LETR: AAC devices

The GDG made amendments to this LETR.

4. LETR: Saliva management

The GDG made amendments to this LETR.

5. Clinical evidence for the review question on nutrition management

JN gave a presentation on the clinical evidence for this review question.

6. Economic evidence for the review question on nutrition management

AH gave a presentation on the economic evidence for this review question.

7. LETR for the review question on nutrition management

The GDG drafted an LETR for this review question.

8. Draft protocol: Communication of diagnosis and prognosis

The GDG discussed this draft protocol and made amendments to the document.

9. Clinical evidence for the review question on timing of gastrostomy

CF gave a presentation on the clinical evidence for this review question.

10. Economic evidence for the review question on timing of gastrostomy

AH led a discussion on the economic evidence for this review question.

11. LETR for the review question on timing of gastrostomy

The GDG drafted an LETR for this review question.

12. Draft protocol: time to diagnosis

The GDG discussed this draft protocol.

13. Discussion of draft protocols: psychological support

The GDG discussed this draft protocol and made amendments to the document.

14. Discussion of draft protocols: social care needs

The GDG discussed this draft protocol and made amendments to the document.

15. Discussion of draft protocols: cognitive assessment tools

The GDG discussed this draft protocol and made amendments to the document.

16. AOB

None.

16. Summary of next steps and close

Date, time and venue of the next meeting:

GDG6: Wednesday 10 December 2014, 10am - 4.30pm, Boardroom, NCGC

GDG7: Thursday 11 December 2014, 9.30am – 4pm, Boardroom, NCGC