

Date and Time: *Tuesday 29th April 2014, 10am-4pm*

Minutes: Confirmed

Guideline Development Group Meeting 2

Place: *Boardroom, National Clinical Guideline Centre, 180 Great Portland Street, London*

Present:

David Oliver	Consultant in palliative medicine and Medical director, Wisdom Hospice
Liz Avital	Hospice
Katie Jones	Associate director, NCGC
Julie Neilson	Project manager, NCGC
Sadia Janjua	Senior research fellow, NCGC
Jill Cobb	Research fellow, NCGC
Edward Griffin	Information scientist, NCGC
Dalia Dawoud	Health economist, NCGC
Caroline Keir	Guideline commissioning manager, NICE
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
Caroline Brown	Principal physiotherapist in Emergency, Cardiothoracic and Specialised medicine, Staffordshire
Chris McDermott	Consultant neurologist, Sheffield
Aleksander Radunovic	Consultant neurologist, London
Annette Edwards	Consultant in palliative care medicine, Leeds
Rachael Marsden	MND Care centre coordinator and Advanced nurse practitioner, Oxford

Apologies: Chris McDermott, Consultant neurologist, Sheffield

In attendance:

NICE Staff:		
NICE attendee 1	Caroline Keir, Guideline commissioning manager, NICE	

Observers:

N/A		
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Notes

1. The Chair welcomed the group to the second meeting of this GDG. Apologies were received from CM. The Chair reviewed and requested updates to the declarations of interest register. No declarations of interest were made and therefore no action was required.

Notes

2. **Evidence review:**
SJ and DD gave presentations on the clinical and economic evidence for the review question concerning the pharmacological management of muscle stiffness, muscle weakness and cramps. The GDG discussed the evidence presented. Linking of evidence to recommendations will be revisited at the next meeting in the light of an additional intervention action point.
3. **Evidence review:**
SJ and DD gave presentations on the clinical and economic evidence for the review question concerning the non-pharmacological management of muscle stiffness, muscle weakness and cramps. The GDG discussed the evidence and reviewed the linking of evidence to recommendations.
4. **Evidence review:**
JN and DD gave presentations on the clinical and economic evidence for the review question concerning equipment needs for people with motor neurone disease. The GDG discussed the evidence and reviewed the linking of evidence to recommendations.
5. **Draft protocols:**
The GDG discussed the draft protocols on nutrition management, timing of gastrostomy, and secretion management. The discussion on communication was postponed to the next GDG meeting due to time constraints.
6. **Prioritisation of areas for health economics:**
EG gave a presentation on the prioritisation of scoping topics for the purposes of economic modelling. The GDG reviewed the relative priority and feasibility of each area.
7. **Summary of next steps and close**

Date, time and venue of the next meeting

GDG3 – Tuesday 24th June 2014, 10am – 4.15pm, Boardroom, NCGC, 180 Great Portland Street, London.