

## Dementia End of Life Care: Community of Practice

Tuesday Dec 5<sup>th</sup> 2017 10.00 - 15.30 pm

Hospice House 34 – 44 Britannia Street, WC1X 9JG

### Meeting Notes

#### Welcome

**Marie Cooper and Karen Harrison-Dening**

#### Hear from the Community of Practice (CoP)

**Dr Sarah Russell (SR) and Marie Cooper (MC)**

- MC invited everyone to get to know the colleagues around their seating areas.
- SR asked everyone to write a quick note about what they are working on during lunch on a post it and put it on the white board for sharing later.

#### Action:

- Please see attached.

#### Key Reflections on the EAPC White paper on palliative care in dementia for the practitioner

**Dr Jenny van der Steen**, Leiden University Medical Center, Department of Public Health and Primary Care -Netherlands

#### Action:

- Please see attached.
- Recorded session to be uploaded to website or slides and key messages. (Please check back in the new year.)

For more information, please see this [resource](#)

#### New approaches to improve experience of living with Dementia in a care home environment

**Katie Smith**, Lead Nurse Belong Wigan

**Jackie Campbell**, Lead Nurse, Belong Morris Feinmann, Didsbury  
Belong Limited

#### Action:

- Presentations to be circulated at a later date. For more information please see [here](#).

## Reflections and Summary

### Karen Harrison-Dening

- Questions about the use of videos as advance care planning documentation versus written documents. There is some evidence for videos as tools to trigger advance care planning decisions but little about them as documentation of wishes and decisions.
- What can be used/prescribed to improve Quality Of Life (such as video, touch, multisensory therapy)?
- Therapy and improvements should also be cost effective and strongly verified
- Wider community conversations to be had for people with dementia.
- Staff resilience – ‘person centred care for staff in order for them to provide person centred care to patients and their families’

The Namaste Care intervention to improve the quality of dying for people with advanced dementia living in care homes: A realist review.

### Professor Francis Bunn

#### Action:

- Please see attached. For more information see [here](#).

Can we prescribe watching videos to those living with dementia?

<https://www.hospiscare.co.uk/dementia-care-videos>

Tina Nadrett, Director of Care, Hospicecare - Exeter

Present CoP review of CoP activities, events and membership in order to inform evaluation and plan 2018 CoP contents.

- Update on Namaste 12 months on
- Variety of speakers from various different industries are useful
- Case studies in practice (perhaps an admiral nurse)
- Methodology and QI approaches? (perhaps a service development case study)
- Fundraising linkage with evidence- pots of funding- dementia related (perhaps in monthly briefings)
- Review and evaluation of hospices/hospitals on how they have improved a process/service.
- Innovative Ideas panel/session
- Early on service models
- Bridging conversations
- Validated measures
- Exploring family dynamics and carers
- Grief and bereavement study
- Looking at new locations for meetings
- HIQ board for Dementia

## What next for 2018 and beyond?

- Marie Cooper is stepping down as Hospice UK lead for Dementia CoP. She will be staying involved with a practice development focus. Sarah Russell will step in as Hospice UK Dementia CoP lead supported by Heather Lovvorn as administration support.
- Karen Harrison-Dening remains as Dementia UK lead.
- Discussion with CoP about format of events – to continue face to face events, monthly e-bulletin, invited expert speakers as well as CoP members, consider different delivery formats, sharing of resources, widening membership.

## Future Dates

June and December 2018 meetings date and venue to be confirmed.