

# In the end, what gives a life meaning is not only how it is lived, but how it draws to a close

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## Background

Care Homes, both residential and nursing, can become home to a small number of people with MS at the end of life, often due to advanced disease and complex care requirements. We know some experience unplanned acute hospital admissions due to infection with 40-50% of admissions from care homes including a high number with pneumonia and neurological conditions at end of life (Smith et al, 2015). These admissions often cause reduced quality of life and financial burden (National Health Interview Survey (NHIS), et al, 2015) with disparity of care for those with advancing disease highlighted by the MS Trust (2015). Further evidence shows inequality at end of life between those with neurological disease vs cancer (National Council for Palliative Care (NCPC), 2016).

Feedback from clinical care and evidence from studies such as that commissioned by Marie Curie (Dixon et al, 2015) indicate both individual and care home staff can feel a sense of abandonment at end of life. The National Palliative and End of Life Care Partnership (NPELCP, 2015) highlights local action is necessary ensuring individuals at end of life, despite their diagnosis, have fair access to care, from staff prepared to care.

## Aims of this poster

To raise awareness of inequity in end of life care for those with MS and other neurological conditions who reside in care homes and how health and social care professionals can use their local influence to redress this imbalance as life **draws to a close.**

## Discussion

### Why does inequality at End of Life in Care Homes exist?

Triggers to consider end of life care in neurological conditions are often missed and include: swallowing and cognitive difficulties, weight loss, decline in physical status, first episode of aspiration pneumonia and recurring infection (NCPC, 2011).

### Why are triggers often missed?

- Uncertain disease trajectory
- Failure to recognise
- Failure to discuss and advance plan in contrast with malignant disease
- Lack of clinical skills

(National Institute for Health and Clinical Excellence (NICE), 2011).

## Conclusion

### Local MS Service Implementation Plan

- Telephone and domiciliary visits offered by MS CNS to support individual and care home staff, assisting with recognition of triggers and promoting advance care planning.
- Work with local Care Homes Team Educators to deliver an End of Life Care in Neurology teaching package to local care homes.
- Utilise opportunities across health and social care to raise awareness of the challenges in end of life care for individuals with neurological conditions as their lives **draw to a close.**

References – see handout in folder alongside this poster