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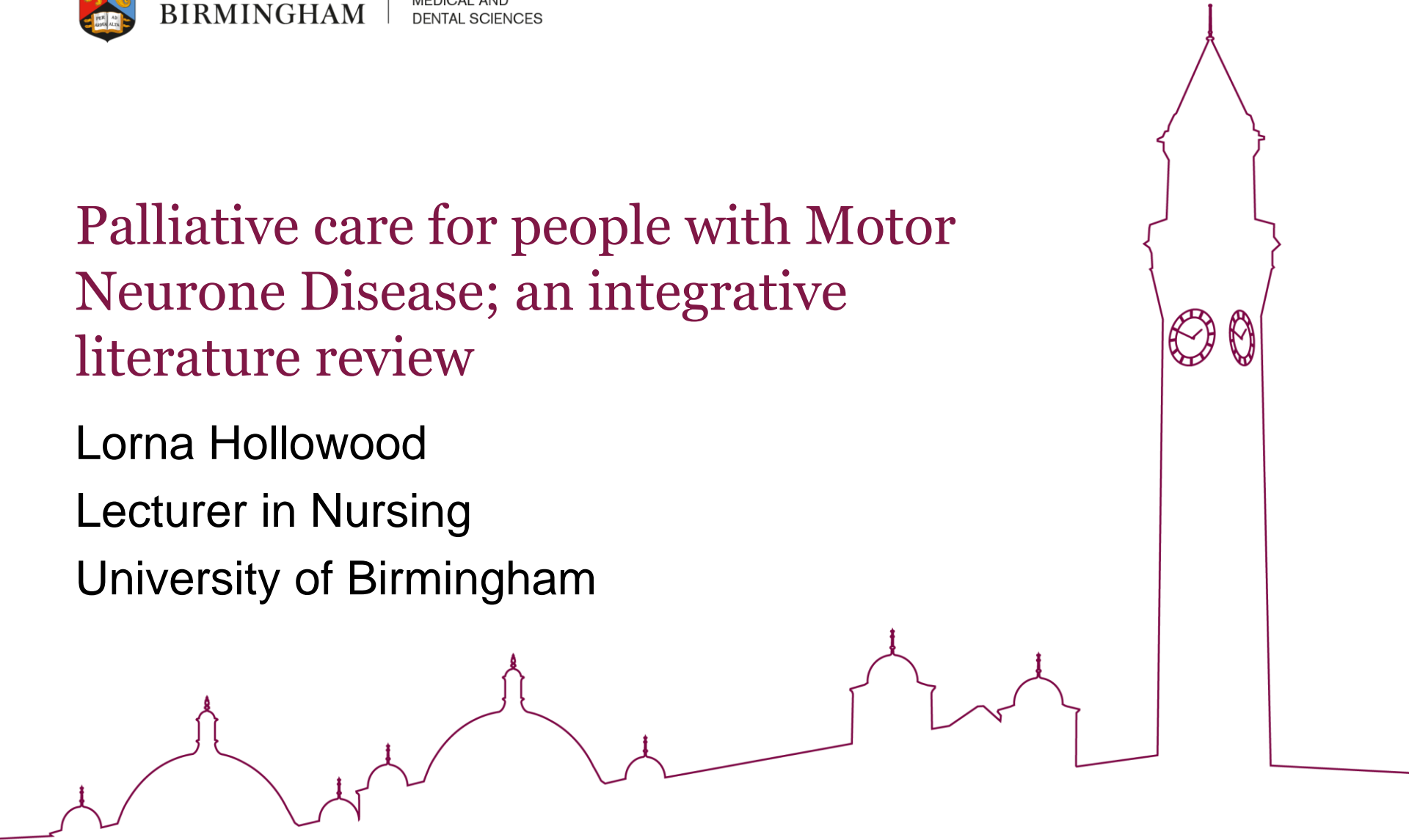
COLLEGE OF
MEDICAL AND
DENTAL SCIENCES

Palliative care for people with Motor Neurone Disease; an integrative literature review

Lorna Hollowood

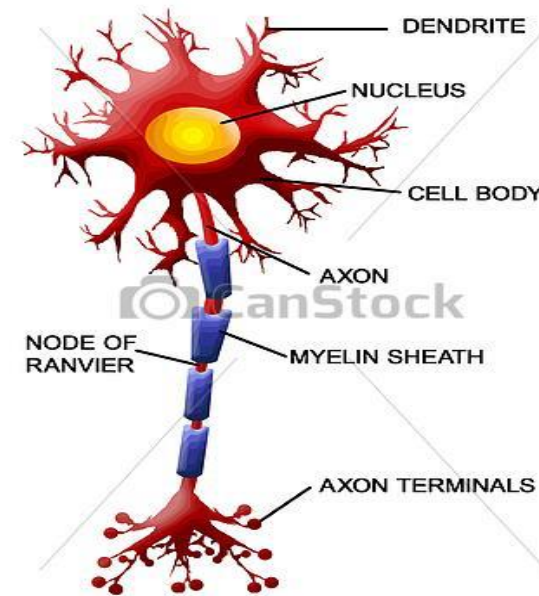
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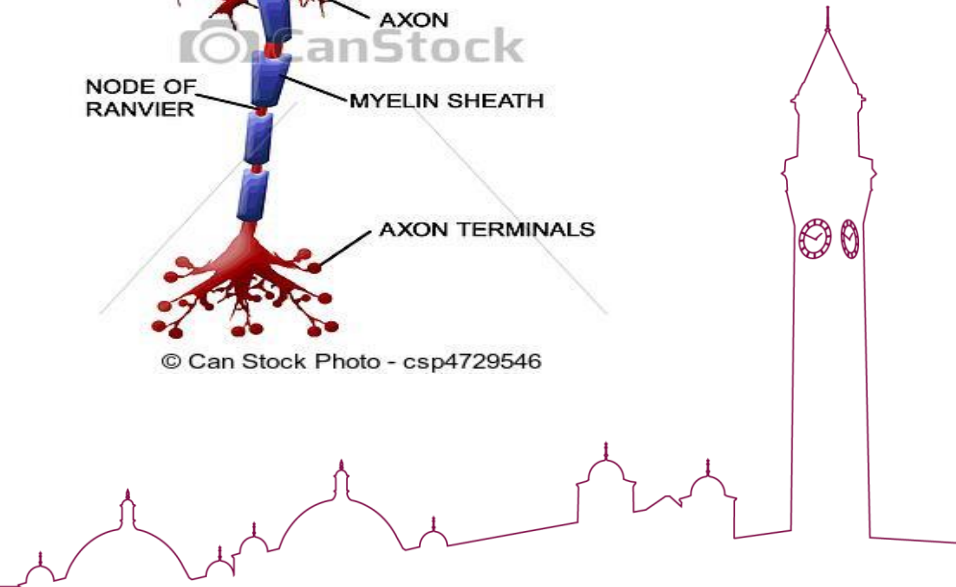


Motor Neurone Disease

- Progressive neurodegenerative disease
- No cure or remission
- Disabling symptoms



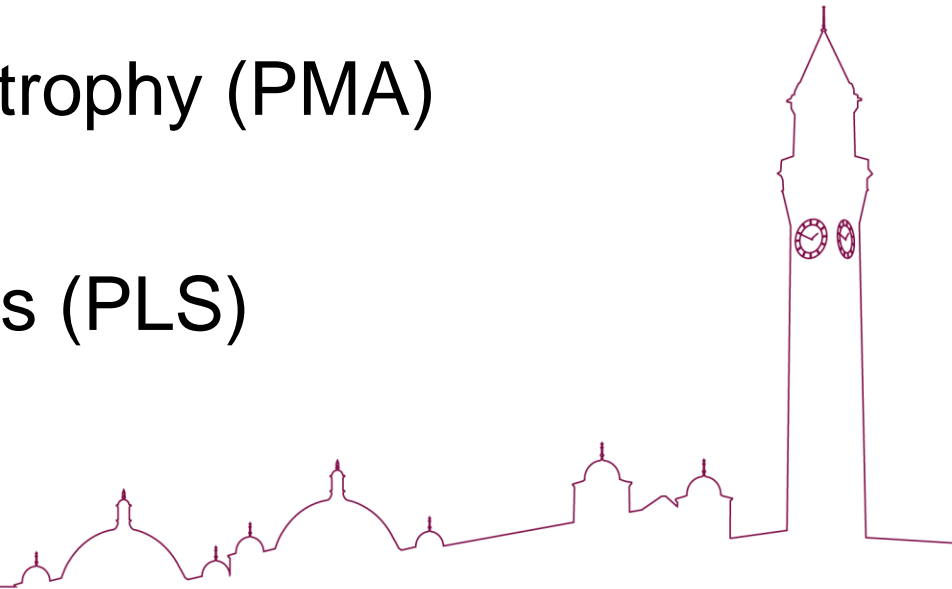
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Motor Neurone Disease



- Amyotrophic Lateral Sclerosis (ALS)
- Progressive Bulbar Palsy (PBP)
- Progressive Muscular Atrophy (PMA)
- Primary Lateral Sclerosis (PLS)
- Familial ALS



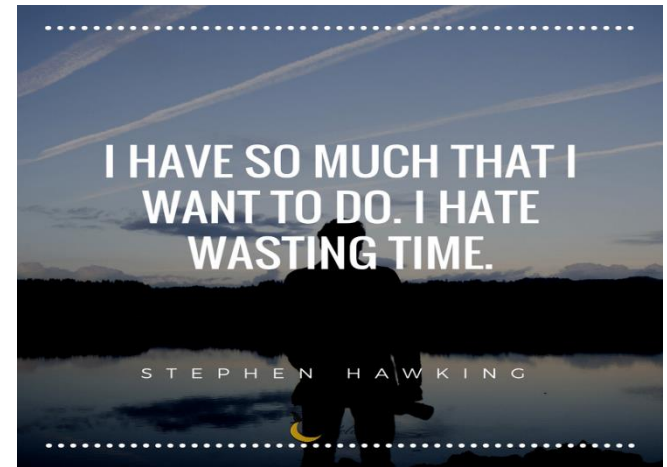
Prognosis

- Median survival

- Limb onset – 3.5 years
- Bulbar onset – 2.5 years

25% diagnosed alive at 5 years

5-10% diagnosed alive at 10 years

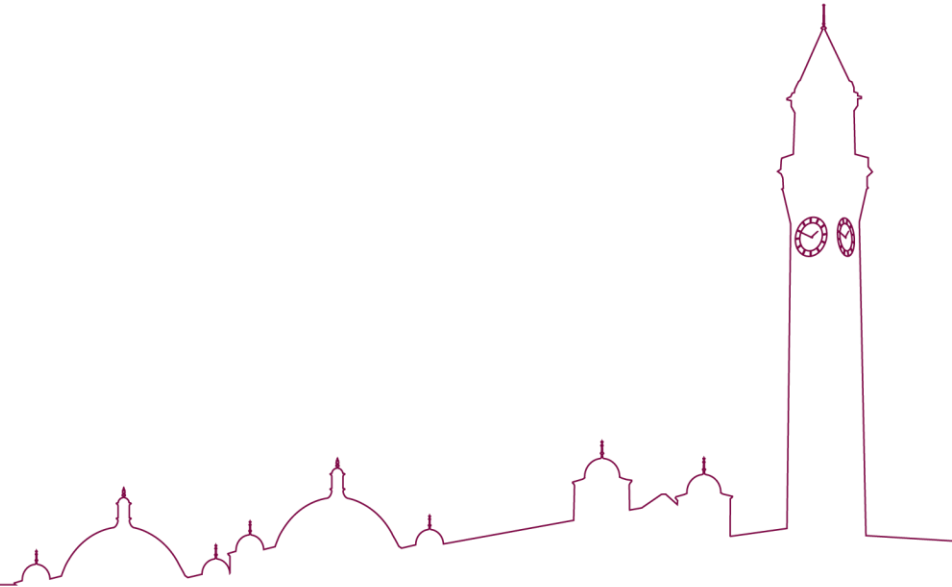


(Oliver 2017)



Treatment

- No curative treatment
- Riluzole (NICE 2016)
- Symptom Management



WHO Definition of Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.



Palliative Care for people with MND; an integrative literature review

- Study aim - to explore what is known about the problems that people with MND experience with provision of palliative care
- Objectives
- Explore Palliative and EOL care and MND
- Identify strategies for improvement



Methodology

- Integrative literature review
- Gough et al (2012) 3 step approach
- Data evaluation - Quality Review Tool (Mackenzie et al 2010)
- Data analysis – Thematic analysis (Thomas and Harden 2008)



Inclusion and Exclusion criteria

Inclusion	Exclusion	Rationale
Empirical studies	Non-empirical literature	Review aims to map current research
Main focus of study is EOL and PC for MND	Comparative treatment studies	Primary aim of understanding PC needs for MND
Language; English	Not published in English	Resources
Research published from 2005 onwards	Pre-2005	Contemporary evidence



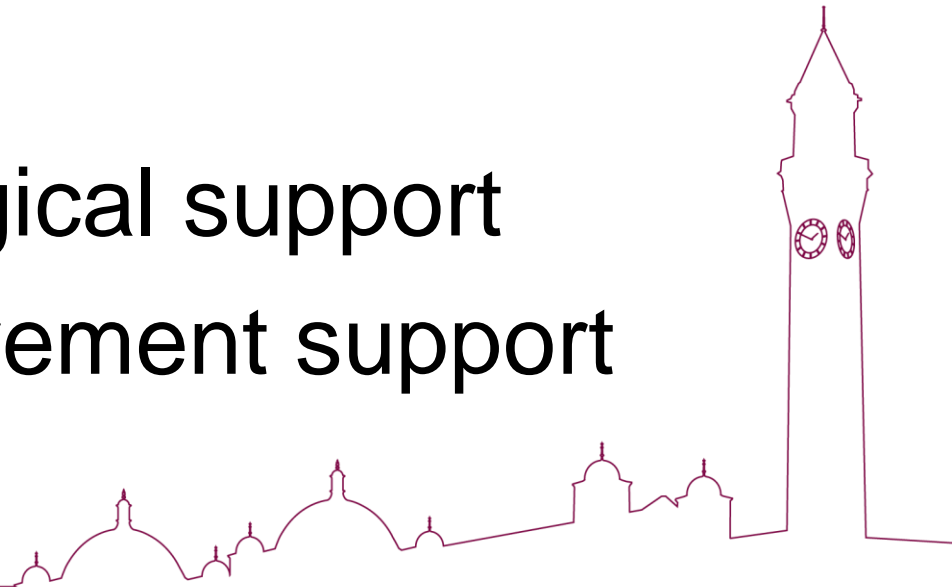
Results

- 16 studies which met the review aim
- All demonstrated to be medium to strong evidence from evaluation process
- Five themes emerged from the data



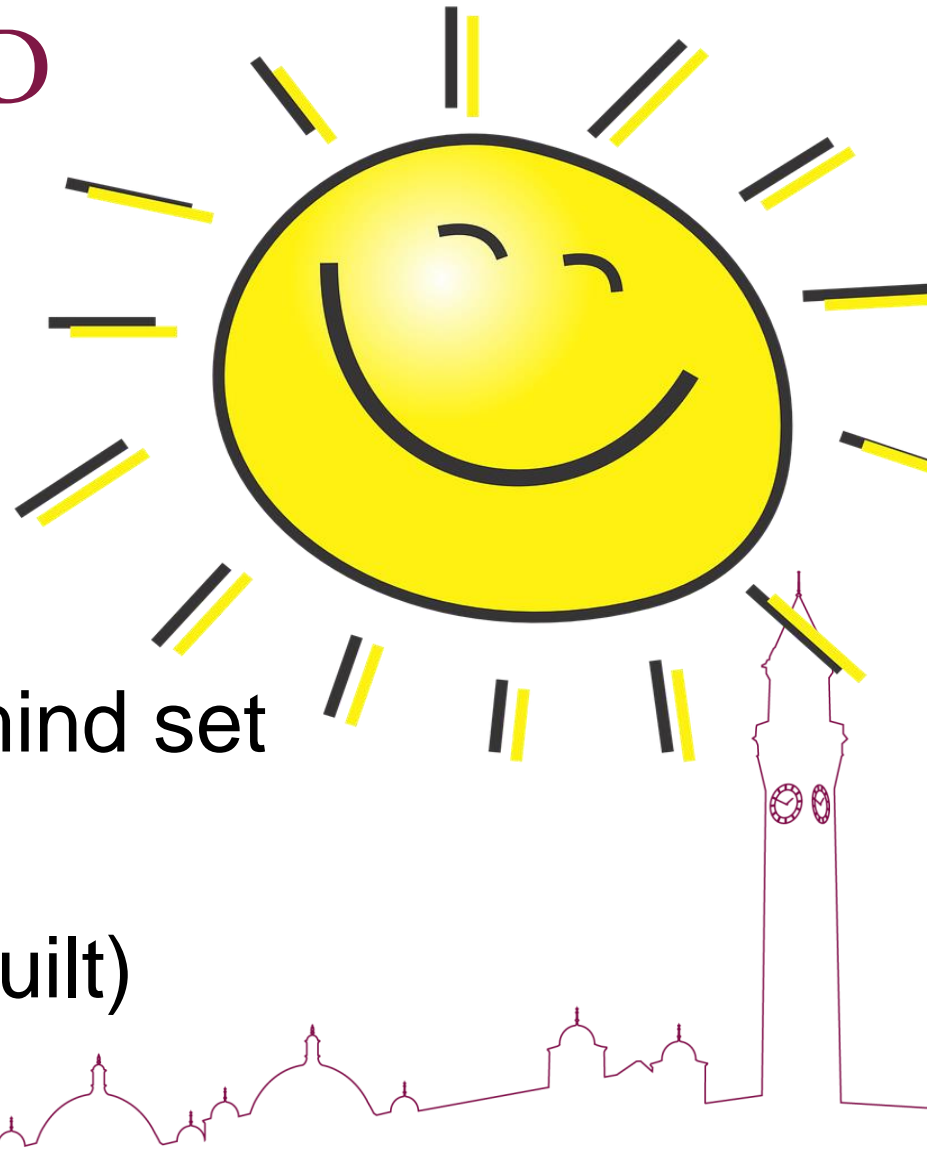
The specific needs of those who care for people with MND

- Access to practical training
- Support to administer medication safely
- Personal support
- Tailored psychological support
- Formalised bereavement support



Positive side of caring for someone with MND

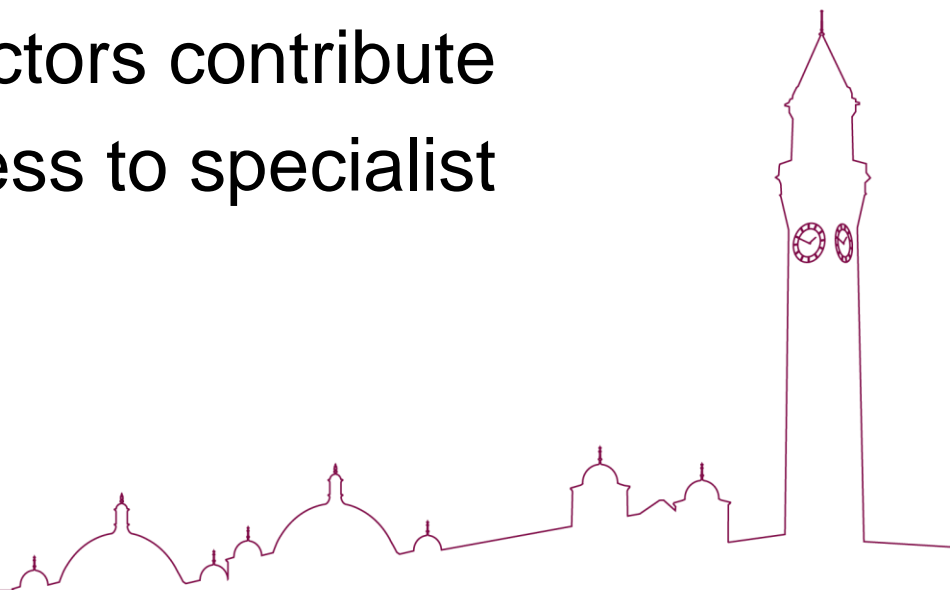
- Skill acquisition
- New family roles
- Developing positive mind set
- Relief (tempered by guilt)



Service provision



- ❑ Low satisfaction and reported poor coordination
- ❑ People with MND have less engagement with services than other conditions
- ❑ Intrinsic and extrinsic factors contribute
- ❑ Case for increased access to specialist palliative care services
- ❑ What services?



Hope and Depression

- Psychological symptoms require careful consideration
- Depression is inevitable?
- Hope as a psychosocial intervention
- Dignity therapy, ACP,
- mindfulness can all support

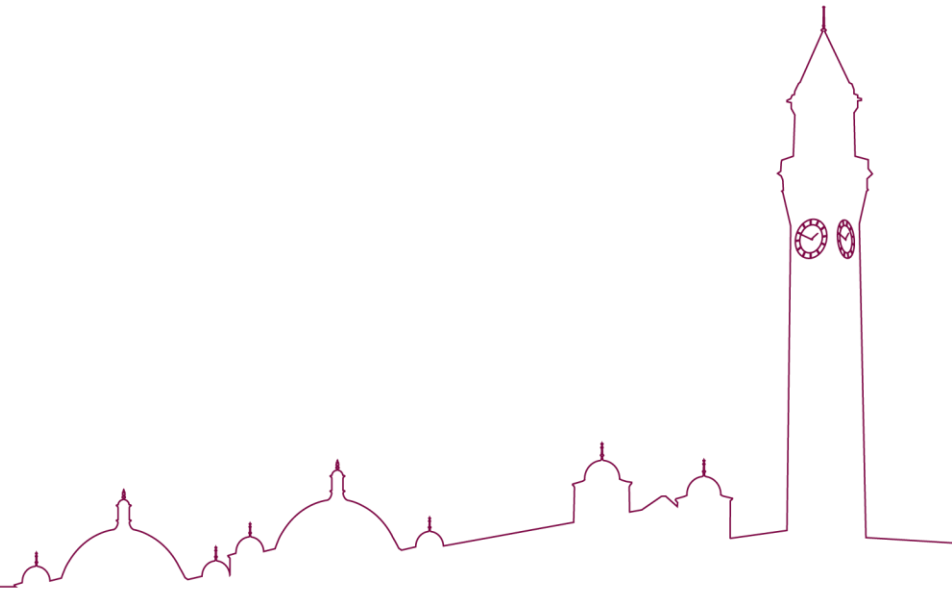
However bad life may seem,
there is always something you
can do, and succeed at. While
there's life, there is hope.

-Stephen Hawking



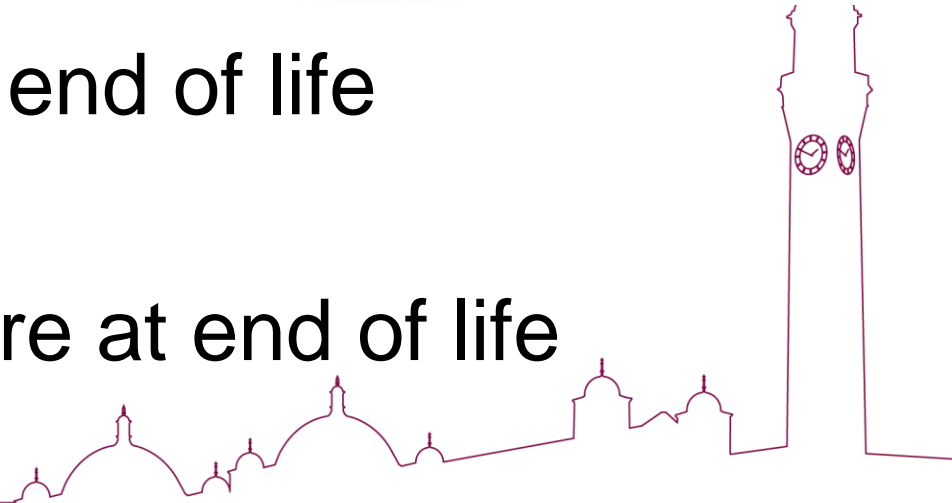
Symptom Management

- ❑ Dysphagia and speech problems
- ❑ Respiratory Failure
- ❑ Pain
- ❑ Weight loss
- ❑ Constipation
- ❑ Drooling



Ethical Decision Making

- Decision making and Advance Care Planning
- PEG Insertion
- Withdrawal of NIV at end of life
- Preferred place of care at end of life



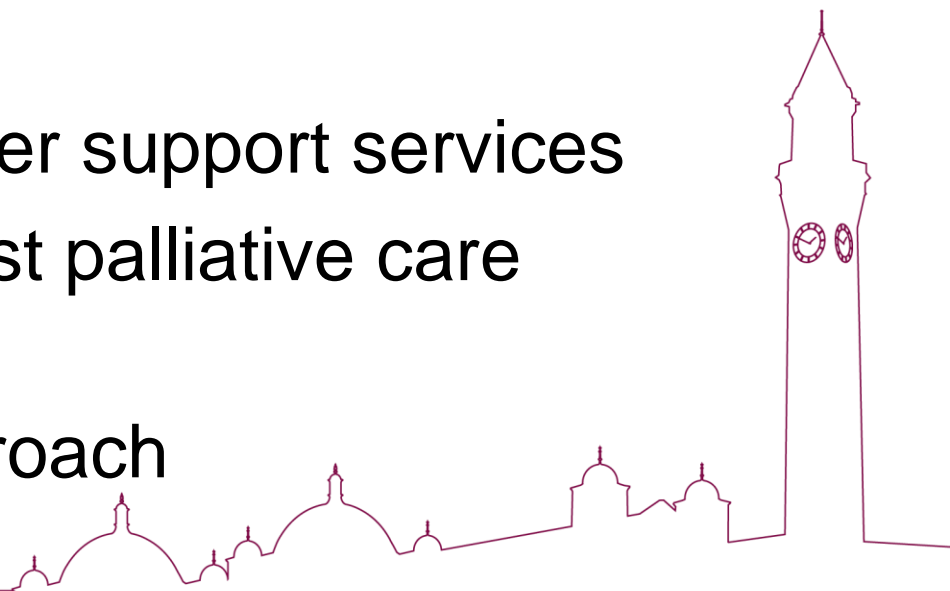
Strengths and Limitations

- Systematic review is more robust
- Potential author bias from self coding of data
- Systematic approach to enhance reproducibility
- Use of Quality Review Tool and Thematic Analysis



Recommendations

- Quality outcomes on management of diagnosis (red flags) and information provision for MND services
- Increased and timely referral to respiratory services
- Model for structured carer support services
- Early referral to specialist palliative care services
- Case management approach



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