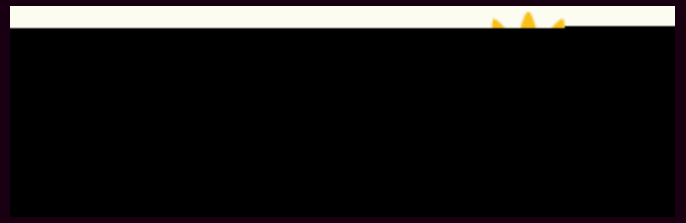
Work funded by

Undertaken in conjunction with



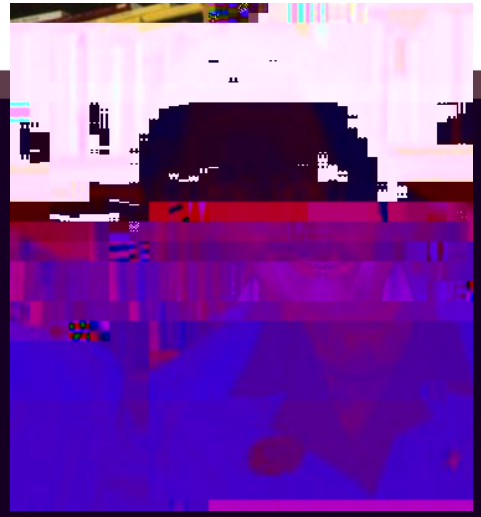
Project team

Samantha Bolscher - Expert by experience

Dr Bill Hulme – Medical Director St Leonard's Hospice

Dr Victoria Turner - Public Health Registrar

Prof Ian Watt – Professor of Primary and Community Care



“The hospice movement has largely concentrated on cancer; we need to look at other things, at what we can do for people with strokes and motor neurone disease. We need to go on learning so that in 10 years’ time we are doing things better than we are now”

Dame Cicely Saunders 2002

https://cicelysaundersinternational.org/dame-cicely-saunders/cicely-saunders-institute

MND

Motor neurone disease (MND) or Amyotrophic Lateral Sclerosis (ALS) is a neurodegenerative disease

It has a sudden onset, rapid progression and brings with it the potential for complex and disabling symptoms and care needs

It is currently without cure, with the average time between diagnosis and death being two to three years

The progression of symptoms and subsequent onset of disability are likely to occur over weeks and months rather than years.

Delays in diagnosis can count for a significant proportion of total illness duration

The need for palliative care

Up to 20% of people with MND opt for physician-hastened death in countries where this is a legal option *(Maessen et al 2009)*

People diagnosed with MND and their caregivers often fear the dying process *(Whitehead et al 2011)*

Why a systematic review?

What - A systematic review summarises the results of available good quality studies

How - Uses a systematic approach to searching for studies and the methods used to synthesise (combine) them together

Why -

Why qualitative research?

Qualitative research is a methodology that explores the perceptions and views of individuals.

Commonly used in health care to understand more about people's experiences of their situation, illness or services.

Synthesising qualitative research can help maximise the contribution of the primary qualitative studies to the evidence base for practice

What we did

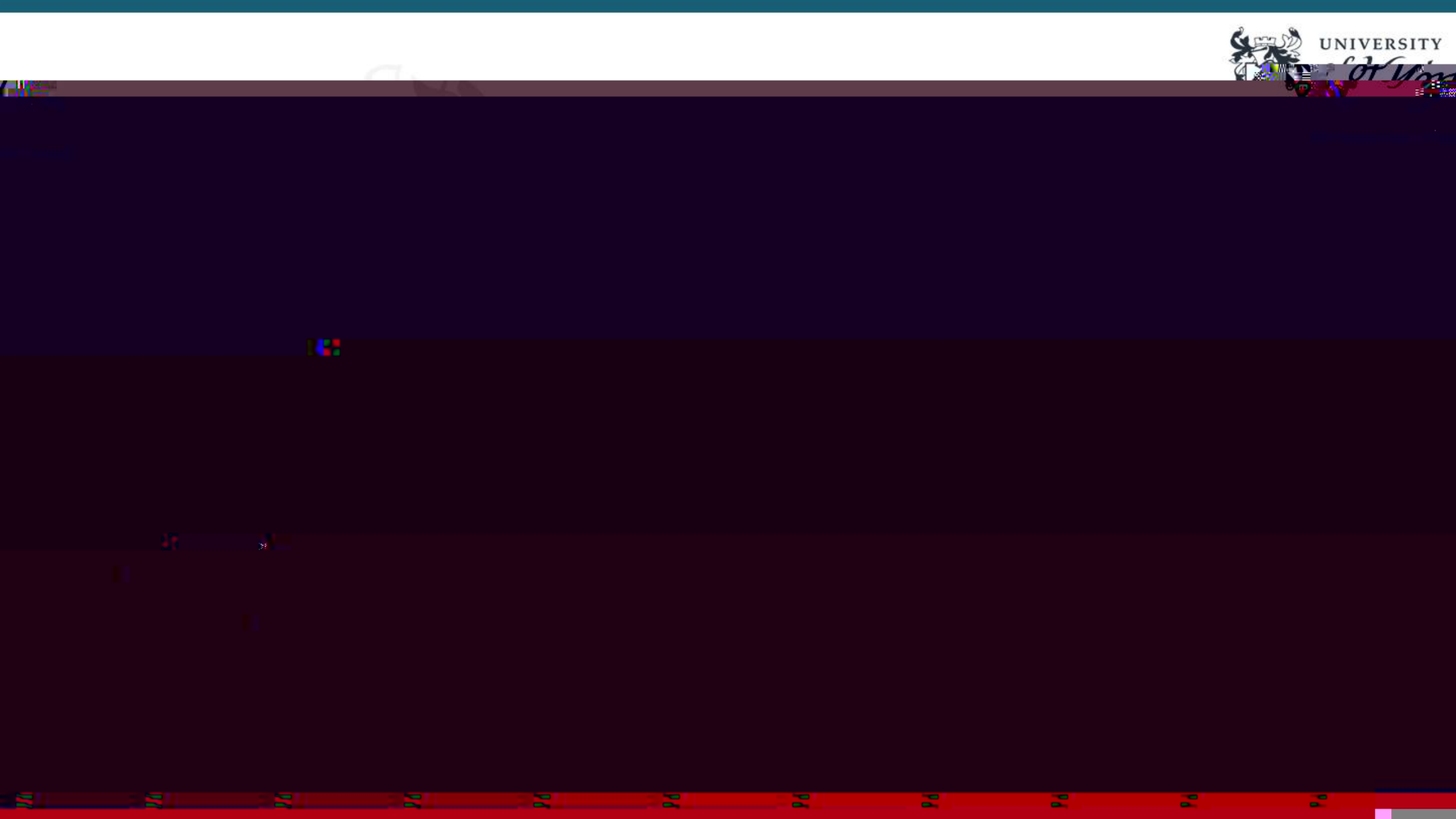
Searches were run in : CINAHL, MEDLINE, PsycINFO, Social Science Citation Index

From 403 results we included **41 papers** in the review

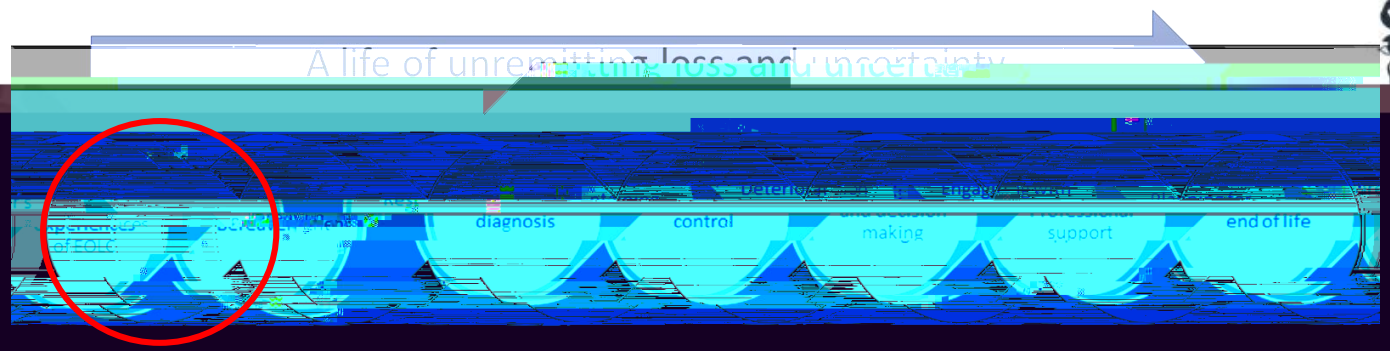
Included the views of **358 people with MND** and **369 carers**

Age range	21-85	25-86
% female	45	65
Time to diagnosis	3-60 months	-
Type of carer	-	78% partner 16% child 6% other (eg parent)
Time as a carer	-	6-96 months

International pool of papers



Diagnosis



Delays of up to 60 months

For some diagnosis came as a shock, for others it confirmed their expectations

Negative responses, including bewilderment, denial, a sense of loss and sadness

"you don't understand the news, you deny it, become very despairing"

(Bolmsjo 2001)

Diagnosis was the time-point where poor communication from HCPs was most noted

Individuals and carers stated a clear need for follow-up support immediately after the diagnosis, which was recalled as a very vulnerable time

Maintaining control

A life of unremitting loss and uncertainty

People sought to maintain control of their lives, keeping a sense of normality and purpose

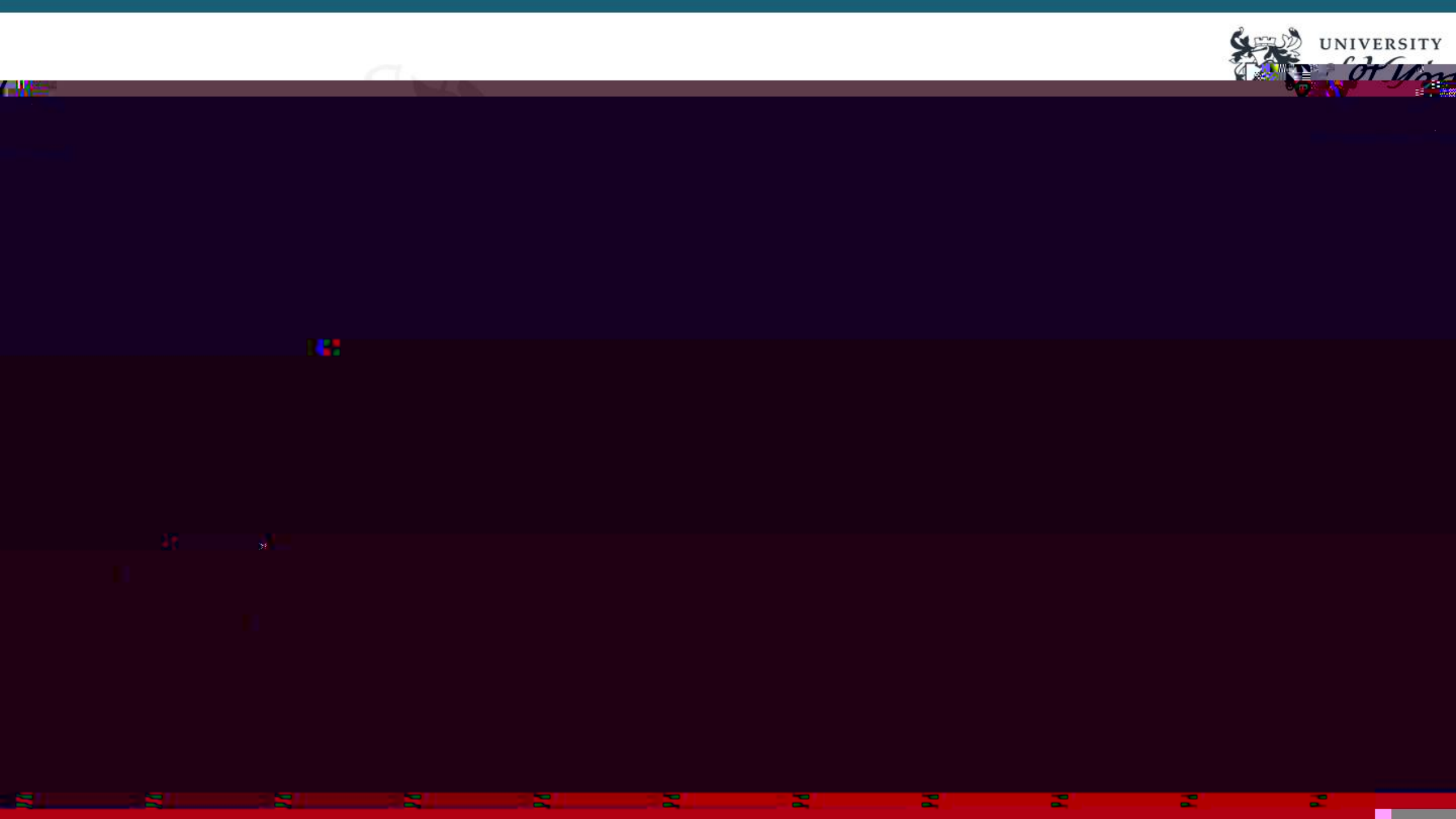
As the disease progressed, both patients and carers tried to find ways to counteract feelings of loss and uncertainty, and to find new meaning in their life

"Determination to do what I can for as long as I can, desire for independence [and a] resilient temperament." (patient)"

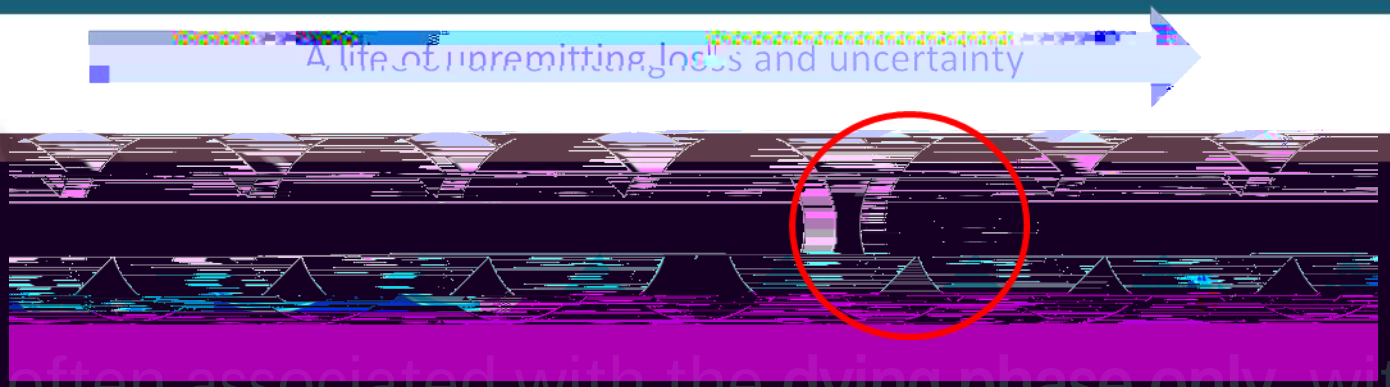
(Hogden et al 2012)

Deterioration & decision making

Deterioration and its physical, emotional and social sequelae had a significant effect on the lives of both patients and carers.



End of life



Palliative care was often associated with the **dying phase only**, with life-sustaining interventions in MND not being related to a palliative care approach

It was associated with treatments that would alleviate suffering at end of life

Assisted suicide and euthanasia were freely talked about by both patients and carers as potential options.

Such considerations were connected with a wish to die before the ‘final stage’ of the illness; both to maintain a sense of control over its timing and the extent of the suffering that would be experienced.

End of life

There is a need for information to help people make decisions regarding end-of-life care. This was commonly perceived to be lacking:

'I would like to know how it will be managed and what my choices are'

'I really do not want to die in hospital unless it is absolutely necessary'

(Whitehead et al 2011)

Discussions concerning dying or death were not common between patient and carer

'I think we were in denial for quite some while you know, we knew it was coming, but we didn't plan anything about it'

(Ray et al 2014)

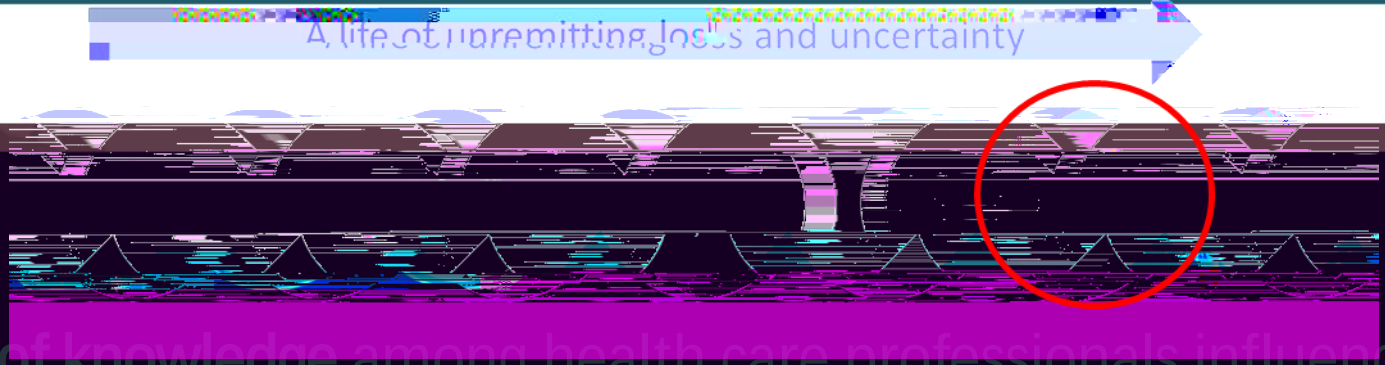
End of life

Discussions concerning dying or death were not common between patient and carer

> *'I think we were in denial for quite some while you know, we knew it was coming, but we didn't plan anything about it'*

If conversations about dying and death had occurred they were generally

Family caregivers



Serious concerns re **lack of knowledge** among health care professionals influences willingness to engage with such services and 'hand over' care

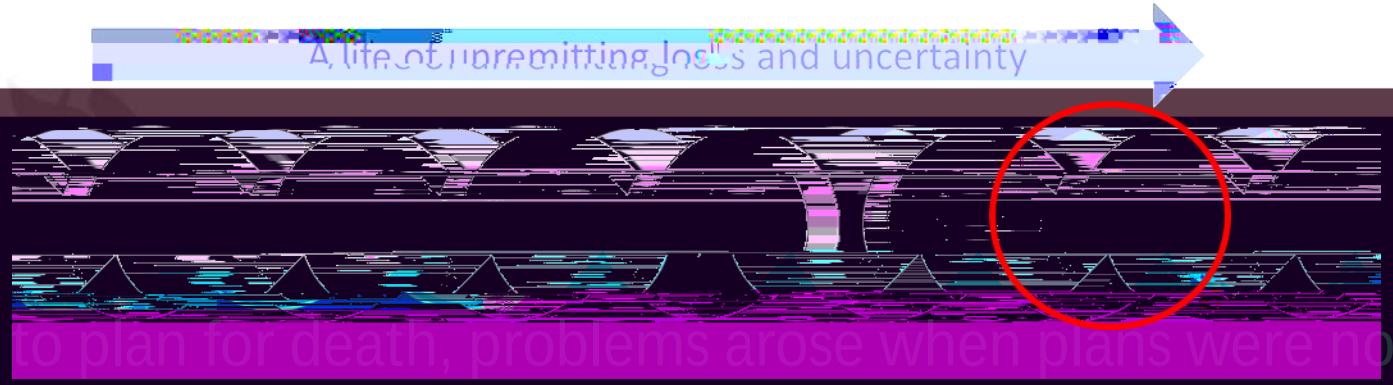
Impacts on care at the end of life - inexperience or lack knowledge from palliative care services for the needs of people with MND

> *'The last 3 weeks of my mother's life… and they made it terrible absolutely terrible, well it was horrific…through their incompetence and through their not knowing, the lack of knowledge of motor neurone…'*
>
> *(O'Brian & Preston 2015)*

Family carers struggled to find answers about the dying process; dealing with a multitude of service providers added to the confusion.

> *'I would have thought that it would be better for the whole MND process to have a single liaison person..'*
>
> *(Bentley & O'Connor 2016)*

End of life



Despite these e orts to plan for death, problems arose when plans were not communicated e ectively eg when 'not for resuscitation' orders and the caregiver's wishes were ignored:

'I couldn't [make them stop] 'stop it, don't give her artificial resuscitation' but..... That's the one disappointment; I would have loved her to go peacefully.'

Living with a neurodegenerative illness raised expectations that the person would eventually die of respiratory failure and this would be anticipated. When people with MND died, it was often sudden and traumatic for their families.

'I didn't understand that her life was in danger. Therefore, even when she was making these dreadful noises.I did not realize that this was near the end.'

(Ray et al 2014, Bentley & O'Connor 2016)

Some recommendations

- Re-framing palliative care to the point of diagnosis and ensuring prompt access
- Encouraging health professionals to initiate advance care planning early in the disease
- Preparation for the next stage of the disease trajectory should take place during the phase before, particularly in relation to the introduction of interventions
- Single point of access or a ‘key worker’ to the multi-disciplinary team and focus for all care
- The lack of knowledge among health care professionals in acute and community services of the needs of people with MND needs addressing – against the challenge of the lack of exposure to caring for people with the condition

Thank you for coming along to listen