Transforming MND Care Audit 2023

MND Team

mnda
motor neurone disease association

NHS
The Walton Centre
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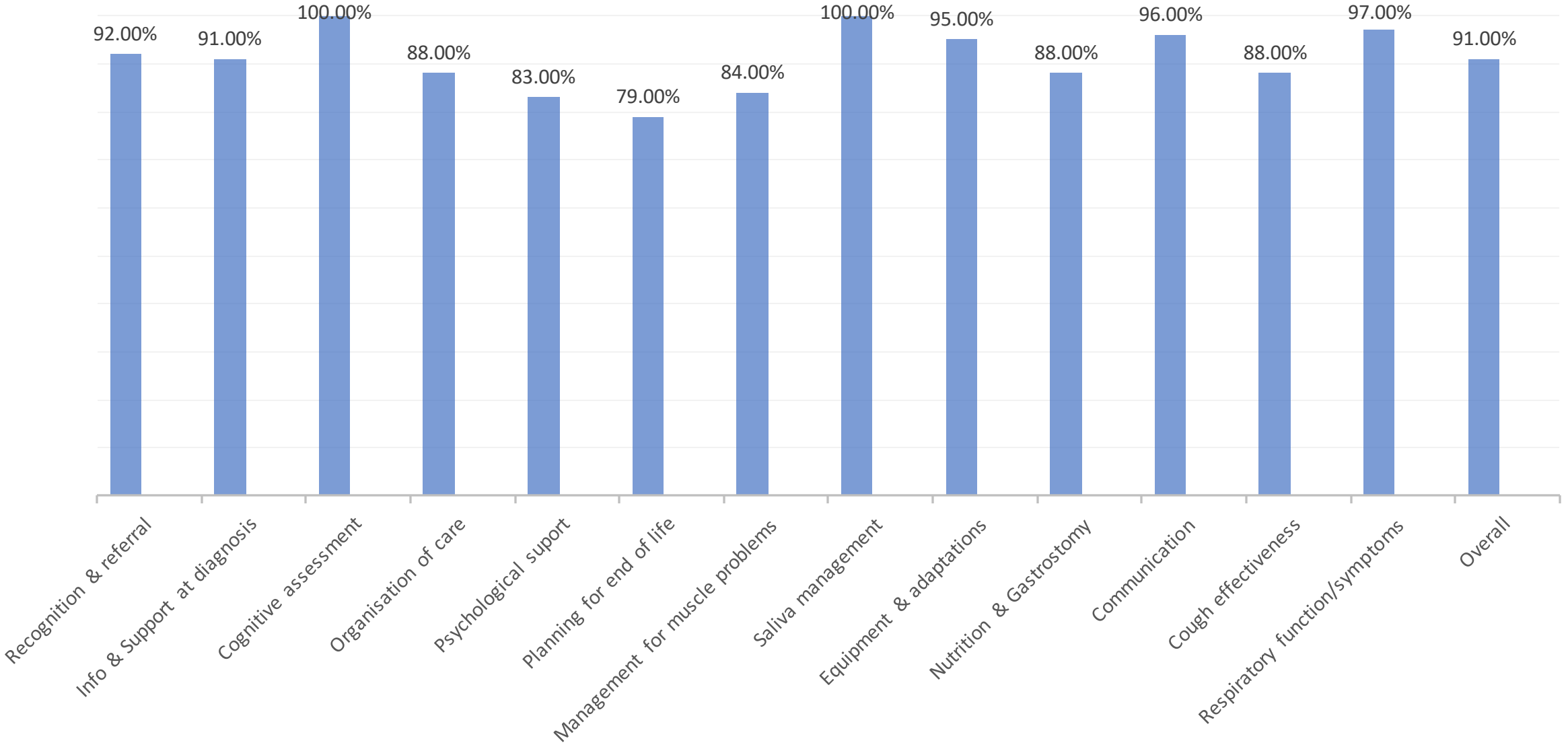
Excellence in Neuroscience

Background

- MND NICE guidelines first published in 2016, revised 2019
- The MNDA developed an audit collection tool to measure services
- MND Care Centres across the country use this tool but open to ambiguity
- Developed to evaluate services provided within our care centre
- Minimum 10% of patient caseload
- Set own criteria; diagnosis >12months

The Walton Centre - audit results by section



What do we do well

- Improved overall compliance;
  - 2019; 79%
  - 2021; 89%
  - 2023; 91%
- Cognitive assessment/Saliva management
- Improvements in; communication, cough effectiveness, respiratory assessment

What can we improve on

- **Planning for end of life**
- **Psychological support**
- **Management of muscle problems**
- **Nutrition and Gastrostomy**
- **Cough effectiveness**
- **Organisation of care**
- **Recognition & referral**

Recommendations…

- Scope palliative care services/provision
- Just in case kits/Advanced care planning
- Discuss psychology services with key stakeholders
- Mindfulness of documentation/communication
- Improved dietetic support due to new role
- Consider earlier referral for cough assessment

What next…

- Repeat
- Review
- Evaluate

Any questions?

MND mortality audit: Remarkably unremarkable

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Introduction to audit

According to NICE guidelines (2016) most people diagnosed with MND die within 2 to 3 years of developing symptoms, but 25% are alive at 5 years and 5% to 10% at 10 years. There is no known cure for MND and current treatments have been shown to increase survival by an average of only a few months (Mehta et al., 2017)

It was perceived by the team that this was possibly exceeded by patients within our care.

Due to earlier interventions and introduction of respiratory assessment based on symptoms and alternative feeding methods and the uptake of Riluzole, it was hypothesised that life expectancy is increased.

Method

The authors identified the most recent 100 patients with a diagnosis of amyotrophic lateral sclerosis (ALS) that have died under the care of our care centre. MND is known as amyotrophic lateral sclerosis (ALS) when both upper and lower motor neurons are affected

The data was collected from patients' case notes and electronic clinical records.

Data was collected as date from symptoms starting, date of diagnosis and date of death

Each patient was checked as taking Riluzole, having NIV intervention, or enteral feeding used.

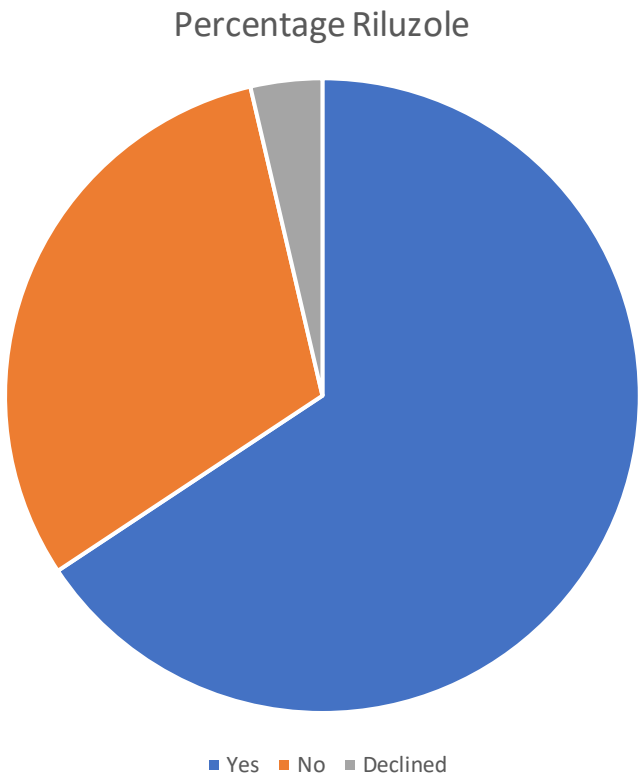
Life expectancy

Most recent 100 ALS patient deaths at Walton

Average survival post onset of symptoms 1060 days (2.9 years)

Average survival post diagnosis 664 days (1.8 years)

Riluzole 50 mg BD



Riluzole only prolongs survival by a median of 2–3 months

Results

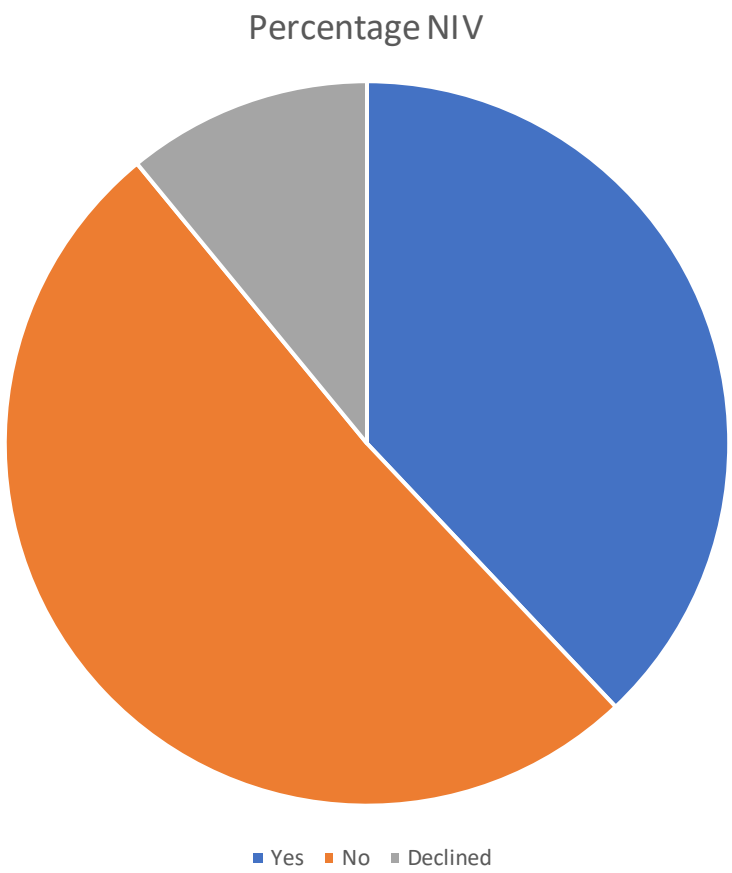
If riluzole was taken (N-73) life expectancy was 945.78 days (2.59 years)

If riluzole was not taken (N-22 + 5) life expectancy was 868.86 days (2.38 years).

Median 747 (2.04 years)days with riluzole

596 (1.63 years) days without

Non-Invasive Ventilation (NIV)



Respiratory failure and pneumonia are the most common modes of death

Results

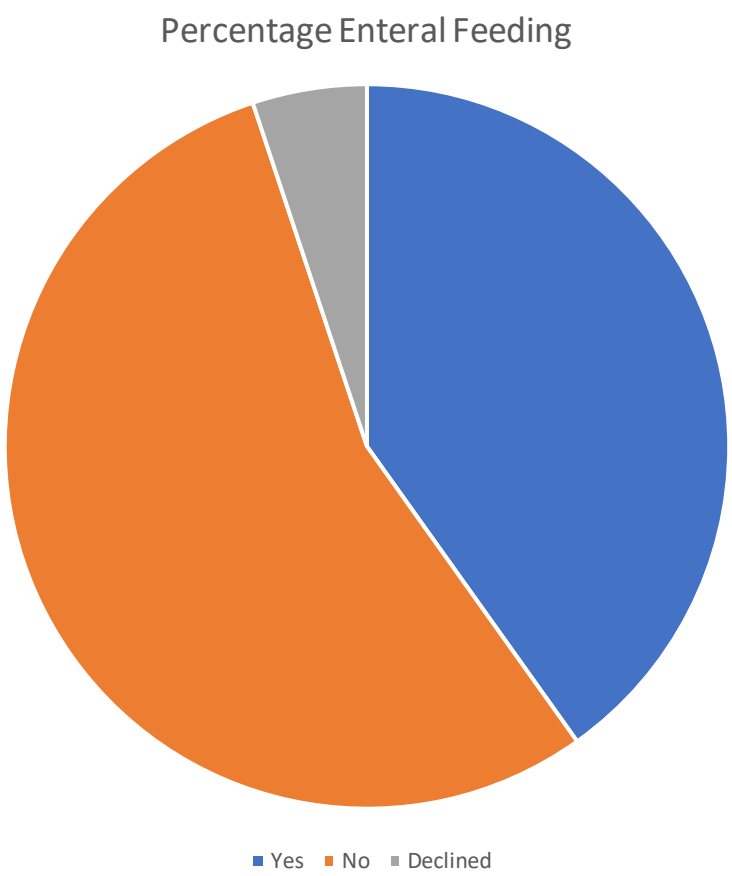
For patients that had NIV intervention (N-41) life expectancy was 1182.76 days (3.24 years)

Without NIV (N-59) 698.17 days (1.91 years)

Median 708 days (1.93 years)with NIV

664 days (1.81 years) without

Nutritional intervention



Malnutrition and consequent weight loss are significant negative prognostic indices to survival

Results

If enteral feeding was introduced (N-33) life expectancy was 1132.394 days (3.10 years)

Without enteral feeding (N-67) 829.81 days (2.27 years).

Median 739.5 days (2.02 years)with enteral feed

696 days (1.90 years)without

Discussion and reflection

Quality of life improved?

Co-morbidities

Age at diagnosis

Sex

First symptom

Social circumstances

Family/carer burden

Follow up care

Health beliefs

Timing of intervention

Trials

Side effects

Ceiling of care

MDT collaboration

Conclusion

Remarkably unremarkable, why??

The results are consistent with known MND progression and reaffirms the NICE guidelines life expectancy.

Is this due to more frequent/regular assessment?

More open and honest treatment discussions with patients?

Findings also emphasise the importance of early referral to support services and provision of disease specific resources

References

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Any Questions???