October 2021 – MND Research Article summary – Sarah Roscoe, PhD student, University of Sheffield

The nutritional care of people living with amyotrophic lateral sclerosis (ALS); a dietician’s view

The nutritional management of people living with amyotrophic lateral sclerosis: A national survey of dietitians

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**Background:** Due to the loss of muscle function, people living with ALS often experience problems cooking, bringing food to mouth and swallowing. These individuals’ may develop a state of malnutrition, which means their energy intake does not match the amount of energy used. This causes significant, irreversible and rapid weight loss, which speeds up the progression of the disease and shortens life expectancy. The reasons for this are not quite clear. However, the motor neurones that run from the brain and spinal cord to the muscle, controlling muscle function and which die during ALS may be using more energy than normal and less efficiently. Therefore, malnutrition may exacerbate abnormal motor neurone function and speed up their death.

**Why is the study important?** The successful management of malnutrition in ALS needs a clear approach used by all healthcare professionals to help the identification, analysis, intervention and monitoring procedures for people with the disease. Dietitians are part of a large and varied team who care for people living with ALS, who focus specifically on nutritional assessment and management and can play an important role in the improvement of nutritional management in the future.

There is not currently a set method to assess the nutritional status of people living with ALS. Measurements of weight and body mass index (BMI -weight in kg divided by height in metres) within the last 3-6 months were found to be the most common methods of assessment. However, there are limitations associated with these methods.

**What did the authors do and how did they do it?** In this paper the authors undertook the largest published survey that aimed to assess when and how dietitians are involved in the care of people living with ALS in the UK. To do this, a survey of 109 questions was sent to dietitians across the UK aimed at identifying dietitians’ views and practice with regard to the nutritional management of ALS.


281 health professionals responded to this survey, and 130 of those answers were analysed as part of this study. Of those who responded, 87% of dietitians were currently providing care to people living with ALS.
What are the results?

Weight measurements are largely impractical for people with mobility issues. However, 82% of dieticians reported the ability to weigh patients who were unable to stand using a range of scales such as wheelchair and hoist scales.

In order to assess someone’s nutritional state, it is important to understand how much food and fluid is consumed, as well as how much energy is used in day-to-day life. 89% of dietitians asked people to recall their food and fluid intake from memory, whilst 5% asked their patients to complete a ‘real-time’ diet diary. From this information, 99% of dietitians manually estimated the nutritional content of these intakes, with only 23% using analysis resources. The reliance on memory for both the recall of food and fluid, as well as the calculation of nutritional content introduces the possibility of error, and may cause an underestimation of the amount of calories consumed.

83% of dieticians reported that they used mathematical energy prediction formulas to predict the amount of energy used by people; however, these formulas have not been proven to be reliable for people living with ALS, due to factors associated with the disease that may interfere with these calculations such as higher neuronal energy states described in the background section or trouble breathing which can also influence energy use.

What do the finding mean going forward for people with ALS?

It is vital to identify people who might be experiencing problems with their nutrition as early as possible.

Whilst 99% of hospitals report having the facilities to assess nutritional state, only 42% of dietitians stated the use of a screening process at their place of work to identify people living with ALS who were most at risk of becoming malnourished. This must improve.

Within the 42% who did report nutritional screening, the most commonly used method was the ‘Malnutrition Universal Screening Tool’ (also known as ‘MUST’). This tool has previously been demonstrated to identify 90% of people living with ALS who are at risk of becoming malnourished. Despite this information, only 52% of dietitians report the use of MUST at the time of diagnosis, this must improve.

Despite the importance of nutritional management in the care of people living with ALS, only 19% of dietitians reported that people living with ALS had been referred to them at the time of diagnosis. By contrast, 44% of dietitians reported that people living with ALS were only referred to them for dietetic care when there was an apparent decline in nutritional state, either after referral from speech and language therapists - due to unsafe swallowing - notable weight loss, or an observed decrease in food and fluid intake. Again, 44% of dietitians reported that these referrals were too late to prevent irreversible malnutrition and weight loss.

Dietitians are experts who are qualified in the nutritional management of people at risk of disease related malnutrition such as ALS. They should be involved early in the diagnosis process, this involvement should be centred around a consistent and systematic approach to monitor and support the nutritional needs of people with ALS.