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Patient, carer and healthcare professional perspectives on increasing calorie intake in Amyotrophic Lateral Sclerosis

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Abstract

Objectives:

Research suggests that higher Body Mass Index is associated with improved survival in people with Amyotrophic Lateral Sclerosis (pwALS). Yet, understanding of the barriers and enablers to increasing calorie intake is limited. This study sought to explore these issues from the perspective of pwALS, informal carers, and healthcare professionals.

Methods:

Interviews with 18 pwALS and 16 informal carers, and focus groups with 51 healthcare professionals. Data were analysed using template analysis and mapped to the COM-B model and Theoretical Domains Framework (TDF).

Results:

All three COM-B components (Capability, Opportunity and Motivation) are important to achieving high calorie diets in pwALS. Eleven TDF domains were identified: Physical skills (ALS symptoms); Knowledge (about high calorie diets and healthy eating); Memory, attention, and decision processes (reflecting cognitive difficulties); Environmental context/resources (availability of informal and formal carers); Social influences (social aspects of eating); Beliefs about consequences (healthy eating versus high calorie diets); Identity (interest in health lifestyles); Goals (sense of control); Reinforcement (eating habits); and Optimism and Emotion (low mood, poor appetite).

Discussion:

To promote high calorie diets for pwALS, greater clarity around the rationale and content of recommended diets is needed. Interventions should be tailored to patient symptoms, preferences, motivations, and opportunities.

Keywords: Amyotrophic Lateral Sclerosis; Motor Neuron Disease; Dietetics; Qualitative Research; Behaviour Change.

Introduction

Amyotrophic lateral sclerosis (ALS), also commonly known as motor neuron disease (MND)ⁱ, is a devastating neurodegenerative disorder characterised by the loss of motor neurons, which causes progressive paralysis and eventually death¹. Onset is typically focal (limb, bulbar, or respiratory), later spreading elsewhere in the body. Since there is no cure for ALS, treatment focuses on slowing progression and managing symptoms, including malnutrition and weight loss². When the muscles involved in swallowing are affected, it can become difficult for people with ALS (pwALS) to eat and drink enough to sustain adequate nutritional intake, thereby placing them at high risk of developing malnutrition². These issues are also exacerbated by hyper-metabolism³, with resting energy expenditure being on average 20% higher than in healthy individuals⁴.

Weight loss at diagnosis is a negative prognostic indicator in ALS, and nutritional parameters typically worsen with disease progression⁵. A population based study found that two thirds of pwALS presented with weight loss at diagnosis, with the risk of death increasing by 23% for every 10% increase in weight loss⁶. Similarly, a recent systematic review has shown that having a higher Body Mass Index (BMI) at diagnosis is associated with greater long-term survival in pwALS⁷. Another study showed that, among pwALS whose BMI had decreased by more than 2 points per year after diagnosis, only 10% were still alive after two years, while 60% of those whose weight had decreased by 2 points or less (or remained unchanged or increased) were still alive. These findings suggest that weight loss before or after diagnosis with ALS, is associated with shorter survival.

Therefore, increasing weight through modifying behaviours that maximise calorie intake is potentially a key therapeutic goal for healthcare professionals (HCPs) treating pwALS, particularly in the early stages of the disease. With regard to this, the use of high-calorie fatty diets in pwALS was recently tested in a placebo-controlled RCT⁸, but there was no significant effect on weight loss or survival. However, post hoc analysis and further analysis of neurofilament light chains levels in study blood samples have suggested a survival and biological effect of a high-caloric fatty diet on pwALS with fast progressing disease⁹. Another study evaluating support from a dietician or an mHealth app did not result in any

ⁱ ALS is the internationally recognised term for this disease, but Motor Neuron Disease (MND) is the preferred term in the UK. ALS is one type of MND. ALS is applied in this paper except where MND is used by participants or to refer to services.

significant differences in weight changes compared to standard care¹⁰. These mixed results may be due to the oral nutritional interventions not being tailored to patients, as well as low adherence, high drop-out and study design. Thus, further research examining the psychosocial and physical barriers and enablers to increasing calorie intake in pwALS is needed to develop more effective interventions.

In addition, previous research on nutrition in ALS has mostly focussed on problems resulting from dysphagia¹¹ or enteral feeding¹², as opposed to addressing issues with oral nutritional interventions ('food first approach') which typically comes before enteral feeding¹³. One qualitative study has investigated psychosocial issues related to dysphagia for pwALS from the caregiver perspective¹⁴, reporting how dysphagia can change mealtime experiences of caregivers and pwALS due to fear of choking, frustration with being unable to prevent weight loss, use of avoidance as a coping strategy, and a desire to maintain normality. Another qualitative study explored the psychological factors influencing nutritional management of pwALS from the HCP perspective¹⁵. This emphasised the importance of ALS-specific knowledge of nutrition, psychosocial aspects of eating and drinking, early engagement and psychological adjustment, as well as promoting perceived control over decision-making. However, these previous studies have not considered the views of patients and how they may differ to those of carers and HCPs.

Consequently, the present study aimed to provide a more comprehensive understanding of the barriers and enablers to high calorie diets in ALS, from the perspectives of pwALS, caregivers and HCPs. In addition, the present study sought to draw on the COM-B (Capability, Opportunity, Motivation, Behaviour) model of behaviour change¹⁶ as an overarching theoretical framework to interpret the key barriers and enablers. The COM-B model proposes that behaviour change is driven by a person's Capability (psychological or physical capability to enact a behaviour), Opportunity (the physical or social environment that enables or inhibits behaviour), and Motivation (reflective or automatic mechanisms that guide behaviour). The model has been used to identify barriers and enablers to a wide range of health-related behaviours, including physical activity in overweight and obese pregnant women¹⁷ and various studies looking at nutritional behaviours¹⁸⁻²⁰. The Theoretical Domains Framework (TDF)²¹ represents an elaboration of the COM-B components into 14 domains, each reflecting a different influence on behaviour: (1) knowledge, (2) skills, (3) social/professional role and identity, (4) beliefs about capabilities, (5) optimism, (6) beliefs

about consequences, (7) reinforcement, (8) intentions, (9) goals, (10) memory, attention, and decision processes, (11) environmental context and resources, (12) social influences, (13) emotion, and (14) behavioural regulation. Together, the COM-B and the TDF provide a theoretical framework to understanding factors that could be targeted in oral nutritional interventions to promote increased calorie intake in pwALS. The adoption of these frameworks was deemed important in light of their successful implementation in previous research around nutritional behaviours in several populations¹⁸⁻²⁰, as well as to facilitate the development of a new intervention to support increased calorie intake by people with ALS.

Methods

Setting and design

A multi-centre qualitative study was carried out in eight MND centres in secondary care National Health Service (NHS) hospitals in the UK. HCPs from all centres took part in focus groups, while patient and carers were recruited from five of these centres for individual or joint interviews.

Eligibility criteria

HCPs involved in nutritional management of pwALS were eligible to take part, including medics, specialist nurses, dietitians, speech and language therapists (SLTs), physiotherapists, occupational therapists (OTs), and psychologists. Patients were eligible to participate if they were aged 18 years or over and had received a diagnosis of ALS. Additional inclusion criteria included the progressive muscular atrophy variant where appropriate investigation excluded mimics of ALS, clinician judgement indicating suitability of patient to take part, and capacity to give informed consent and fluency in English. Patient exclusion criteria were: co-morbidity that would affect survival or metabolic state (e.g., unstable thyroid disease or diabetes mellitus) and BMI $\geq 35\text{kg/m}^2$. Anyone acting as one of the main carers for pwALS was eligible to participate.

Sampling technique

The eight NHS MND centres were sampled purposively based on geographical location, hospital size, and service configuration. Within each centre, individual staff were recruited for focus groups (FGs) using convenience sampling to reflect team composition, staff availability, and willingness to participate. Where feasible, the objective was to achieve

representation from all clinical disciplines present in local teams, with up to a maximum of eight participants in each FG. Patients were sampled purposively from five of these centres to capture variation in terms of age, gender, time since diagnosis, carer presence, stage of the disease, and presence of eating and drinking difficulties.

Recruitment

Local gatekeepers in each centre made the initial approach to HCPs by introducing the study during a staff meeting or via email. Staff members could opt-in by contacting the research team directly or providing consent for the gatekeeper to pass on contact details. The research team then contacted all volunteers to provide them with more study information and FG logistics.

Clinical staff from participating centres identified and recruited patients via current caseloads, clinics, and local advertising. Patients were asked to opt-in by contacting the research team directly or giving consent for the clinical team to pass on contact details. Members of the research team then contacted potential participants to provide more information and confirm eligibility. Following confirmation of eligibility and based on the purposive sampling strategy, patients and carers were contacted to organise a mutually convenient time and place for the interview. Where participants had significant communication difficulties, they were sent a communication support plan to complete, to ensure that they were adequately supported during interviews. A simplified version of the interview schedule was also sent to all participants beforehand ²².

Ethics

Ethical approval for this study was granted by the North West – Greater Manchester East NHS Research Ethics Committee (ref: 18/NW/0638), and governance approval was granted by the Health Research Authority (ref: 250732). Access to research sites was granted via local NHS Research and Development departments. All participants provided informed consent to take part.

Participants and procedure

In total, 51 HCPs took part in eight FGs that were conducted across the eight MND centres (see Table 1). The number of participants in each FG varied from five to nine, and the composition of each varied in line with local team membership and their availability to

participate. Discussions were completed face-to-face on NHS property sites convenient to participants. The median length of the focus groups was 62 minutes (58-75 minutes). See details of FG discussion guide in Supplementary Material 1.

Thirty-four pwALS and carers were interviewed, comprising 20 individual interviews (eleven patients and nine carers) and seven joint interviews. These took place face-to-face at their homes or on hospital premises. The median length was 40 minutes (25-60 minutes) for individual interviews and 71 minutes (59-81 minutes) for joint ones. Details of the interview schedule are in Supplementary Material 2. The recruitment flow chart is provided in Supplementary Material 3.

Table 2 outlines the demographic and nutritional characteristics of pwALS ($n=18$). Sixty-one percent of participants were male, median 67 years old, and generally in their second year post-diagnosis. Two-thirds (67%) of patients reported limb onset ALS, 61% reported dysphagia and 28% reported placement of an enteral feeding (PEG: percutaneous endoscopic gastronomy) tube, although all patients were still able to take food by mouth. The majority reported reasonably good mobility (61%). Participants' median BMI was $25\text{kg}/\text{m}^2$, and there was a fairly even split between those with stable weight and those who experienced weight loss or gain. Most participants had received some nutritional advice, could still eat until they were satisfied, and felt that they took longer to finish their meals since diagnosis. Around half of participants reported modifying their food texture and fewer followed an enriched diet.

All data were collected between 11 December 2018 and 7 March 2019. Data collection stopped when data saturation was reached. All interviews and focus groups were conducted by NZ, IW and EC, were recorded using a digitally encrypted recording device, and transcribed verbatim.

Data analysis Data were analysed with a template analysis approach²³, using NVivo® software to support data processing. For the purposes of analysis, the dataset was divided into (1) FGs with HCPs and (2) patient and carer individual and dyad interviews. The template analysis was completed by EC, NZ and IW, following the six key stages, i.e., (1) familiarisation with the datasets by reviewing all the transcripts; (2) identifying preliminary codes in the data and (3) organising them into hierarchy or structure, and then using this to (4) develop an initial coding template, which was then (5) applied to the dataset and

developed iteratively to lead to the last stage (6) where the template was finalised and applied across the dataset.

Following completion of the template analysis and identification of codes for both datasets, the codes were deductively mapped to the TDF²¹ and COM-B model²⁴ by PN (and double mapped by EC) to help structure the interpretation of the identified barriers and enablers.

Results

Fifty-three codes regarding barriers and enablers to increasing calorie intake in pwALS emerged from both datasets (Table 3). These are presented below, structured around the COM-B model components and TDF domains. Specific codes are highlighted in *italics* and illustrated with quotes from HCPs, pwALS (P) and carers (C) given in Supplementary Material 4.

Physical Capability

Physical skills and disease characteristics

A number of physical changes were identified by pwALS, carers, and HCPs as barriers to increasing calorie intake. These included *swallowing difficulties (dysphagia)* causing difficulties with particular food textures; *breathing difficulties* which may increase the risk of *aspiration or choking*; *general muscle weakness, fatigue* and *reduced mobility*, which can affect the *conduct of everyday nutritional behaviours*, such as shopping, cooking, handling cutlery, eating, or sitting upright. Other physical changes included excessive *salivation and secretions*, *chewing difficulties*, issues with *lip seal*, *loss of sense of taste*, *weight loss* and *body shape changes*.

HCPs consistently highlighted the *heterogeneous nature of the physical changes caused by ALS*. This reflects the characteristics of different disease onsets, but also the heterogeneity of symptoms and disease course, which can exacerbate the challenge of initiating nutritional interventions in a timely fashion.

Psychological Capability

Knowledge

Patients' and carers' knowledge about food and nutritional behaviours served as both a barrier and enabler to increasing calorie intake of pwALS, with the contrast between individual *knowledge of healthy eating* and *ALS recommended diets* being difficult for many to reconcile.

This was more of an issue for those participants with a greater interest in healthy lifestyles (see 'Reflective Motivation'). For others, there was a willingness to increase the calorie value of their diets in line with HCP advice, albeit amidst confusion about the appropriateness of this approach. HCPs consistently demonstrated their knowledge of the potential benefit of

high-calorie diets for pwALS, and explained the rationale for this approach, relating it to their knowledge of current research.

In contrast, some HCPs critiqued the evidence and, despite their support for increasing calories, they were keen to convey both its strengths and weaknesses during patient consultations. Related to this, HCPs reported a general *lack of guidance* specific to the nutritional management of pwALS. Although NICE guidelines (both MND care and nutrition support) and MND Association standards for care were mentioned, many HCPs still relied on professional experience to inform practice. Whilst HCPs were typically confident about their level of expertise, not directly identifying this as a barrier, the differences in care caused by a lack of clear guidance were acknowledged (see ‘Physical Opportunity’), especially in terms of addressing potential unhelpful beliefs.

Memory, attention and decision processes

Another challenge identified by HCPs related to *cognitive difficulties* affecting some patients’ *capacity to comprehend* dietetic advice alongside all of the other healthcare advice imparted to them, particularly if they are *overwhelmed at diagnosis*. HCPs were conscious of how overwhelming the time post-diagnosis can be, and the challenges of educating patients about high-calorie diets when their priorities may lie elsewhere.

Physical Opportunity

Environmental context/resources

The *presence of informal carers* (partners, family members, friends) was another important enabler of nutritional behaviours identified by HCPs, pwALS, and carers themselves. Where available, support from informal carers was important to the *availability of food* and conduct of shopping, cooking and eating, although this sometimes came at the cost of carer burden (see ‘Automatic Motivation’). As a potential solution for some patients, *formal carers* (including visiting care assistants, nurses, or live-in carers) provided other essential sources of support.

However, for pwALS who did not have access to family or peer support, and for whom formal care or living in a care home are the only options, the caring experience may vary

considerably based on income or financial availability, especially in terms of control over nutritional choices.

More generally, some pwALS and their carers also highlighted the importance of a wider *peer support network* and how this can help facilitate oral nutritional behaviours.

Notwithstanding the difficulties posed by the contrast between healthy eating and ALS dietary advice, the *availability of healthcare professional advice and support* was key to promoting or impeding behaviours to increase calorie intake. Some patients reported that they had not received any advice or were unable to recall this, and that they felt unsupported. This issue was corroborated by HCPs, who recognised the challenges of delivering timely, person-centred nutritional care within a ‘window of opportunity’ (FG3, FG4), given the speed of deterioration of ALS: an issue which was compounded in those centres with inadequate funding for staff time. This issue was exacerbated by the time-consuming nature of ALS care, for which a typical appointment duration was described as insufficient.

HCPs also identified several other issues that *impede continuity of care* and create *geographical variation* in services offered. These included inconsistent team composition (absence of dietitian), variation in funding available for nutritional management interventions (adaptive cutlery, oral nutritional supplements), limited specialist knowledge beyond the multi-disciplinary team (e.g., non-specialist neurological departments, GPs or community services), or the presence of special interest in ALS by staff, which could act as both a strength and limitation of teams. The passion and commitment to ALS of some HCPs was duly recognised, but so was the vulnerability of the staffing arrangement.

Social Opportunity

Social influences

Corresponding with their availability, the *influence of informal or formal carers* was another major influence (both positive and negative) on nutritional behaviours identified by all participants. Specifically, the wider *peer support network* was identified as a facilitator of social opportunities for eating and drinking by pwALS and carers.

More generally, the *social aspects of eating* and drinking, such as socialising, eating together as families or visiting restaurants and cafes were highlighted during all FGs. HCPs spoke about the loss they see for pwALS and their families as the disease progresses. Carers and pwALS also explained how disease progression can hamper the *social aspects* of eating, such as meal sharing or eating out.

The influence of *health professional advice and support* was also key for pwALS, despite varied levels of receptivity and acceptance of the diagnosis (see ‘Reflective Motivation’). Adopting a proactive approach to nutrition was often described by HCPs as another enabling aspect of *patient-centred care* for pwALS. This included the chance to offer dietetic and speech and language therapy advice before developing problems with eating and drinking, as well as undertaking frequent home visits and sharing insights across the Multi-Disciplinary Team. Introducing ideas proactively and sensitively was believed to provide a platform for future care discussions when patients might be more ready to make changes to nutritional behaviours. Correspondingly, most HCPs spoke about the facilitative value of *building relationships with patients* and their families to help understand priorities as well as promoting patient choice and compromise.

Reflective Motivation

Beliefs about consequences

A major aspect which could enable or inhibit changes to nutritional behaviours was differing *beliefs about healthy eating versus high calorie diets* to promote good health. These were largely in line with the knowledge of pwALS, their carers, and HCPs (see ‘Psychological Capability’). However, when in conflict, reconciling them could prove challenging, making it difficult for pwALS and their carers to adopt higher calorie diets.

Identity and goals

Increasing calorie intake was often seen as problematic for those pwALS who used to be very active and for whom living a *‘healthy lifestyle’* and meeting desired *body weight goals* was previously an important part of their identity.

HCPs also reported a range of patient responses to being encouraged to consume more calories, from the positive, to the confused or resistant, and they related this to patients' perspectives on *healthy lifestyles*.

Despite some positive feedback of promoting high calorie diets, HCPs in each FG also spoke about the challenges of encouraging *adherence* to high-calorie diets by pwALS who have strong beliefs about *healthy lifestyles*. They also spoke about the facilitative potential of *patient choice and compromise* by working closely with them to understand their *priorities*, knowledge, and beliefs about food.

Many patients and carers were keen to express their *receptivity to advice* and support from HCPs, but this varied considerably among participants. The contrast between 'healthy eating' and high calorie dietary advice for pwALS, or the absence of regular or timely support, were influential factors.

Another theme related to pwALS' *acceptance of the ALS diagnosis* and lack of psychological adjustment to the need to change nutritional behaviours, which presented a potential barrier to achieving a high calorie diet. Conversely, others talked about feelings of *control* and *independence*, and how exercising agency or decisional input over some aspects of nutrition may be an empowering experience, at least whilst they were still able to maintain their independence.

Optimism

Levels of *optimism* about the diagnosis and the future also influenced how pwALS approached their nutritional management. For example, where pwALS approached their illness in a more positive way or were more accepting of their condition, they were typically more keen to make changes to their diets, and vice versa.

Automatic Motivation

Reinforcement

Eating habits and routines relating to food choices and household roles in shopping and cooking were other influences on the nutritional behaviours of pwALS. Food preferences can be very difficult to change in line with dietary advice as the disease progresses, as this can affect the whole household. Many participants described changes to roles in the maintenance

of food-related activities which could prove challenging to both the pwALS and carer, regardless of their domestic roles pre-diagnosis. Relinquishing responsibility for shopping and cooking could be upsetting to pwALS regardless of gender, as well as a source of tension in relationships.

Emotion

The physical changes that pwALS experience can also impact on *appetite and thirst*, and impede efforts to maintain a high calorie intake. Physical symptoms also impacted on the *enjoyment of food and drinks*. Although many pwALS were able to continue eating and drinking as usual, others found this less enjoyable over time, and this was a source of loss.

Some participants also talked about feelings of *resistance and denial*, from both patients and carers, which could interfere with increasing calorie intake. HCPs also noted how challenging it can be to engage more resistant individuals.

Low mood, coupled with the *embarrassment* of challenges with eating or drinking in public or social settings was identified as another barrier to achieving high calorie diets.

Finally, emotional responses from spouses, family members, and friends – and the *carer burden* of providing long-term support to pwALS – were also mentioned as barriers to changing eating behaviours. More specifically, asking pwALS to change their dietary intake and seeing the person deteriorate can place a substantial burden on informal carers, triggering low mood or anxiety, which in turn could limit their capacity to support changes to food and drink.

Discussion

Summary of main findings

This study identified a complex range of factors that influence the uptake of high calorie diets among pwALS. To our knowledge, this is the first qualitative investigation to specifically triangulate explore the views of pwALS, carers, and HCPs on high calorie diets in ALS. The use of the COM-B model²⁴ and TDF²¹ was helpful in structuring the analysis and interpretation of barriers and enablers. To achieve high-calorie diets for pwALS, the analysis highlighted the need to address all three COM-B components and 11 TDF domains.

In relation to the ‘Capability - Physical’ component, many physical symptoms associated with the progression of ALS affect people’s eating and drinking capabilities over time. In line with evidence documenting the risks of weight loss in ALS⁷, most current research has focussed upon clinical management of these symptoms, including dysphagia¹¹ or enteral feeding¹². Whilst it is important not to diminish the impact of the physical progression of the disease, our analysis also highlighted the importance of social and psychological influences on eating and drinking behaviours in ALS.

The ‘Capability – Psychological’ component captured the importance of knowledge about healthy eating and high calorie diets. Whilst some pwALS were keen to increase their intake as they enjoyed calorie-dense foods, others struggled to make those changes due to concerns about the impact on general physical health, influenced by pre-existing views about healthy eating. Despite some evidence that high calorie diets may be beneficial, along with considerable support for this approach amongst HCPs in this study, the limits of the evidence base and a lack of specific supporting guidance represents a challenge for current practice. This finding is consistent with recent evidence charting the provision of ALS nutritional management with HCPs^{15,25}.

Within the ‘Opportunity – Physical’ and ‘Opportunity – Social’ components, the availability and influence of both formal healthcare provision and informal caring networks were highlighted. A lack of care continuity and geographical variation, and the facilitative power of person-centred care, have also previously been documented in a survey of ALS HCPs²⁶. The importance of case management in ALS has also recently been highlighted^{27,28}. Similarly, the significant role played by informal carers in ALS is well documented^{29,30}, but our study sheds light on how they contribute in relation to eating and drinking.

Considering the ‘Motivation – Reflective’ and ‘Motivation – Automatic’ components, this study also identified a number of psychological factors. These included beliefs about healthy eating and high-calorie diets, the varied importance of pre-diagnosis identity and lifestyle, as well as adjustment to diagnosis and engagement with healthcare interventions. Moreover, pwALS, their carers, and HCPs drew attention to the impact of different goals, levels of optimism, existing habits, and routines on behaviour. Finally, a number of emotional barriers to changing behaviour, such as emotional burden upon carers and low mood, resistance, denial, and embarrassment amongst pwALS were documented. Whilst new within the context of psychosocial issues related to eating and drinking, these findings are consistent with previous evidence on the general impact of dysphagia in pwALS^{14,15}. Likewise, there is a body of work which considers the psychological burden of ALS on both people with the disease and carers³⁰.

Strengths and limitations

This is the first study to provide an in-depth exploration of the barriers and enablers to increasing calorie intake in pwALS within a relatively large qualitative sample of patients, carers, and HCPs in the UK. This will aid the development of effective interventions to prevent weight loss and potentially increase survival in pwALS.

Nonetheless, this study has some limitations. In particular, the self-selecting sample may have introduced some biases. It is possible that we have not accurately captured the impact of some aspects, such as patient shock at diagnosis and disengagement from healthcare provision, as those pwALS are unlikely to participate in research. Nonetheless, participants highlighted a wide range of factors affecting dietary behaviour. Moreover, the insights of HCPs, who spoke at length about the challenges of changing eating behaviour in resistant or disengaged patients, may also give confidence that a full range of important barriers were identified (notwithstanding the possibility that disengaged patients may have different views about these issues to HCPs). Finally, while it is possible that we mainly captured the perspectives of the HCPs most engaged with ALS nutritional care, as the HCPs were self-selecting, we nonetheless recruited a broadly representative sample of staff involved in the nutritional management of pwALS

Implications for clinical practice

Our results clearly outline the need for nutritional management interventions for pwALS which can be tailored in order to accommodate differing symptoms, knowledge, beliefs, and nutritional preferences, as well as the environmental contexts/resources and social influences at play. In tailoring interventions, HCPs must also consider where pwALS are psychologically – in terms of acceptance of the diagnosis, adjustment to symptoms, and other emotional responses³¹ – because, without this wider perspective, our findings suggest that the effectiveness of interventions will be restricted. Future research should therefore focus on developing and evaluating complex interventions that are able to address the wide range of barriers in the oral nutritional management of pwALS. We believe our findings provide a valuable starting point in this direction.

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Table 1*Number and specialism of focus group attendees*

Focus group	Specialism attended									
	Participants	Doctor	Nurse	Dietitian	Speech and Language Therapist	Occupational Therapist	Physiotherapist	Community Outreach	Psychology	Care Co-ordinator
1	7	1	1	1	1	1	0	1	1	1
2	7	1	3	1	1	0	1	0	0	0
3	9	1	1	3	2	1	0	0	0	1
4	6	0	1	4	1	0	0	0	0	0
5	5	3	1	1	0	0	0	0	0	0
6	6	0	2	2	0	0	1	0	0	1
7	5	0	0	1	1	1	0	0	0	1
8	6	2	1	2	0	0	0	0	0	1
Total	51	8	10	15	6	3	2	1	1	5

Table 2***Demographic and nutritional characteristics of patients (N=18)***

Characteristic	Value
Median age (min-max)	67.0 (40.0-75.0)
Female N (%)	7 (38.9)
Median months since diagnosis (min-max)	17.0 (11.0-84.0)
ALS onset N (%)	
<i>Limb</i>	12 (66.7%)
<i>Bulbar</i>	6 (33.3%)
Reported dysphagia N (%)	11 (61.1%)
PEG placement N (%)	5 (27.8%)
Reported comorbidities N (%)	3 (16.7)
Reported mobility N (%)	
<i>Good</i>	11 (61.1)
<i>Average</i>	3 (16.6)
<i>Poor</i>	4 (22.2)
Median Body Mass Index (min-max)	24.7 (15.70-28.0)
Weight change (%)	
<i>Reduced</i>	6 (33.3)
<i>Stable</i>	7 (38.9)
<i>Increased</i>	5 (27.8)
Nutritional intervention (%)	
<i>Has received support/advice</i>	14 (77.8)
<i>Follows an enriched diet</i>	7 (38.8)
<i>Modifies food texture</i>	8 (44.4)
<i>Takes longer to finish meals</i>	11 (61.1)

Table 3 – Barriers and enablers to increasing calorie intake for people with ALS, mapped to the COM-B model and TDF

COM-B Component	TDF Domain	Code	Barrier or enabler	P/Cs	HCPs
Capability - Physical	Physical (skill)	Swallow/dysphagia	B	✓	✓
		Chewing	B	✓	✓
		Weakness and fatigue	B	✓	✓
		Capacity to eat	B	✓	✓
		Capacity to cook or shop	B	✓	✓
		Choking or aspiration	B	✓	✓
	N/A (Disease characteristic)	Weight	B	✓	✓
		Body shape changes	B	✓	✓
		Taste	B	✓	✓
		Salivation or secretions	B	✓	✓
		Heterogeneity of changes	B	✓	✓
		Mobility	B	✓	✓
		Breathing	B	✓	✓
		Lip seal	B	✓	
		Other health needs	B		✓
Capability - Psychological	Knowledge	Knowledge about ‘healthy eating’	B&E	✓	✓
		Knowledge about high calorie diets	B&E	✓	✓
		Lack of guidance	B		✓

	Memory, attention and decision processes	Cognitive difficulties	B	✓	✓
		Comprehension of healthcare professional advice or support	B&E	✓	
		Overwhelmed at diagnosis	B		✓
Opportunity – Physical	Environmental context/resources	Availability of informal carers or support	B&E	✓	✓
		Availability of formal carers or support	B&E	✓	✓
		Availability of peer support network	B&E	✓	
		Availability of food	B&E	✓	
		Availability of healthcare professional advice or support	B&E	✓	✓
		Lack of care continuity and geographical variation	B		✓
Opportunity - Social	Social influences	Social aspects of eating	B	✓	✓
		Influence of informal carers or support	B&E	✓	✓
		Influence of formal carers or support	B&E	✓	✓
		Influence of peer support network	B&E	✓	
		Influence of healthcare professional advice or support	B&E	✓	✓
		Delivery of person centred care	E		✓
		Building relationships with patients	E		✓
Motivation – Reflective	Beliefs about consequences	Beliefs about healthy eating	B&E	✓	✓
		Beliefs about high calorie diets	B&E	✓	✓
	Identity	Interest in healthy lifestyles	B	✓	✓

		Acceptance of and adjustment to diagnosis	B&E	✓	✓
	Goals	Body weight goals	B	✓	
		Adherence / receptivity to healthcare professional advice	B&E	✓	✓
		Sense of control	B&E	✓	✓
		Independence	B&E	✓	✓
		Patient priorities (i.e. not food)	B		✓
		Importance of patient choice and compromise	B&E		✓
	Optimism	Living in the present	E	✓	✓
		Uncertainty about future	B	✓	✓
Motivation – Automatic	Reinforcement	Eating habits and routines	B&E	✓	✓
	Emotion	Appetite and thirst	B	✓	✓
		Food enjoyment	B&E	✓	✓
		Resistance and denial	B	✓	✓
		Low mood	B	✓	✓
		Embarrassment	B	✓	✓
		Carer burden	B	✓	✓

Patient, carer and healthcare professional perspectives on increasing calorie intake in Amyotrophic Lateral Sclerosis

Supplementary material 1 – Focus group discussion guide

Context

1. Please tell me briefly about yourself and the work you do with people with MND /ALS? [keep this brief - just for introductions]

Prompts

- a. Job role
- b. Time in post

2. Do you *routinely* provide nutritional management services to people with MND/ALS?

3. Please tell me about what nutritional management services are given to people with MND/ALS in this area. [Note to interviewers: keep this brief (approx. ten minutes)]

Prompts

- a. Who delivers this and where?
- b. How and when are patients with nutritional needs identified?
 - i. What happens after diagnosis?
 - ii. What routine assessments are undertaken?
 - iii. Do patients have to raise issues themselves (who are they referred to)?
- c. Which interventions are provided in your area?
 - i. Examples: food first/dietary enrichment, types of ONS, written / online support, face-to-face support from dietician etc.
- d. What guidance is used to inform how nutritional management?

4. What do you think about increasing calorie intake for people with MND / ALS?

Prompts

- a. Can you say a little more about that?
- b. Do you have a clear idea about nutrition and MND/ALS?
- c. If so, why do you think that is?
- d. If not, what is confusing?

Barriers and enablers

Service delivery

5. What are the main challenges to delivering nutrition and dietetic services to people with MND/ALS in your area?

Prompts

- a. Is nutritional management seen as important in your area?
- b. Do healthcare professionals have the knowledge and skills to provide effective nutritional management?
- c. Do you have the right staff in the team?
- d. Are the services commissioned appropriately in your area?

6. How could you overcome the barriers to delivering nutrition and dietetic services to people with MND/ALS in your area?

Prompts

- a. Could the importance of nutritional management be emphasised among healthcare professionals? How might this be achieved?
- b. What would effective training for healthcare professionals look like?
- c. How would the MDT be best structured to support nutritional management?
- d. Are there any better ways to commission services in your area?

7. Is there anything that do you do already that you think works well or is successful?

Nutritional interventions

8. What are the key challenges that you face when attempting nutritional management?

Prompts

- a. Do you have enough guidance on what can help patients?
- b. Availability of different interventions/management strategies?
- c. Acceptability of different interventions/management strategies?
- d. Is it difficult to get the timing right?
- e. Do patients struggle to follow your advice?
- f. How easy is it for patients to implement your suggestions?
- g. How do patients feel about their nutritional management?

9. What might help you to overcome the barriers that you or your patients face when you are supporting their nutritional intake?

Prompts

- a. Would any additional literature / leaflets be helpful? What might they look like?
- b. How about education / training for yourself or the patient?
- c. Might different equipment / tools support you / the patient to overcome these barriers?

10. Is there anything that do you do already that you think works well or is successful?

Other ways of working

11. If we were to advise all people living with MND/ALS to increase their calorie intake, how do you think we could best support them to do this?

12. If we asked patients to increase their calorie intake at diagnosis, how do you think this would work for your local area?

Prompt

- a. How do you think patients and carers would respond to being asked to increase their calorie intake at the point of diagnosis?

Closing remarks

13. Is there anything else that you would like to say that you haven't had the opportunity to say yet?

Patient, carer and healthcare professional perspectives on increasing calorie intake in Amyotrophic Lateral Sclerosis

Supplementary material 2 – Patient and carer interview schedules

Patients

Context

1. Please tell me briefly about yourself and your MND/ALS?

[Note to interviewers: this is a warm up question – need to be mindful of time and energy given to answer this- - try to keep it factual]

Prompts

- a. Diagnosis – process, details, time since
- b. Stage of the disease
- c. Treatments received
- d. Other healthcare received – e.g. hospital and community care
- e. Other support received

2. What does food and eating mean to you?

Prompts

- a. What kind of food do you like?
- b. Who prepares the food you eat? Who does the cooking in the house?
- c. Who does the food shopping in the house?
- d. How important is food and nutrition to your life?
 - Explore social aspects, current perceptions about food and weight
- e. How much control do you feel with food and nutrition choices?

Experiences

3. Do you have any issues with eating / swallowing / chewing?

[Note to interviewers: Prompts a and b are key questions to identify/explore key barriers and enablers - spend time of these]

Prompts

- a. What are the difficulties / issues?
- b. What helps?
- c. Do you get any help with eating? What does this involve?
- d. Did you experience any issues before diagnosis?

4. Has your experience of food and eating changed since your symptoms first began?

Prompts

- a. If so, what has become more difficult (taste, appetite, chewing/swallowing, functional status, attitudes to eating, motivation to eat, ability to feed self)? What, if anything, helps?
- b. If it has not become more difficult, can you say a little more about that?

5. Have you received any support or advice for food and eating since your symptoms first began?

Prompts

[Note to interviewers: need to tailor this to issues experienced by participants/response to Q3/4]

- a. What kind of advice have you received?
 - i. When were you advised about this and by whom?
 - ii. What did you think of this? (Like/dislike and reasons)

- b. What kind of support / interventions have you been given?
 - i. When were these introduced to you and by whom?
 - ii. What do you think of this? (Like/dislike and reasons)
- c. What is your experience of how your nutrition has been managed since your symptoms first began?
 - i. How was the need for these interventions explained to you?
 - ii. Did you agree with the reasons? Did you think it was important to follow the advice given?
 - iii. Did you find any differences between approaches of different health professionals?
- d. What helps you to keep to the advice or support given?
 - i. How were you supported to keep to the advice (examples: monitoring frequency; face-to-face vs phone; use of self-monitoring; written information given; use of patient specific plans.)?
- e. What challenges have you experienced following the advice given?

Views

Introduction: Research suggests that people with MND/ALS need more calories and many are being advised by health professionals to eat a high calorie diet.

6. What do you think about increasing calorie intake in MND?

Prompts

- a. What impact, if any, do you believe increasing your calorie intake might have on your health / MND?
- b. Can you say a little more about that?
- c. Do you have a clear idea about the impact of nutrition on and MND/ALS?
 - a. If so, why do you think that is?
 - b. If not, what is confusing?
- d. [For people who haven't been asked to increase calorie intake before]: How would you feel about being asked to increase your calorie intake?

7. How do you think you could increase your calorie intake?

Prompts

- a. What do you think are the challenges with these approaches?
- b. What might help you to overcome them?

8. How do you think we could best support you to increase your calorie intake them to do this?

Prompts

- a. What about other people with MND/ALS?

Closing remarks

9. Is there anything else that you would like to say that you haven't had the opportunity to say yet?

Carers

Context

1. Please tell me briefly about yourself and the person in your life who has MND/ALS?

[Note to interviewers: this is a warm up question – need to be mindful of time and energy given to answer this - try to keep it factual]

Prompts

- a. What is your relationship to this person?
- b. Diagnosis – process, details, time since
- c. Stage of the disease
- d. Living arrangements
- e. How do you care for this person?
- f. Other support received (formal carers, healthcare professionals)

2. What does food and eating mean to you?

Prompts

- a. Who does the cooking in the house?
- b. Who does the food shopping in the house?
- c. How important is food and nutrition to your life?
 - i. Explore social aspects, current perceptions about food and weight
- d. How much control do you feel with food and nutrition choices?

Experiences

3. Does [person with MND/ ALS] have any issues with eating / swallowing / chewing?

Prompts

- a. What are the difficulties?
- b. What helps?
- c. Do you give them any help with eating? What does this involve?

4. Has your experience of food and eating with [person with MND/ALS] changed since their symptoms first began?

Prompts

- a. If so, what has become more difficult (taste, appetite, chewing/swallowing, functional status, attitude to eating, motivation to eat, ability to feed self)? What, if anything, helps?
- b. If things have not become more difficult. If not, can you say a little more about that?

5. Has [person with MND /ALS] received any support or advice for food and eating since their symptoms first began?

[Note to interviewers: need to tailor this to issues experienced by participants/response to Q3/4]

Prompts

- a. What kind of advice has been received?
 - i. When was this advice given and by whom?
 - ii. What did you think of this (like/dislike and reasons)?
 - iii. How did the person with MND/ALS respond to this?
- b. What kind of support / interventions have been received?
 - i. When were these introduced and by whom?
 - ii. What do you think of this (like/dislike and reasons)?
 - iii. How did the person with MND/ALS respond to this?
- c. What did you think of the advice and support the person in your life with MND/ALS has been given for eating?
 - i. How was the need for these interventions explained?

- ii. Did you agree with the reasons? Did you think it was important to follow the advice given?
- d. As a carer, what helps you to keep to the advice or support given?
 - i. How were you/they supported to keep to the advice (e.g., monitoring frequency; face-to-face vs phone; use of self-monitoring; written information given; use of patient specific plans)?
- e. As a carer, what challenges have you experienced following the advice given?

Views

Introduction: Research suggests that people with MND/ALS need more calories and many are being advised by health professionals to eat a high calorie diet.

6. What do you think about increasing calorie intake in MND/ALS?

Prompts

- a. What impact, if any, do you believe increasing their calorie intake might have on their health / MND?
- b. Can you say a little more about that?
- c. Do you have a clear idea about the impact of nutrition on and MND/ALS?
 - i. If so, why do you think that is?
 - ii. If not, what is confusing?
- d. [For people who haven't been asked to increase calorie intake before]: How do you think the person in your life with MND/ALS would feel about being asked to increase their calorie intake?

7. How do you think you could increase calorie intake in people with MND/ALS / how do you already try to increase calorie intake for the person in your life with MND/ALS [use the person's name]?

- a. What do you think are the challenges with these approaches?
- b. What might help people with MND/ALS to overcome them?

8. How do you think we could best support people living with MND / ALS to increase their calorie intake?

Prompts

- a. How do you think you and the person in your life with MND/ALS would have responded to these suggestions?

Closing remarks

9. Is there anything else that you would like to say that you haven't had the opportunity to say yet?

Patient, carer and healthcare professional perspectives on increasing calorie intake in Amyotrophic Lateral Sclerosis**Supplementary material 3 – Recruitment flow chart**

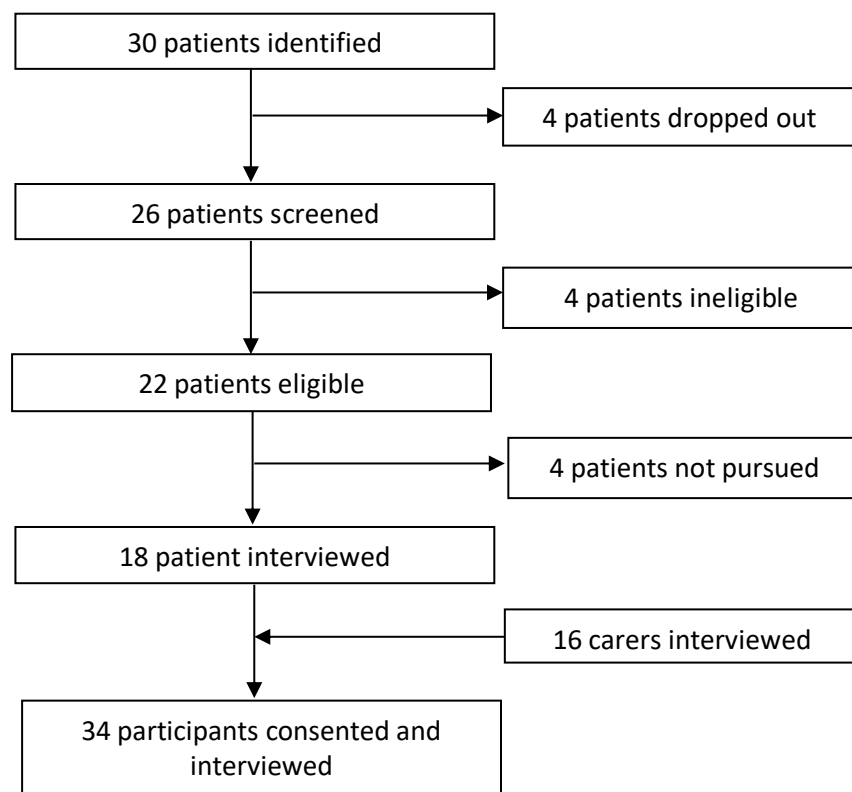


Figure 1 - Recruitment flowchart for patients and carers

Patient, carer and healthcare professional perspectives on increasing calorie intake in Amyotrophic Lateral Sclerosis

Supplementary material 4 – Table of quotes to illustrate codes by COM-B component and TDF domain

COM-B Component	TDF Domain	Code	Quote(s)
Capability – Physical	Physical (skill)	Swallow/dysphagia	‘That is hard, as I can’t chew and swallow, and have to use cloth to put over mouth. My chewing is odd because my tongue does not work to stir food in mouth and deliver to throat to swallow.’ (P9)
		Chewing	
		Weakness and fatigue	
		Capacity to eat	
		Capacity to cook or shop	
		Choking or aspiration	
	N/A (Disease characteristic)	Weight	‘Crumbly things in, it’s not the swallowing, [...] it’s the phlegm and the saliva that gets, everything gets caught in his throat because of that, and that makes it difficult to eat.’ (C30)
		Body shape changes	
		Taste	
		Salivation or secretions	
		Heterogeneity of changes	
		Mobility	
		Breathing	
		Lip seal	
Other health needs	‘I think because MND can you know manifest itself in so many different ways can’t it? I mean we had somebody who was very, very dependent on having, you know, respiratory support that actually could eat fairly well. So never had a PEG tube.’ (Community Nurse, FG6)		
Capability - Psychological	Knowledge	Knowledge about ‘healthy eating’	‘Modern day culture is to reduce calories, not increase.’ (P25)
			‘I don’t know, [...] my only worry would be that we’re substituting one problem for another, in that we’re substituting weight loss with too much fat in the body, and you’re gonna die of a heart attack instead. [...]’ (C20)
			‘That’s what we’re taught’ (P19)

		Knowledge about high calorie diets	<p>‘The research that says generally people who have an average, or above average, BMI, basically do better than people that are on the low average BMI. And you know, we didn’t do the research, but that’s what it says. So that’s what you do.’ (MND Nurse 1, FG2)</p> <p>‘We know that it is better for them if they stay nourished for as long as they can... so I suppose we go for that, but still there isn’t any research to say that yes definitely this is the way we have to go.’ (Dietitian, FG1)</p>
		Lack of guidance	<p>‘That’s where we’re on a sticky wicket, cos you don’t really have a good evidence base, other than established practice, you know [...] we seem to chuck down calories, it seems to slow down your weight loss. (Dietitian, FG4)</p>
	Memory, attention and decision processes	Cognitive difficulties	<p>‘Sometimes they’re so shell shocked about their diagnosis... so leave it to for the community dietitian to pick up, you know, rather than do everything within three days, it’s easier to have that in a couple of weeks.’ (MND Nurse, FG4)</p>
		Comprehension of healthcare professional advice or support	
Overwhelmed at diagnosis			
Opportunity – Physical	Environmental context/resources	Availability of informal carers or support	
		Availability of formal carers or support	<p>‘I’m fortunate to have a live-in carer. So, you know, if I can’t use, I can usually feed myself in the mornings, but basically, I’ve got someone who can feed me, so, you know, in a good place compared to many others.’ (P13)</p> <p>‘The nursing home just didn’t seem able to cater for his swallow and that’s another thing, he was just losing weight cos he couldn’t eat the food despite talking to the kitchens and, [...] so he just had a PEG.’ (MND Nurse, FG5)</p>

		Availability of peer support network	‘As soon as my friends knew that I was not well, they’ve all without exception said lets go and have lunch, so I’ve had lunch with lots of friends and most weeks we go out to lunch now which we never did in our lives before.’ (P45)
		Availability of food	
		Availability of healthcare professional advice or support	‘Not in the last four and a half years has anyone made any suggestions in specifics. [...] It just seems to be our own common sense about what we eat. You know. We could have been eating a really crap diet, honestly, and nobody probably would have said anything, you know.’ (C2)
		Lack of care continuity and geographical variation	‘It’s the variability even within a team... so one of our local teams might have had somebody who was very interested in MND, so they religiously saw them every month, but then that person leaves and there’s no... it’s the lack of continuity of care and consistency of standard that is a big barrier.’ (Speech and Language Therapist, FG8)
Opportunity - Social	Social influences	Social aspects of eating	<p>‘Must be an impact on them wanting to go out to enjoy meals or go out to a normal restaurant because they might need to have added things in their meals, they would normally just eat a curry. [...] All of these little things that people anticipate and it then becomes a barrier and you’ve got a whole new issue, with mental health.’ (OT, FG3)</p> <p>‘We all just sit there and we have a meal together and talk about the day, and suddenly that kind of thing’s almost been taken away from you...’ (Community Nurse, FG6)</p> <p>‘That’s a part of going out as well too, isn’t it? If you’re eating outside, you enjoy where you’d want to eat. And you lose that too.’ (P10)</p>

			‘We don’t go out as much as we used to, eating out. We sort of have to be a little bit selective to make sure that she can, places we visit she can get in, in and out easily enough.’ (C34)
		Influence of informal carers or support	
		Influence of formal carers or support	
		Influence of peer support network	‘What’s kept him going the last year, the fact that we can still get him out with his mates even though it’s a struggle, and they’re all brilliant with him.’ (C18)
		Influence of healthcare professional advice or support	‘The ability just to very quickly build up a rapid rapport with someone and their family and to be able to build that trust almost instantly is really key and core skills, and then you’re going where you wanna take it.’ (Community Dietitian 1, FG6)
		Delivery of person centred care	
		Building relationships with patients	
Motivation – Reflective	Beliefs about consequences	Beliefs about healthy eating	‘I think for optimum health you should be eating a balanced diet in terms of fruit, veg, you know, carbohydrate, protein and if you eat that and you felt in the past you’d eaten it, how you felt it was normal for you and to continue doing that would be a benefit, you know, much more enjoyable really.’ (P11)
		Beliefs about high calorie diets	
			‘How do you up someone’s calories but keep them healthy keep them fit, especially if he can’t exercise as much as he used to we’re already noticing that he can’t exercise as much as he used to because he gets fatigued he’s just gonna get heavy he’s gonna put on weight.’ (C32)
	Identity	Interest in healthy lifestyles	‘I spent most of my adult life either dieting, trying to eat healthy... it’s been, it’s been a big factor, trying to eat healthy, banning cakes. And now, suddenly given a bit of a green light to eat anything as long as it’s

		<p>high in calories and so, I put loads of weight on like my tummy and hated every bit of it.’ (P19)</p> <p>‘It’s almost in a way counter to what they believe.’ (Community Dietitian, FG3)</p>
	Acceptance of and adjustment to diagnosis	<p>‘A lot of people diagnosed with MND suddenly shut off from wanting to use the internet and look at anything that might give them bad news, or whatever. I think there’s a lot of people like me, a lot of people that don’t, that don’t wanna know, don’t wanna even mention MND.’ (P19)</p> <p>‘It can happen at any stage. You know, quite often MND is a diagnosis that is difficult to come to terms with emotionally, psychologically.’ (Community Dietitian, FG6)</p>
Goals	Body weight goals	
	Adherence / receptivity to healthcare professional advice	<p>‘I am very accepting of the intention, good intentions, of healthcare professionals. When they give me advice as the solution to a problem, I stick with it.’ (P15)</p> <p>‘It’s a matter of finding a balance of, there’s lots of guidance saying: we don’t want you to lose weight. There’s very little that says how we want you to stop this weight loss or slow this weight loss down. [...] You’re not really given advice on that. As long as they can see the scales saying the same.’ (P19)</p>
	Sense of control Independence	<p>‘I don’t have as much control, because I can’t go and get the foods that I want to buy. And unless I write a list with specifics, I don’t get the foods that I would probably choose myself if I went shopping, so I don’t have as much control. [...] It’s just... well I’ve always been very independent and done everything for myself, and to suddenly step back and let other people do it, I find it really frustrating.’ (P43)</p>

		Patient priorities (i.e. not food)	‘There’s also them ones that are particularly healthy and fit that who really struggle [...] to go for the high calorie diet.’ (MND Nurse 1, FG1)
		Importance of patient choice and compromise	
	Optimism	Living in the present	‘A lot of MND patients I’ve come across there’s not much that they have control over is there with their condition. So, some of them are trying to grip on to you know with their behaviour with like when they’re refusing or eating at risk, it’s those things that they still have control over those decisions that they can still do that might be important to them.’ (OT, FG7)
		Uncertainty about future	
Motivation – Automatic	Reinforcement	Eating habits and routines	‘I get, quite honestly, a bit fed up with cooking, and towards this summer I really felt, I just don’t know what to cook anymore and we were having the same meals, same meals, so we’ve got to have a radical change.’ (C2)
	Emotion	Appetite and thirst	‘I do try to keep the calories up. One of the problems is that I rarely feel hungry. [...] I was always hungry [before MND].’ (P6)
		Food enjoyment	‘It was very important! I mean it was a lot of pleasure centred around you know, food... food was a big pleasure, particularly in [patient’s] life. Wouldn’t you?’ (C30)

			<p>‘I feel fed up sometimes seeing real food and can’t have it. Can’t get a steak in PEG. Makes me sad and I lose my flavours, it has slowly got worse over the 14 months, so now I am relaxed more having PEG, in case I can’t swallow.’ (P9)</p>
		Resistance and denial	<p>‘I’m still very much a thing of denial or fighting it, if you like. Well, at the moment, trying to say well, everything’s alright, I’m still in control. I don’t need to worry about things like that.’ (P31)</p> <p>‘I think sometimes people do think, you know, it’s not something they want to talk about, because it’s just one, when they’re trying to come to terms with the diagnosis and things like that, you know, if we don’t talk about it won’t be happening. So, there’s an element of denial there.’ (MND Nurse 1, FG2)</p>
		Low mood	<p>‘I think socially, the impact can be massive so just feeling you know, even if it’s not to do with their swallowing, just if their speech is slurred they may not want to go out and order in a restaurant [...] so I think that can be massive and their mood as well, after diagnosis...’ (Speech and Language Therapist, FG7)</p> <p>‘In a restaurant, if you haven’t got the right knife or if the food is tough then, of course, that adds to it and I kind of think “I wish I hadn’t ordered this” or “I don’t really wanna eat this cause it’s just hard work”, especially in a restaurant.’ (P31).</p>
		Embarrassment	
		Carer burden	<p>‘I’m very, very conscious of how much he eats and making sure that he eats enough, you know, that we are getting the right calories, I think I’m a bit paranoid about weighing him.’ (C40)</p> <p>‘I think again, you know, it must be hard to, you know, I’m sure as a carer to keep setting the table for someone who’s not got a very good appetite and to keep cooking a meal and trying. And we find that a lot with carers, you know, it’s so hard...’ (Physiotherapist, FG2)</p>

Note. P = patient. C = carer. FG = focus group.