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RESEARCH ARTICLE

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Living with cough and secretion issues: the experiences of people with amyotrophic lateral sclerosis and their caregivers

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ABSTRACT

Purpose: To explore the experiences of people living with amyotrophic lateral sclerosis (ALS) and their caregivers managing cough and secretion problems.

Methods: A qualitative study was completed with 15 individuals participating in 10 interviews; 10 people living with ALS and five informal caregivers. Interview methods were adapted to ensure inclusivity of participants who had physical, respiratory and communication impairments. Data was analysed inductively using reflexive thematic analysis.

Results: Our analysis identified the challenges of living day to day with cough and secretion problems. Care coordination and the presence of informal caregivers were important in ensuring that cough and secretion interventions could be implemented successfully. Participants felt access to cough and secretion knowledge and skills specific to ALS was key to supporting care and supported them to acquire information which influenced decision-making around their care.

Conclusion: Cough and secretion care in ALS is multifaceted and multifactorial. Future development of clinical interventions in this area are needed to support the complex web of professionals, treatments and knowledge to optimise care.

➤ IMPLICATIONS FOR REHABILITATION

- Amyotrophic Lateral Sclerosis (ALS) is a rapidly progressive neurological disease which causes loss of motor, respiratory and swallowing functions with no cure.
- Problems with cough weakness and managing secretions are common in ALS and present a day to day "battle" for people living with these issues.
- Knowledge and skills of ALS for healthcare professionals, people with ALS and caregivers, are important to ensure coordination of cough and secretion care and support implementation of supportive interventions.
- Interventions that upskill healthcare professionals, people with ALS and caregivers in the knowledge and skills of cough and secretion management need to be developed.

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Amyotrophic lateral sclerosis (ALS); motor neuron disease (MND); cough; secretion management; sialorrhoea; multidisciplinary care

Introduction

Amyotrophic Lateral Sclerosis (ALS) is a progressive neurological condition caused by the degeneration of motor neurons, with no cure currently available. Disease phenotype and progression are variable. Current treatments focus on supporting the loss of motor, respiratory, and swallowing functions to improve quality of life (QoL), though they have limited impact on survival. Respiratory issues are the primary cause of death in ALS. Respiratory dysfunction in ALS is caused by a combination of declining ventilatory function, difficulty coughing to clear secretions, and aspiration of food or liquids due to swallowing difficulties [1,2].

ALS care is complex, with care co-ordinated over multiple organisations in different geographical locations, and numerous different specialists and professionals involved [3]. Current guidelines [4–6] recommend that people receive multidisciplinary care from a specialist team regularly (every 2–3 months) which includes care coordination from the various professionals involved. This has been shown to

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improve survival and quality of life and is independent of interventions such as Non-Invasive Ventilation (NIV), Riluzole and gastrostomy [7–9].

The incidence of cough impairment in ALS is not clearly documented, however given a cough is a combination of respiratory muscle strength and bulbar function it is expected that most people with ALS will have an element of cough dysfunction. Excessive oropharyngeal and respiratory secretions affect up to 70% of people with ALS [10,11] and significantly impact QoL and ability to implement respiratory interventions such as NIV and Mechanical Insufflation-Exsufflation (MI-E) [12]. Existing guidelines [4,5,13,14] recommend that an airway clearance technique (e.g. MI-E) is given to people with ALS if they have evidence of cough weakness. They also recommend pharmacological treatment of oropharyngeal and respiratory secretions and/or other treatments such as optimising posture and positioning or orthotics to support secretion management. However, the guidelines do not advise on how these treatments and interventions may interlink which is important to support decision-making and treatment planning in clinical practice.

Berlowitz et al. [15] highlighted the intricacies of clinical decision-making in ALS respiratory care and the wider ramifications of these decisions. For example, a decision to have a gastrostomy to support swallowing and reduce the risk of aspiration may first require optimum pharmacological secretion management to be able to support set up of NIV, as NIV is required to be able to undertake the gastrostomy procedure safely. This process involves multiple steps and professionals, and often numerous health organisations to ensure smooth transition and to support the decision-making of the person with ALS.

Previous research has stressed the importance of good provision of information to support decision-making in ALS [16,17]. Studies have focused on decision-making of people with ALS considering NIV, including initiation and withdrawal [18], and gastrostomy [18–21] but there has been little research looking at cough and secretion management. These studies highlighted that people with ALS often make decisions, alongside their families and caregivers, within the context of their current circumstances. These decisions are influenced by previous life experiences and are rarely made in isolation, for example a decision about having a gastrostomy has to take into account the ability to care for it long term and suitability for the procedure.

Understanding the experiences of people living with ALS and their caregivers is a priority and is key to ensure that future care interventions can be tailored and targeted appropriately. People with ALS experience feelings of *"loss"* and constant change as the disease progresses [3,22] and relationships with caregivers and family, and healthcare professionals are integral [23,24]. Limited research has explored the experiences of people with ALS and their caregivers living with cough and secretion issues and navigating the management of these. Our previous research has explored the current practice [25], and experiences of healthcare professionals [26]. We found that healthcare professionals often feel underconfident managing these issues and several barriers were identified such as limited access to specialist care, equipment and opportunities to gain knowledge and skills. However, the views of people with ALS and their caregivers remain unexplored.

The present study aimed to explore the experiences of people living with ALS and cough and secretion problems, and experiences of their caregivers and their perceived barriers and facilitators to care.

Methods

Study design

A UK-wide qualitative study was conducted. A topic guide and interview schedule were developed based on a literature review and work with our public and patient involvement and engagement (PPIE) group. Discussions were held with a PPIE group, consisting of people with ALS and their family members, and bereaved family members. The interview questions were discussed and decided on, before a final draft was reviewed, and the proposed format and structure of the interviews was considered. This led to adaptations in the consent process and offering flexible interview formats. Semi-structured interviews were used with a flexible approach to support people with ALS with respiratory, communication, cognitive and physical impairments in a person-centred way [27], enabling data on the individual perspectives including the context and circumstances around this [28]. An

interpretive, constructivist qualitative approach was used to support understanding of the experiences of individuals within their own social and cultural context. This included focusing on how the language used by participants constructed the experiences described, which supported the coding process and interpretation of themes. We also identified that the medical backgrounds of the researchers involved in both the initial coding and defining and refining of themes may have impacted the way the data was analysed, from a more medical model. The participants were aware that the interviewer held dual roles as a physiotherapist and a researcher therefore this may have impacted the language chosen by them during the interviews and therefore the analysis process. The consent process was adapted to allow support for different methods of consent according to participant communication and physical ability [17,27,29] either a) verbal consent, b) typed consent or c) consent using written yes/no responses. Caregivers were also invited to participate, due to their involvement in decision-making in ALS care and to support communication [17]. Interviews were offered *via* video-conferencing, face to face in the participants' homes or *via* email, in line with recommendations [30]. To ensure full inclusion of those with communication impairment, interview questions were emailed to participants ahead of time [31,32].

Participants

People living with ALS in the UK who had a cough and/or secretion issue were eligible to participate and eligibility was clarified during the recruitment process by explicitly asking participants to self-report their cough and secretion issues. Caregivers were invited to participate alongside the person with ALS if they wished. Caregivers were also able to support communication during the interview. Interviews with caregivers were not completed separately and caregivers were not able to participate if the person they cared for living with ALS did not participate.

Recruitment

Participants were recruited from two UK National Health Service (NHS) ALS care centres and online. Potential participants were approached by a member of their clinical care team, issued with a participant information sheet and consent was sought for them to be contacted by a member of the research team. Twenty people were invited to participate from NHS care centres. The study was also advertised *via* social media, the Motor Neurone Disease Association (MNDA) website and at PPIE group meetings. It is not known how many people engaged with these adverts, but one person was recruited *via* online advertisement.

Ethical considerations

Ethical approval was obtained from the NHS Health Research Authority (IRAS 331082) in December 2023. Informed consent was obtained *via* an online consent form prior to participation.

Data collection

Interviews were completed between January and June 2024 by CM. Extra time and resources were made available for interviews to support those using assisted augmented communication (AAC) to ensure diverse healthcare experiences were captured [33,34]. In order to promote inclusive practices, careful consideration was given to ensure that all participants who wished to participate were able to. All participants were sent the questions prior to the interview, allowing those with communication impairment to prepare answers on their AAC or on paper if they wished. If an AAC user was being interviewed alongside a caregiver, the caregiver was invited to respond first to give the participant longer to compose their answer on their AAC. Regular breaks were offered to those using AAC, NIV or pen and paper during the interview. It has been stated that email interviews and interviews using AAC may produce shortened responses and less rich data than other forms of interview [35], however offering interviews in these formats allowed participants who may have declined, an opportunity to share their experiences which adds to the richness of the data. An interview topic guide was used to support questioning. This

was piloted and iteratively developing during the interviews. Interviews were video or audio recorded and transcribed verbatim.

Reflexivity

The research team brings together expertise in neuromuscular and respiratory disorders, with clinical neurological experience in ALS (CMD and EH), specialist physiotherapist experience (CM) and health service delivery research (CMD, EH and AG). A reflexive diary was completed to document any biases or assumptions. These were regularly discussed with the wider research team, paying particular attention to any views that conflicted with research team positionality. This included acknowledging our clinical practice and research backgrounds within ALS care which align with supportive multidisciplinary person-centred care. We aimed to recognise biases throughout data collection and analysis and be aware of any personal beliefs which contradicted the research team positionality.

Data analysis

The six phases of reflexive thematic analysis were followed [36,37]. Initial coding was conducted on a subset of transcripts by three researchers (AG, CM and EH) using NVivo v14, and remaining transcripts were coded by CM and reviewed by AG and EH. These codes were then analysed to look for shared meanings and initial themes were generated. The dataset was rereviewed and initial themes and codes were examined to ensure that they fit with the research question [36]. The data was re-analysed considering the detail of each theme. It was reported illustratively and then analytically, and the final names of the themes were agreed between all reviewers. The COREQ checklist was used to ensure quality of reporting (Supplementary Material 1).

Results

Participant demographics

Fifteen participants took part in ten interviews (as an individual or dyad), representing a combination of people living with ALS ($n=10$) and informal caregivers ($n=5$). Fourteen participants were recruited from the NHS and one participant was recruited *via* social media. All participants except one ($n=9$) used NIV to support ventilation, either nocturnally only ($n=5$) or nocturnally and for periods during the day to manage symptoms of breathlessness ($n=4$; see Table 1 for participant demographics). Participants were all in later stages of the disease, according to the Kings staging classification [38], with significant cough and secretion issues. The average time for face-to-face interviews was 41 min (range 35–47 min) and for online interviews was 44 min (range 32–55 min).

Thematic analysis of interviews

Five themes were identified that impacted experiences of living with cough and secretion issues (Figure 1).

Surviving from day to day

Cough and secretion issues were one of the most impactful symptoms on comfort and quality of life for people with ALS and their caregivers.

> Drooling and the secretions, it's one of the biggest issues really, to keeping him comfortable. {Caregiver 4}

Participants described the day to day psychological and social impact of living with cough and secretion issues including the impact on communication and embarrassment of drooling in social situations. This led to participants avoiding enjoyable activities.

> Interviewer: "Does it stop you doing anything that you want to do and enjoy?"
>
> Participant: "Yes, my art classes" {Person living with ALS 3}

Table 1. Participant demographics.

Type	Age	Sex	Ethnicity	Site of symptom onset	Disease duration (years)	Kings stage	Respiratory support at home	Social situation	Communication method	How interview completed
ALS	50–59	M	White European	Limb	5	4	NIV, MI-E	Lives with spouse	Speech	Video call
ALS	50–59	M	Asian	Bulbar	1	4	Suction	Lives with family	Typing	Email
ALS	60–69	F	White British	Bulbar	3	4	NIV	Lives with spouse	Eye gaze	Face to face
CG	–	M	White British	–	–	–	–	Lives with spouse	N/A	Face to face
ALS	70–79	F	White British	Bulbar	1	4	NIV, MI-E	Lives alone	Pen and paper	Face to face
ALS	50–59	M	White other	Limb	9	4	NIV, MI-E	Lives with spouse	Speech	Video call
CG	–	M	White other	–	–	–		Live in carer	N/A	Video call
ALS	60–69	M	White British	Bulbar	3	4	NIV, MI-E Suction	Lives with spouse	Typing	Email
ALS	40–49	M	White British	Limb	4	4	NI-E, NIV	Lives with spouse	Carer supported communication	Video call
CG	–	F	White British	–	–	–		Lives with spouse	N/A	Video call
ALS	60–69	M	White British	Limb	6	4	NIV, MI-E	Lives with spouse	Eye gaze	Face to Face
CG	–	F	White British	–	–	–		Lives with spouse	N/A	Face to face
ALS	70–79	F	White British	Bulbar	2	4	NIV, suction	Lives with spouse	Yes/No gestures	Face to face
CG	–	M	White British	–	–	–		Lives with spouse	N/A	Face to face
ALS	70–79	M	White British	Bulbar	2	3	NIV, suction	Lives alone	Speech with spastic dysarthria	Video call

CG = caregiver, ALS = Amyotrophic Lateral Sclerosis, NIV = Non-invasive ventilation, MI-E = Mechanical insufflation-exsufflation.

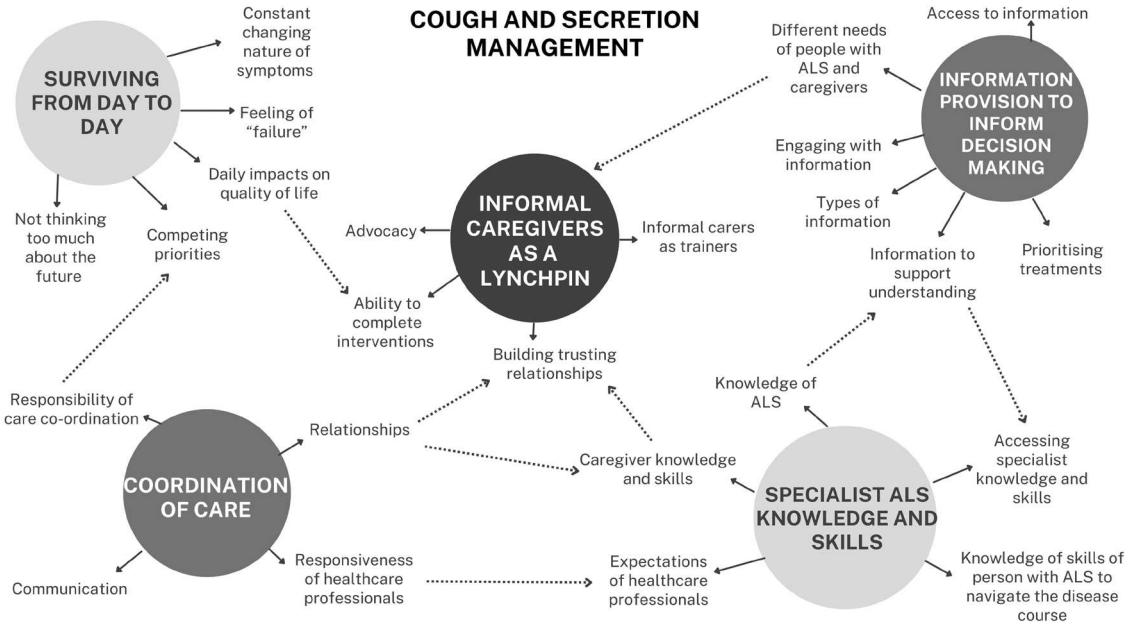

Figure 1. Thematic map of the five identified themes.

Participants depended on equipment such as MI-E, suction and NIV. The constant changing nature and progression of saliva and secretions was *"exhausting"*. Participants experienced feelings of fear and panic when they had retained secretions that they could not clear, followed by feelings of relief when these were cleared.

> It was painful and sometimes frightening, and I thought, Jesus, I'm not gonna be able to breathe here. {Person living with ALS 1}

Ineffective pharmacological treatments also led to psychological and social impacts, for example problems communicating with others or inability to participate in social activities. Participants often described an attempt at a treatment such as Botulinum Toxin, as a *"failure"* if it was ineffective, reporting that they *"failed"* the treatment, and felt responsible for its lack of effectiveness. An example of this described by participants was when MI-E was ineffective due to bulbar impairment. Side effects of pharmacological treatments to manage sialorrhoea had consequences, such as blurred vision impacting communication ability, and dry mouth leading to fears of choking.

> He got one of the "fun side effects" of blurred vision which doesn't help with using the eye gaze. {Caregiver 2}

Participants reflected on psychological coping strategies they used to manage living day to day with cough and secretion issues. They approached the disease on a stage-by-stage basis and avoided thinking too far into the future. Participants sometimes struggled to identify and prioritise what is most important to them.

> It can be a bit overwhelming because I've got several fronts open, which one could be the wheelchair. How, as my disease has progressed, all the modifications, that's one front. Then I've got to talk to the respiratory group. Then I've got to do my [financial] benefits. It's a lot of fronts open. {Person living with ALS 1}

Information provision to inform decision-making

Participants discussed diverse ways and processes used to access information to support decision-making and promote self-care, including information from healthcare professionals, peer support and support groups, and doing their own research. Good quality information helped participants make informed decisions about their cough and secretion care.

> I like information, good information leads to good decisions. {Person living with ALS 8}

However, being provided with information could be overwhelming. One participant highlighted that healthcare professionals should always consider *"if I need to know"* when giving information, placing the onus on healthcare professionals to make this judgement. Participants expressed that they lived day to day and did not want to know about interventions, such as cough augmentation, until they were required. The future was seen as an unknown, to avoid being thought about.

> The less I know what the future holds the better…I live in the present. {Person living with ALS 4}

However, the preferences of people with ALS for the amount and timing of information could be different to their caregivers.

> As the carer, I like to plan in advance and know things in advance and see what's coming up. So, although [person with ALS] very much wants it in the moment and each step is a sign of a change. So, it's like just deal with that as and when it comes because there'll be a change and another change and another change and various things. I'm like right what is this thing, what do I need to know, what will I do when it comes along, who do I speak to, where do I go? {Caregiver 3}

Participants held informal agreements with their care team to support them to get the right information at the right time, to avoid them becoming overwhelmed.

> [person with ALS] has always said to [the care team]: if we need to know something, let us know in time but don't tell us too soon and they've been very good at saying 'I think perhaps you should have this now or perhaps you should start thinking about this'. I think that's probably because right from the word go if you heard too much it's too scary. {Caregiver 4}

How people with ALS and their caregivers seek information and the way they choose to engage with it was consistently noted as an important factor in supporting optimum care.

> If things are reasonably stable, so I don't always feel there's a burning need to communicate face to face. {Person living with ALS 1}

Consideration of how people chose to access, engage and share knowledge and information prior to their diagnosis was important. One participant had worked in the technology industry therefore felt very comfortable accessing and sharing information online or using informal methods of communication such as email. Others felt less confident due to lack of experience or being older. Additionally, participants reported that people with ALS may have different cognitive, functional and communication abilities therefore information needs to be provided in a range of ways. As the condition progresses accessibility may change, and the forum required to share information may change depending on the current disease trajectory.

Some participants used telehealth to share information with their care team. Some felt this could support decision-making around secretion management; however, others felt that completing patient reported outcomes was burdensome and time consuming and did not lead to timely changes in their care.

> [Completing the online questionnaires] might have helped if I could have had the [medication] prescribed earlier. {Person living with ALS 7}

How information provision occurs when a new device or treatment is prescribed was key to ensuring optimisation. Participants felt overwhelmed during this time and unable to absorb all the information being given to them.

> I was a bit overwhelmed with the NIV and the cough assist. I think I would have been better to have two separate appointments. {Person living with ALS 4}

Often several different treatments may be needed simultaneously, or given in a specific order, for example pharmacological management of secretions to support NIV or cough assist set up. Participants did not always feel the rationale for this was clear to them. Caregiver presence was key to effective training on devices or new medications, as they would be operating the device or administering the medication at home. Caregivers preferred hands-on practice with the ability to gain feedback from the healthcare professional to support optimum confidence.

> I was happy with having a bit of a hands on, like seeing them demonstrate it with [name], me having a go and them correcting my technique. {Caregiver 3}

Participants sought additional information about options for pharmaceutical management of secretions. They felt that healthcare professionals did not give sufficient information about side effects and methods of administration to allow them to make an informed decision. Participants expressed poor knowledge about drug interactions, which was further complicated by receiving different messages from healthcare professionals, which led to confusion.

> I asked the nurse and she said I could go up to 1.5 mls three times a day, but the consultant said no because it worked against the carbocisteine. {Person living with ALS 4}

Participants felt strongly that information around off-label prescriptions needs to be shared with them and the pharmacists prescribing the medication to avoid confusion and delays in care.

> There was a bit of confusion sort of on my end whether we'd got the right medication in the first place because [Medicine A] is a very similar name to [Medicine B] and depending on what you read on the leaflets and what you read on the NHS websites, one looks like it's designed for dealing with dribble and the other one looks like a completely different medication altogether. {Caregiver 2}

Developing understanding about why a particular treatment may not work for them, helped make decisions about future care. This was important to ensure participants did not feel that time had been wasted or feel "*a failure*".

> I had the cough assist trial. Unfortunately, it didn't help me because it made my cheeks puff up and it didn't help me to cough. I was a bit disappointed but one good thing that came out of the trial was that when they put the camera down my nose to see what was going on in my throat, they were able to tell me that my throat muscles are working ok. The problems with swallowing are caused by my tongue not being able to push the saliva to the back of my mouth. This was helpful information for me. So, I was pleased that I had the trial. {Person living with ALS 3}

Specialist knowledge and skills in ALS cough and secretion management

People living with ALS develop knowledge and the skills to navigate life with the condition. Many described themselves as "*experts*" of their own condition but highlighted that at diagnosis they had no knowledge and needed to acquire this. All participants felt that healthcare professionals' specific knowledge and skills around cough and secretion management was poor compared to other aspects of ALS.

Most participants felt that non-specialist services had poor knowledge of ALS and did not have the necessary skills to effectively support their cough and secretion issues. Services did not understand the rapid progressive nature of ALS, meaning that access to support was not always available fast enough.

> We waited 33 weeks for that appointment. {Person with ALS 5}

Specialist ALS care centres were more likely to have teams with specialist knowledge and skills to support participants, which was well received by participants.

> [Care centre 1] is far to go but I prefer the care there. {Person with ALS 4}

Difficulties in accessing the care centre were noted, increasing as participants' physical function deteriorated. Travelling to the care centre often impacted participants for numerous days due to fatigue and pain. Therefore, many were keen to explore options to access specialist care closer to home or remotely.

> At the moment we can't get there. [Name] can't sit in a wheelchair because she's in pain for more than two or three hours, but we can be waiting up to seven hours for an ambulance to bring us home. So, you're really looking for two or three hours in the wheelchair waiting for them to come. An hour and a half ride down there, an hour or so with them, and then wait seven hours before we get back home and get her into bed so it's a long day. She is shattered. It might take her a day and a half to get over it. {Caregiver 5}

Participants expected non-specialist staff to have a basic understanding of ALS and to maintain communication with specialist centres to help support care. Access to specialist expertise, particularly for managing secretions, was seen as a crucial element to ensure consistent care. Participants also emphasised the importance of receiving knowledgeable and meaningful care close to home.

> For the Botox we know we've got to go there [to the specialist ALS centre]. It'd be lovely if someone could come here and do it from here. {Caregiver 4}

Several participants had experienced an acute admission to a non-specialist hospital with respiratory issues. In all instances, both the person with ALS and their caregiver reported trauma and long-lasting effects. Participants had to educate healthcare professionals on the condition itself and their treatments. This led to role reversal, where the person with ALS felt that they were having to educate others.

> There was no understanding of what MND is… There was a cough machine there. And I would say only 1 or 2 nurses knew how to use it properly… It felt like I was leading the group and I'm not a doctor, I'm the patient. {Person with ALS 1}

This was further exacerbated if there were any communication difficulties or cognitive impairment, with alternative communication devices that were not set up or healthcare professionals that did not have the skills to use them.

> They're not familiar with eye gaze technology, they didn't know how to… So, we had to have somebody with her all the time who knew her and her specific needs in relation to having MND. {Caregiver 1}

This led to participants changing their behaviour during subsequent episodes of respiratory impairment, opting to stay at home due to concerns around whether the hospital would provide appropriate care.

> [person with ALS] didn't want to go to hospital, we didn't feel it would be much help. {Caregiver 1}

Coordination of care

Coordination of care was seen as fitting together pieces of a puzzle that, when optimised, led to high quality care. Participants reflected on balancing different treatments, side effects, prioritisation of treatments and ensuring different team members were coordinated. This placed a large responsibility on the person living with ALS.

> Because he's got so much saliva it [hyoscine] just didn't work because the saliva was so bad… We then tried a whole patch but it just dried too much. It was actually quite scary because his mouth was really dry. {Caregiver 4}

Participants valued responsiveness from care teams, which led to them feeling connected to and cared for.

> The respiratory unit, they are always on call… {Person with ALS 1}

Participants reflected how current pressures within the NHS had impacted responsiveness and reduced their expectations of services.

> Yeah, but they don't have the resources. They are really busy. {Person with ALS 2}

Participants wanted care to be prioritised, ensuring the right location for care, offering virtual or local care if possible, and the right person, with the right skills, to complete the care. Currently many felt the co-ordination of this did not exist and described a sense of helplessness, and willingness to accept any care offered.

> I don't care who or where it comes from. {Person with ALS 4}

Care coordination across services felt unclear and unknown to participants. Communication between local services and specialist care centres was at times not optimum or lacked transparency. Participants were often unclear if key information around cough and secretion treatments had been shared. Participants discussed how they had given their consent to the sharing of medical records but were confused about who had access to which parts of their medical records. They felt frustrated when they repeated information multiple times, or where healthcare professionals were not aware that a treatment had been tried and failed previously. More informal forms of communication were used, which participants responded well to.

> It's a WhatsApp [message] and within 2 days or less I've got it delivered to my home. The [respiratory] unit works really good for me. {Person with ALS 1}

Relationships between people with ALS, their caregivers and healthcare professionals were central to ensuring coordination of care. Participants found NHS systems and structures confusing, especially given the *"web of care"* they operated within. One participant described how different healthcare professionals assisted her with different aspects, but she was not sure how they linked together given the direct impact of saliva management on cough augmentation.

> I go to them for different issues. {Person with ALS 4}

Almost all described a key point of contact, or a coordinator, who they would approach first for help and support, regardless of the issue needing support. This was often a nurse specialist or care coordinator, or a local contact who they had frequent contact with, such as their GP or community physiotherapist. They highlighted that this person may not always have the solution but could direct them to the right person, almost using this person as a key to unlocking care options.

> If we speak to [place 1] then they tend to know where to direct us. {Person with ALS 5}

People with ALS and caregivers took responsibility to coordinate and advocate for their own care. Some initiated their own plan for care coordination, involving email correspondence and sending their

care plans to multiple healthcare professionals to "*manage them*". This seemed acceptable to many people, but concerns were raised about how people could manage this if they had a cognitive impairment. They also discussed how, given the heterogeneity of the condition, making plans or knowing what is next can be challenging as there is *"no roadmap"*. Some participants preferred to contact healthcare professionals for support as and when they felt it was needed, however others reported that changes in symptoms were often gradual and they did not feel the onus should be on them to recognise these changes.

Informal caregivers as a lynchpin

Participants highlighted the importance and the impact of formal and informal caregivers in supporting their cough and secretion management. They were integral to completion and management or treatment plans, being responsive to changes and trying different options. Informal carers often solved immediate issues at home without involving any healthcare professionals.

> We tried using normal hyoscine patches as well as the Botox and trying to, you know, do half a patch instead of a quarter patch, replace it more often and so on. {Caregiver 4}

A trusting relationship between the person with ALS and their caregiver was considered key to successful day to day cough and secretion management. Participants described the practical need for an informal caregiver; *"I need support because my hands don't work"*. However, more than offering practical support, participants reflected on their unique understanding of their needs, adapting techniques to suit them.

> The recommended way they tell you to do it which is keep the mask on for 5 or 6 coughs and we kind of worked out if you do have one, do a bit of a break and then another that suited him. {Caregiver 3}

All participants highlighted how important it was for caregivers to have knowledge and skills around the condition itself, alongside specialist skills to support specific care tasks. This skill acquisition was vital to support good quality care at home. Social care, through formal paid caregivers, supported participants. However, finding formal carers with existing knowledge of ALS or the skills needed to support with MI-E was challenging, and often the responsibility of the person with ALS and their caregiver.

> Yeah, I think, people the first time they use it (suction), they're quite nervous and don't go too far. {Caregiver 4}

Informal caregivers were often required to train formal carers on individual adaptations and support them to deliver care in the home. This gave formal carers confidence to complete care tasks and knowledge of individual adaptations, and also gave the person with ALS confidence in their skills. Care transitions between informal caregivers and formal caregivers were also challenging. One caregiver discussed how she had managed all MI-E and suction care for her husband until she fell and fractured her arm and was unable to do this.

Participants relied on their informal carers to support and advocate for their care, especially during acute admissions. This included sharing treatment or management plans, bringing equipment into the hospital, linking in with specialist services, or providing personalised care on the ward. One caregiver shared the distress of his loved one being in hospital.

> From my experience as a carer it's very alarming and distressing. At that period over Christmas, she had to be on the ventilator. We were constantly having to take the ventilator off to clear the secretions. {Caregiver 1}

Caregivers also experienced distress when their loved one was unable to clear secretions. This feeling of helplessness was uncomfortable, therefore caregivers sought relief from this by upskilling in different treatment techniques. Participants who lived alone asked friends and family to support tasks they were unable to complete.

How to improve care

Participants were asked to suggest what they would like to see from the development of interventions to support cough and secretion management. All participants felt that an intervention designed to

support cough and secretion management was much needed and had the potential to improve their care pathway and patient journey immensely. They recommended several key attributes to consider:

1. **Accessible** – Recognising the variable nature of ALS and the need for multiple options to support people with different physical, cognitive, and communication abilities.
2. **Personalised** – Including areas for personalised information about healthcare professionals, treatment regimes and management plans
3. **Timely** – Ensuring information is easily accessible when needed, recognising the challenges of navigating healthcare systems
4. **Technological** – Incorporating telemonitoring and visual aids that are compatible with augmentative and alternative communication (AAC) devices.

Discussion

The care of people living with ALS is complex with care coordinated across multiple organisations in different geographical locations [39]. There are numerous factors that interplay and impact people with ALS and caregiver experiences, and cough and secretion care provides an example of the wider challenges. The constant changing nature of cough and secretion issues, the interdependency of treatment modalities, the numerous healthcare professionals involved and the requirement of self-management by people with ALS and caregivers makes cough and secretion management in ALS an extremely complex intervention. This study allowed us to gain a greater understanding of these experiences, to ensure that future interventions and treatments are appropriate, and therefore more likely to be implemented successfully. Living day-to-day with cough and secretion issues was described as frustrating, exhausting, variable and anxiety-inducing for both people with ALS and caregivers. This aligns with findings that intensity of thick mucus was an important factor in influencing quality of life [40]. The most serious psychological effect was fear for patients and caregivers, and this impacted day-to-day life. Caregivers also described a feeling of *"helplessness"* and distress when trying to manage secretions at home [40]. These feelings were echoed in this study.

Care coordination

The 2019 NHS long term plan strives for the right care, from the right person, at the right time, in the right place. However, in the present study many felt that – and could demonstrate that – this was not being consistently achieved. People with ALS were often co-ordinating, prioritising, balancing and advocating for their own care, in line with evidence from people living with rare diseases in the UK [41]. A recent discrete choice experiment in rare diseases has highlighted that patients and caregivers report clinical expertise and access to specialist care as the most important attributes to support care coordination [42]. This is particularly important in cough and secretion care due to the variable symptoms, complexity and interaction of different treatments.

Relationships and the importance of informal caregivers

Relationships were imperative to support care coordination and implementation of cough and secretion interventions. Most participants identified a healthcare professional as their key point of contact to support and direct them as and when required. Participants highlighted the importance of regular, timely interventions in cough and secretion management due to the variable nature and complex interplay of symptoms. Interestingly, Morris et al. [41] found that only 12% of patients affected by a rare disease, and 14% of parents and caregivers, reported having a formal care coordinator; however, it appears that healthcare professionals may take on this role of a coordinator for people with ALS informally, which impacts their workload and role within the MDT. Relationships between people with ALS and their caregivers was vital to support successful implementation of supportive care devices such as MI-E or pharmacological treatments. Research suggests that users' acceptance of new technology is linked to competency [43], that

competency can be influenced by patient and caregiver relationships [44] and that people's quality of life when using respiratory interventions was linked to the competency of their caregiver [18]. Furthermore, the patient and caregiver relationship supported trust and confidence using the device [45].

Information provision to support decision-making

Information provision was key to supporting decision-making, but participants felt this could, at times, be overwhelming and a diverse, personalised approach to it should be implemented. Information sharing is integral to person-centred care [17]; however, the complexity of these decisions cannot be underestimated, with people with ALS frequently asked to make anticipatory decisions about care, and responsibility for these decisions often shared with caregivers. This was particularly pertinent in cough and secretion management where these anticipatory decisions can impact each other, for example the need for pharmacological secretion management to be able to use MI-E or NIV. Information was vital to allow participants the opportunity to make informed decisions about their care; however, they may choose not to have information until they feel they need it or want information at different times to their caregivers [16,17]. This could reflect denial of symptoms [20], which presents a challenge for healthcare professionals who therefore must be very skilled to make judgements around what content to give when, and to who.

Family members often value early information to support decision-making [3] and information provision has been identified as an ongoing unmet need for caregivers [16,46] particularly when there is discordance between the timing of information acceptance between the patient-carer dyad. There were examples of *"information provision agreements"* between healthcare professionals and people with ALS/their caregivers which have been shown to work in ALS and other neurological conditions [47]. However, it is not clear how these would work if people with ALS and their caregivers/family members had different information needs, and there has been limited research into how to support information provision for caregivers separately. The method used to provide and share information was important to ensure effective communication. Consideration should be taken around how individuals sought information prior to their diagnosis as their habits and behaviours are often consistent with this.

Knowledge and skills

The acquisition of knowledge and skills to support cough and secretion management was key to supporting care. This was applicable to healthcare professionals, people with ALS and both formal and informal caregivers. For effective treatment and management, people with ALS and their caregivers often had to learn new skills such as using MI-E, suction or knowledge around pharmaceutical management. Training and skill acquisition are crucial for patients and caregivers when issued with MI-E [45,48]. Our participants described that successful training needed sufficient time and clear, simple instructions, and what was required for informal caregivers may not meet the needs of formal caregivers; these components led to successful implementation [45].

Participants and caregivers reflected on their expectations for care. They valued responsiveness from healthcare professionals, even if a solution was not instant, enabling them to feel supported. Responsiveness to the needs of people with ALS and their caregivers may enhance collaboration and encourage tailored care within care settings [24]. However, participants' expectations of the NHS appeared to be changeable. They did not expect non-specialist services to have expert knowledge, but they did expect a basic knowledge of the condition. This was found in recent studies who found that generalist community healthcare professionals have limited knowledge of ALS and therefore found it harder to tailor treatment to complex patients and support them with decision-making [24,49]. This led to stressful encounters, poor confidence in professionals and often a role reversal where the patient was educating the healthcare professional on ALS, negatively impacting their experiences.

Strengths and limitations

This study explored experiences of cough and secretion management care within the UK for people with ALS. All the participants were severely disabled and in the end stages of ALS so inclusive and adaptable

methods enabled us to interview people who may have previously been excluded, to hear their often "*lost voice*". Questions were adapted to allow yes/no or shortened responses, or the style of the interview was adapted. Adapted interviews often did not elicit anticipated data richness but this does not impact the credibility of this data [27]. Participants could choose to compete their interview with a caregiver, which allowed a more inclusive approach to interviews. It is known that informal carer outcomes are inextricably linked with that of the person they care for [50] and carer distress can negatively impact on the quality of care they are able to provide [51]. Therefore, it was deemed important to get the view of caregivers alongside those living with ALS. However, participants may express different views without another person present [52]. Our focus was on making the research as inclusive as possible.

All participants accessed care through an ALS care centre, therefore experiences cannot be generalised to those who do not have access to a specialist care centre. We sought recruitment from areas with different ethnic, environmental and socioeconomic demographics, however despite efforts, our sample showed limited diversity. No people living with a tracheostomy were interviewed as part of the study, and future research should incorporate the views of these individuals as their experiences may differ.

Implications for research and clinical practice

The results from this study outline that care is multifaceted and numerous factors need to be considered when supporting people with ALS in clinical practice; however, coordination of care is key. Information provision and needs of people with ALS and caregivers may differ and time needs to be taken to assess and manage this accordingly. Responsiveness is valued and impacts experiences of care, therefore this should be prioritised. Training and education for people with ALS and both formal and informal caregivers on devices issued and pharmacological strategies is key to supporting confidence and therefore adherence, however caregiver burden should also be considered. This training should be personalised, and accessible resources should be issued following training, with visual training materials preferred. Knowledge of ALS amongst healthcare professionals who are not specialists fluctuates and this impacts patient experience and confidence in care. Considerations of how this can be improved, including care coordination to support this, must be key in further research projects. Future development of interventions, using existing frameworks to support complex intervention development [53], should look at training healthcare professionals to be able to provide key information, training and skills for people with ALS and their caregivers, and to improve their knowledge of ALS to be able to improve patient experience and confidence in care.

Conclusion

This study explored the experiences of living with ALS and cough and secretion issues. Cough and secretion management is a complex interaction between healthcare professionals (both specialists and non-specialists), pharmaceutical interventions and equipment, relying on the behaviours of people with ALS, caregivers and healthcare professionals alongside self-management for success. The physical, cognitive and psychological impairments in people living with late-stage ALS exacerbate these issues and increase the complexity of care interventions. People with ALS described effective care as timely, responsive, co-ordinated, personalised and holistic, and highlighted that improving symptoms and the ability to self-care and advocate for themselves were important outcomes of effective care. Clinical interventions are needed to optimise cough and secretion management care.

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References

[1] Bourke SC, Tomlinson M, Williams TL, et al. Effects of non-invasive ventilation on survival and quality of life in patients with amyotrophic lateral sclerosis: a randomised controlled trial. Lancet Neurol. 2006;5(2):140–147. doi:10.1016/s1474-4422(05)70326-4.

[2] Sancho J, Bures E, De La Asunción S, et al. Effect of high-frequency oscillations on cough peak flows generated by mechanical in-exsufflation in medically stable subjects with amyotrophic lateral sclerosis. Respir Care. 2016;61(8):1051–1058. doi:10.4187/respcare.04552.

[3] Foley G, Hynes G. Decision-making among patients and their family in ALS care: a review. Amyotroph Lateral Scler Frontotemporal Degener. 2018;19(3–4):173–193. doi:10.1080/21678421.2017.1353099.

[4] NICE. Overview | Motor neurone disease: assessment and management. | Guidance | NICE [Internet]; 2016. Available from: https://www.nice.org.uk/guidance/ng42

[5] Van Damme P, Al-Chalabi A, Andersen PM, et al. European Academy of Neurology (EAN) guideline on the management of amyotrophic lateral sclerosis in collaboration with European Reference Network for Neuromuscular Diseases (ERNEURO-NMD). Eur J Neurol. 2024;31(6):e16264. doi:10.1111/ene.16264.

[6] Miller RG, Jackson CE, Kasarskis EJ, et al. Practice parameter update: the care of the patient with amyotrophic lateral sclerosis: multidisciplinary care, symptom management, and cognitive/behavioral impairment (an evidence-based review). Neurology. 2009;73(15):1227–1233. doi:10.1212/wnl.0b013e3181bc01a4.

[7] Van Den Berg JP, Kalmijn S, Lindeman E, et al. Multidisciplinary ALS care improves quality of life in patients with ALS. Neurology. 2005;65(8):1264–1267. doi:10.1212/01.wnl.0000180717.29273.12.

[8] Rooney J, Byrne S, Heverin M, et al. A multidisciplinary clinic approach improves survival in ALS: a comparative study of ALS in Ireland and Northern Ireland. J Neurol Neurosurg Psychiatry. 2015;86(5):496–501. doi:10.1136/jnnp-2014-309601.

[9] Aridegbe T, Kandler R, Walters SJ, et al. The natural history of motor neuron disease: assessing the impact of specialist care. Amyotroph Lateral Scler Frontotemporal Degener. 2013;14(1):13–19. doi:10.3109/17482968.2012.690419.

[10] Hobson EV, McDermott CJ. Supportive and symptomatic management of amyotrophic lateral sclerosis. Nat Rev Neurol. 2016;12(9):526–538. doi:10.1038/nrneurol.2016.111.

[11] Pearson I, Glasmacher SA, Newton J, et al. The prevalence and management of saliva problems in motor neuron disease: a 4-year analysis of the Scottish Motor Neuron Disease Register. Neurodegener Dis. 2020;20(4):147–152. doi:10.1159/000514615.

[12] Cazzolli PA, Brooks BR, Nakayama Y, et al. The oral secretion scale and prognostic factors for survival in subjects with amyotrophic lateral sclerosis. Respir Care. 2020;65(8):1063–1076. doi:10.4187/respcare.07005.

[13] Shoesmith C, Abrahao A, Benstead T, et al. Canadian ALS best practice recommendations (2749). Neurology. 2020;94:1453–1468 (15_supplement). doi:10.1212/WNL.94.15_supplement.2749.

[14] Khan A, Frazer-Green L, Amin R, et al. Respiratory management of patients with neuromuscular weakness. CHEST J. 2023;164(2):394–413. doi:10.1016/j.chest.2023.03.011.

[15] Berlowitz DJ, Mathers S, Hutchinson K, et al. The complexity of multidisciplinary respiratory care in amyotrophic lateral sclerosis. Breathe. 2023;19(3):220269. doi:10.1183/20734735.0269-2022.

[16] Hogden A, Greenfield D, Nugus N, et al. What are the roles of carers in decision-making for amyotrophic lateral sclerosis multidisciplinary care? Patient Prefer Adherence. 2013;7:171–181. doi:10.2147/ppa.s40783.

[17] Paynter C, Mathers S, Gregory H, et al. The impact of communication on healthcare involvement for people living with motor neurone disease and their carers: a longitudinal qualitative study. Int J Lang Commun Disord. 2022;57(6):1318–1333. doi:10.1111/1460-6984.12757.

[18] Wilson E, Palmer J, Armstrong A, et al. End of life decision making when home mechanical ventilation is used to sustain breathing in motor neurone disease: patient and family perspectives. BMC Palliat Care. 2024;23(1):115. doi:10.1186/s12904-024-01443-1.

[19] White S, O'Cathain A, Halliday V, et al. Factors influencing decisions people with motor neuron disease make about gastrostomy placement and ventilation: a qualitative evidence synthesis. Health Expect. 2023;26(4):1418–1435. doi:10.1111/hex.13786.
[20] Greenaway LP, Martin NH, Lawrence V, et al. Accepting or declining non-invasive ventilation or gastrostomy in amyotrophic lateral sclerosis: patients' perspectives. J Neurol. 2015;262(4):1002–1013. doi:10.1007/s00415-015-7665-z.
[21] Martin NH, Lawrence V, Murray J, et al. Decision making about gastrostomy and noninvasive ventilation in amyotrophic lateral sclerosis. Qual Health Res. 2016;26(10):1366–1381. doi:10.1177/1049732315583661.
[22] Mistry K, Simpson J. Exploring the transitional process from receiving a diagnosis to living with motor neurone disease. Psychol Health. 2013;28(8):939–953. doi:10.1080/08870446.2013.770513.
[23] Locock L, Brown JB. 'All in the same boat'? Patient and carer attitudes to peer support and social comparison in Motor Neurone Disease (MND). Soc Sci Med. 2010;71(8):1498–1505. doi:10.1016/j.socscimed.2010.06.043.
[24] Lerum SV, Solbraekke KN, Frich JC. Healthcare professionals' accounts of challenges in managing motor neurone disease in primary healthcare: a qualitative study. Health Soc Care Community. 2017;25(4):1355–1363. doi:10.1111/hsc.12432.
[25] Massey C, Griffiths AW, McDermott C, et al. How healthcare professionals support cough and secretion management in Amyotrophic Lateral Sclerosis (ALS): a UK national survey. Amyotroph Lateral Scler Frontotemporal Degener. 2025. 1–12. doi: 10.1080/21678421.2025.2522401.
[26] Massey C, Hobson E, Griffiths AW, et al. Exploring mechanisms of behavior change for healthcare professionals in cough and secretion management in ALS. Neurodegener Dis Manag. 2025;15(4):149–160. doi: 10.1080/17582024.2025.2506954.
[27] Wilson E, Turner N. Expanding qualitative interviewing for studies involving adults with different communication needs: reflections on research with people living with motor neurone disease. Int J Qual Methods. 2024;23. doi:10.1177/16094069241251537.
[28] King N, Horrocks C. Interviews in qualitative research. Sage, London; 2010.
[29] Pinto C, Geraghty AWA, Pagnini F, et al. How do people with MND and caregivers experience a digital mental health intervention? A qualitative study. Front Psychiatry. 2023;14:1083196. doi:10.3389/fpsyt.2023.1083196.
[30] Fritz RL, Vandermause R. Data collection via in-depth email interviewing: lessons from the field. Qual Health Res. 2018;28(10):1640–1649. doi:10.1177/1049732316689067.
[31] Madsen LS, Jeppesen J, Handberg C. "Understanding my ALS". Experiences and reflections of persons with amyotrophic lateral sclerosis and relatives on participation in peer group rehabilitation. Disabil Rehabil. 2019;41(12):1410–1418. doi:10.1080/09638288.2018.1429499.
[32] Anglade C, Tousignant M, Gaboury I. Rigorous qualitative research involving data collected remotely from people with communication disorders: experience from a telerehabilitation trial. Neurorehabil Neural Repair. 2022;36(8):557–564. doi:10.1177/15459683221100489.
[33] Broomfield K, Judge S, Sage K, et al. Using longitudinal qualitative research to explore the experience of receiving and using augmentative and alternative communication. Int J Lang Commun Disord. 2024;59(3):1043–1065. doi:10.1111/1460-6984.12981.
[34] Murray S, Hopf SC. Attitudes toward the use of low-tech AAC in acute settings: a systematized review. Augment Altern Commun. 2022;38(3):184–195. doi:10.1080/07434618.2022.2122870.
[35] Dahlin E. Email Interviews: a guide to research design and implementation. Int J Qual Methods. 2021;20. doi:10.1177/16094069211025453.
[36] Braun V, Clarke V, Hayfield N, et al. Doing reflexive thematic analysis. UK: Springer eBooks; 2022. p. 19–38. doi:10.1007/978-3-031-13942-0_2.
[37] Byrne D. A worked example of Braun and Clarke's approach to reflexive thematic analysis. Qual Quant. 2022;56(3):1391–1412. doi:10.1007/s11135-021-01182-y.
[38] Balendra R, Khleifat AA, Fang T, et al. A standard operating procedure for King's ALS clinical staging. Amyotroph Lateral Scler Frontotemporal Degener. 2019;20(3-4):159–164. doi:10.1080/21678421.2018.1556696.
[39] Foley G, Timonen V, Hardiman O. Exerting control and adapting to loss in amyotrophic lateral sclerosis. Soc Sci Med. 2014;101:113–119. doi:10.1016/j.socscimed.2013.11.003.
[40] Bublitz SK, Mie E, Wasner M, et al. Thick mucus in ALS: a mixed-method study on associated factors and its impact on quality of life of patients and caregivers. Brain Sci. 2022;12(2):252. doi:10.3390/brainsci12020252.
[41] Morris S, Hudson E, Bloom L, et al. Co-ordinated care for people affected by rare diseases: the CONCORD mixed-methods study. Health Soc Care Deliv Res. 2022;10(5):1–220. doi:10.3310/LNZZ5321.
[42] Morris S, Walton H, Simpson A, et al. Preferences for coordinated care for rare diseases: discrete choice experiment. Orphanet J Rare Dis. 2024;19(1):1–13. doi:10.1186/s13023-024-03353-0.
[43] Knox L, McDermott C, Hobson E. Telehealth in long-term neurological conditions: the potential, the challenges and the key recommendations. J Med Eng Technol. 2022;46(6):506–517. doi:10.1080/03091902.2022.2040625.
[44] Lehoux P. Patients' perspectives on high-tech home care: a qualitative inquiry into the user-friendliness of four technologies. BMC Health Serv Res. 2004;4(1):28. doi:10.1186/1472-6963-4-28.
[45] Siewers V, Holmøy T, Frich JC. Experiences with using mechanical in–exsufflation in amyotrophic lateral sclerosis. Eur J Physiother. 2013;15(4):201–207. doi:10.3109/21679169.2013.834513.
[46] O'Brien MR, Whitehead B, Jack BA, et al. The need for support services for family carers of people with motor neurone disease (MND): views of current and former family caregivers a qualitative study. Disabil Rehabil. 2012;34(3):247–256. doi:10.3109/09638288.2011.605511.

[47] Crocker TF, Brown L, Lam N, et al. Information provision for stroke survivors and their carers. Cochrane Database Syst Rev. 2021;11(5):CD001919. doi:10.1002/14651858.cd001919.pub4.
[48] Travlos V, Drew K, Patman S. The value of the CoughAssist® in the daily lives of children with neuromuscular disorders: experiences of families, children and physiotherapists. A brief report. Dev Neurorehabil. 2016;19(5):321–326. doi:10.3109/17518423.2014.993771.
[49] Walls M, Claffey A, Mockler D, et al. Working with people living with motor neurone disease and the impact on professionals' emotional and psychological well-being: a scoping review. Palliat Med. 2025;39(2):221–244. doi:10.1177/02692163241291745.
[50] Pagnini F. Psychological wellbeing and quality of life in amyotrophic lateral sclerosis: a review. Int J Psychol. 2013;48(3):194–205. doi:10.1080/00207594.2012.691977.
[51] McCabe MP, O'Connor EJ. Why are some people with neurological illness more resilient than others? Psychol Health Med. 2012;17(1):17–34. doi:10.1080/13548506.2011.564189.
[52] Riffin C, Van Ness PH, Iannone L, et al. Patient and caregiver perspectives on managing multiple health conditions. J Am Geriatr Soc. 2018;66(10):1992–1997. doi:10.1111/jgs.15501.
[53] Skivington K, Matthews L, Simpson SA, et al. A new framework for developing and evaluating complex interventions: update of Medical Research Council guidance. BMJ. 2021;374:n2061. doi:10.1136/bmj.n2061.