

Supplementary material 1

Co-development of survey with advisory panel

Meeting	
1	<ul style="list-style-type: none">• Advisory panel shared their experiences of living with, or caring for a person with, neuromuscular disease and dysphagia.• Experiences were recorded by lead author plus an additional person for administrative support.
2	<ul style="list-style-type: none">• Data analysed by first author to identify patterns (themes).• Themes reviewed by advisory panel to assess representativeness and completeness.
3	<ul style="list-style-type: none">• Survey sections developed using themes from advisory panel experiences.• Advisory panel made recommendations regarding survey format, length, and question types.
4	<ul style="list-style-type: none">• Survey questions reviewed by advisory panel.• Revisions made to question format, sequence, and style.
5	<ul style="list-style-type: none">• Electronic survey piloted by advisory panel.• Revisions made in response to feedback.

Supplementary material 2

Survey contents for i) people living with neuromuscular disease and dysphagia
and ii) caregivers

Survey for people living with neuromuscular disease and dysphagia

Question 1: I confirm that I:

Am over 18 years of age
Have a neuromuscular condition
Experience swallowing difficulties

Question 2: Please tick the box to confirm:

I have read the information about this project and understand that by submitting responses to this survey that my data will be used for research purposes.

Question 3: Are you:

18-30 years of age
31-45 years of age
46-60 years of age
61-75 years of age
76 years or over

Question 4: Which neuromuscular condition are you living with?

Duchenne Muscular Dystrophy
Inclusion Body Myositis
Motor Neurone Disease
Myotonic Dystrophy Type 1
Oculopharyngeal Muscular Dystrophy
Spinal Muscular Atrophy Type 2
Spinal Muscular Atrophy Type 3
Currently not confirmed or unclassified
Other (please specify)

Question 5: How was your neuromuscular condition confirmed? Select all that apply

Genetic testing
Muscle or nerve biopsy
Nerve conduction testing
Muscle testing (EMG)
Blood test
I'm unsure / can't remember
Other (please specify)

Question 6: How long have you lived with the symptoms of your neuromuscular condition?

12 months or less
For the last 1-5 years

For the last 6-15 years
For more than 15 years
Since birth
I'm not sure/can't remember

Question 7: In what way does your neuromuscular condition affect you? Select all that apply

Mobility (difficulty walking or moving around)
Using my hands and/or arms
Breathing (perhaps needing a ventilator)
Speaking or communicating
Chewing and swallowing
Stomach and bowels
Heart problems
Difficulty with thinking, memory or mood
Daytime fatigue, sleepiness and/or tiredness
Other (please specify)

Question 8: Do you have any additional medical diagnosis not related to your neuromuscular condition?

No
Yes (please state which condition)

Question 9: Who has confirmed that you have swallowing difficulties? Select all that apply.

A friend or family member
Your GP
Your neurologist
A Speech and Language Therapist
I am aware of the swallowing difficulties myself
Other (please specify)

Question 10: How long have you been aware of your swallowing difficulties?

12 months or less
For the last 1-5 years
For the last 6 -15 years
For more than 15 years
Since birth

Question 11: Have your swallowing problems changed overtime?

Yes, they have got worse
Yes, they have got better
No, they have stayed the same

Question 12: Did you know that your neuromuscular condition could cause swallowing problems?

No
Yes (please state how you knew)

Question 13: What are the signs and symptoms of your swallowing difficulty? Select all that apply.

Coughing or choking when eating
Coughing or choking when drinking
A feeling of food sticking or lodging in the mouth
A feeling of food sticking or lodging in the throat
A feeling of food sticking or lodging in the chest
Pain or discomfort whilst swallowing
Difficulty swallowing tablet medication
Drooling, gurgling or coughing on saliva
A feeling of sticky secretions in the mouth or throat
A chest infection (or infections) that require treatment from the GP or a hospital admission
Weight loss
I have to take extra care when eating and drinking
Mealtimes take longer
I can't talk or socialise when eating and drinking
I need to adapt what and how I eat (for example select softer foods, add sauces, cut food up smaller or avoid certain textures)
I have to drink with meals
I have to thicken my drinks
I don't enjoy eating and drinking any more
I am nervous or scared when eating and drinking
Other

Question 14: Of the signs and symptoms you have selected, which one(s) were you aware of first?

Question 15: Of the signs and symptoms you have selected, which ones are the most difficult or challenging to live with day to day?

Question 16: How long did it take for a health care professional to investigate your swallowing difficulties?

I was investigated for swallowing difficulties before my neuromuscular condition was diagnosed.
I was investigated for potential swallowing problems as soon as I was diagnosed with my neuromuscular condition.
I was asked about swallowing problems sometime after my neuromuscular condition was diagnosed but before I was aware of any swallowing problems.
I was investigated as soon as I had my first sign or symptom of swallowing difficulty.
I was investigated within 6 months of my first sign or symptom of swallowing difficulty.
I was investigated within 12 months of my first sign or symptom of swallowing difficulty.
It took longer than 12 months to investigate my difficulties after my first sign or symptom.
I was only investigated for swallowing difficulties after I was admitted to hospital with a chest infection and/or had a severe choking episode.
I have never discussed swallowing difficulties with a health care professional or had them investigated
I can't remember
Other

Question 17: Which person or professional do you think should be responsible for identifying the early signs of swallowing difficulty?

- I should be responsible
- My family or carers should be responsible
- My GP should be responsible
- My neurologist should be responsible
- It should be the responsibility of a swallowing specialist
- I'm not sure
- Other

Question 18: How was your swallowing problem assessed? Select all that apply.

- A swallowing x-ray using a white barium drink (known as a videofluoroscopy)
- A camera into the nose and throat (known as a fiberoptic endoscopic evaluation of swallowing or FEES)
- A healthcare professional watched me eat and drink
- I haven't been assessed
- Other

Question 19: Were these tests helpful?

- Yes
- No
- I don't know/I'm not sure

Question 20: How important do you think it is to have swallowing problems diagnosed early?

- Very important
- Quite important
- Not very important

Question 21: When do you think is the best time to raise awareness of potential swallowing problems that may be associated with a neuromuscular condition?

- At the same time as being given a neuromuscular diagnosis
- After the neuromuscular diagnosis but before swallowing problems occur
- After the first symptom of swallowing difficulty
- After you have had swallowing difficulties for some time
- Only if swallowing problems cause significant problems
- Other

Question 22: Have you had any advice on how to manage your swallowing difficulties? Select all that apply

- Yes, from my GP or neurologist
- Yes, from a Speech and Language Therapist
- Yes, from a family member or friend
- Yes, somebody else with my condition
- No, I've managed them on my own
- No, my swallowing problems are not managed at all
- No, I don't need any advice at the moment

Yes, from another healthcare professional (please specify)

Question 23: How well do you think this person (or these people) understood your swallowing problems in relationship to your neuromuscular disease?

- Very well
- Quite well
- Not very well
- Not at all

Question 24: Were any of these people part of a specialist neuromuscular team?

- No
- I don't know
- Yes (please state which person)

Question 25: If you have had help, what advice was given to you? Select all that apply

- Eat and drink slow, allowing time for a rest or break
- Try to sit upright
- Take smaller mouthfuls
- Cut food into small pieces
- Avoid certain food textures
- Change the texture of your foods (for example, choose softer or pureed options or add extra sauces)
- Add thickener to drinks
- Have a drink with meals
- Swallow more than once to get things down
- Tuck your chin downwards when eating and/or drinking
- Request liquid or dispersible medications
- Take liquid food supplements (such as milkshakes)
- Use or consider a feeding tube (gastrostomy)
- Request home antibiotics to treat early signs of a chest infection
- Use coughing or chest clearance techniques
- Medications to dry-up saliva
- Train friends or family members in first-aid for choking
- Change medications to dispersible or liquid forms
- Other (please specify)

Question 26: Of the advice you've been given, which has been most useful? Select up to two.

Question 27: How much did this advice help you?

- A lot
- A fair amount
- A small amount
- Not at all

Question 28: How was the swallowing advice given to you? Select all that apply

- In conversation (either face-to-face or on the telephone)
- Via a leaflet or letter
- By demonstration

It wasn't given to me
Other (please specify)

Question 29: Have you found any techniques or strategies of your own that help with swallowing?

No
Yes, please tell us about your techniques

Question 30: Have you been provided with any exercises for your swallowing?

No
Yes, please tell us which exercises have you been provided with

Question 31: Have you found these exercises helpful? If you can, please explain your answer in the box below.

No
Don't know
Yes

Question 32: How well do you think you are currently managing your swallowing problems?

Very well
Quite well
Not very well
Not at all

Question 33: Have you had a serious choking event requiring emergency attention or hospital admission?

Yes, I have had a few choking events needing emergency attentions or hospital admission
Yes, I have had one choking event needing emergency attention or hospital admission
No, I have never had a choking event needing emergency attentions or hospital admission

Question 34: If food ever gets stuck in your throat, how do you clear it?

I cough it up successfully
I try to cough it up but my cough isn't strong enough
I keep swallowing or eating/drinking to push the food down
I take a drink
I wretch or regurgitate the food
I just have to wait until it goes down on its own
I don't do anything
Food doesn't get stuck
Other (please specify)

Question 35: Which method to clear your throat do you find most effective? Select only one from the above.

Question 36: Have you ever had a chest infection that you think (or have been told) was related to food and drink going down the wrong way?

Yes, I've had one in the last 6 months
Yes, I've had one in the last 12 months

Yes, I've had one in the last 3 years

Yes, I've had more than one in the last 12 months

No, I've haven't experienced any chest infections at all

No, I've had some chest infections but as far as I'm aware they were not related to swallowing

Other (please specify)

Question 37: If yes, how was your chest infection treated?

I needed admitting to hospital

The GP prescribed me with a course of antibiotics

I used my breathing and coughing exercises

I didn't need any treatment

Other (please specify)

Question 38: From your perspective, are you currently:

Over weight

About right

Under weight

Question 39: How anxious or fearful are you about your swallowing problems?

Very anxious

Quite anxious

A little anxious

Not anxious at all

Question 40: How embarrassed are you about your swallowing problems?

Very embarrassed

Quite embarrassed

A little embarrassed

Not embarrassed at all

Question 41: Who do you think is the most concerned about your swallowing problems?

Me

My family member(s) or carer

My doctor or healthcare team

Nobody

Other (please specify)

Question 42: Beginning with the difficulty that affects you most, please rank the following:

Please note that you do not have to rank all of the items, only the ones that apply to you.

Once you have ranked an item it will grey-out so that you can not include more than one item at the same rank. You are able to change your mind about the rankings. Selecting the tick box for a second time will remove your original ranking.

Breathing (perhaps needing a ventilator)

Chewing and Swallowing

Coughing (perhaps needing a cough assist)

Daytime tiredness or fatigue

Speech and Communication

Stomach and Bowels
Thinking, memory or mood
Using the arms and hands
Mobility (difficulty with walking or moving)

Question 43: If you were going to improve services for people with swallowing difficulties and neuromuscular conditions – which two of the below would be the most important to you?

Better communication between healthcare professionals about swallowing
Earlier access to a local swallowing specialist
Access to a specialist neuromuscular swallowing professional
Swallowing training for patients living with neuromuscular conditions
Swallowing training for healthcare professionals working with neuromuscular conditions
Earlier discussion and assessment of swallowing problems
Better treatment for swallowing difficulties
Access to online forums or support groups
I'm not sure
Other (please specify)

Question 44: Below is a space for you to add any additional comments about any aspect of swallowing difficulties and neuromuscular conditions you would like to share.

Question 45: Please let us know where you first heard about this survey by selecting an option from below.

Charity newsletter
Charity website
Disease registry
A friend or family member
Hospital, clinic or GP surgery
Social media
Other (please specify)

Survey for caregivers

Question 1: I confirm that I am:

Over 18 years of age

Question 2: Please tick the box to confirm:

I have read the information about this project and understand that by submitting responses to this survey that my data will be used for research purposes

Question 3: I confirm that:

I am currently the main carer for an individual living with neuromuscular disease and swallowing difficulties

Have previously been the main carer for an individual with neuromuscular disease and swallowing difficulties in the last 18 months.

Question 4: As a current carer, I will answer the survey based on my experiences over the past 6-12 months of being a carer.

Question 5: As a former carer, I will answer the survey based on my experiences over the last 6-12 months of being a carer.

Question 6: Are you:

18-30 years of age

31-45 years of age

46-60 years of age

61-75 years of age

76 years or over

Question 7: Which neuromuscular disease does the person you care for live with?

Duchenne Muscular Dystrophy

Inclusion Body Myositis

Motor Neurone Disease

Myotonic Dystrophy Type 1

Oculopharyngeal Muscular Dystrophy

Spinal Muscular Atrophy Type 2

Spinal Muscular Atrophy Type 3

Currently not confirmed or unclassified

Other (please specify)

Question 8: How was the neuromuscular condition confirmed? Select all that apply

Genetic testing

Muscle or nerve biopsy

Nerve conduction testing

Muscle testing (EMG)

Blood test

I'm unsure / can't remember

Other (please specify)

Question 9: How long has the person lived with the symptoms of their neuromuscular condition?

12 months or less

For the last 1-5 years

For the last 6-15 years

For more than 15 years

Since birth

I'm not sure/can't remember

Question 10: The following two questions will ask you to rank how the neuromuscular condition affects the person you care for and then how you as a carer are affected by aspects of the condition. From your perspective, how does the neuromuscular condition affect the person you care for most? Please note that you do not have to rank all of the items, only the items that apply to the person you care for. Once you have ranked an item it will grey-out so that you can not include more than one item at the same rank. You are able to change your mind about the rankings. Selecting the tick box for a second time will remove your original ranking.

Mobility (difficulty walking or moving around)

Using their hands and/or arms

Breathing (perhaps needing a ventilator)

Speaking or communicating
Chewing and swallowing
Stomach and bowels
Heart problems
Difficulty with thinking, memory or mood
Daytime fatigue, sleepiness and/or tiredness
Other (please specify)

Question 11: Now rank how the neuromuscular condition affects you as a carer the most.

Question 12: Does the person you care for have any additional medical diagnosis not related to their neuromuscular condition that affects them day to day?

No
Yes (please state these conditions)

Question 13: How old is the person you care for?

18-30 years of age
31-45 years of age
46-60 years of age
61-75 years of age
76 years or over

Question 14: What is the relationship between you and the person you care for?

Spouse or romantic partner
Parent
Son or daughter
Friend
Unpaid carer
Paid carer
Other (please specify)

Question 15: How long have you cared for this person?

12 months or less
1-5 years
6-10 years
More than 10 years
Since birth

Question 16: Who confirmed that the person you care for has swallowing difficulties? Select all that apply.

A neurologist
A GP
A Speech and Language Therapist
I noticed them
They noticed the difficulties themselves
Other (Please specify)

Question 17: How long have you been aware of their swallowing difficulties? Select only one

12 months or less
For the last 1 - 5 years
For the last 6 – 15 years
For more than 15 years
Since birth
Other (please specify)

Question 18: Have the swallowing difficulties changed since you have been caring for them?

Yes, they have got worse
Yes, they have got better
No, they have stayed the same

Question 19: Did you know that neuromuscular conditions could cause swallowing problems (before the person you care for was diagnosed with them)?

No
Yes (please state how you knew)

Question 20: What are the signs and symptoms of the swallowing difficulty? Select all that apply

I witness coughing or choking when they are eating
I witness coughing or choking when they are drinking
They report a feeling of food sticking or lodging in the mouth
They report a feeling of food sticking or lodging in the throat
They report a feeling of food sticking or lodging in the chest
They report pain or discomfort whilst swallowing
They find it difficult to swallow tablet medication
They drool, gurgle or coughing on saliva
I see (or they report) sticky secretions in the mouth or throat
A chest infection (or infections) that require treatment from the GP or a hospital admission
Weight loss
They have to take extra care when eating and drinking
Mealtimes take longer
They can't talk or socialise when eating and drinking
They need to adapt what and how they eat (for example select softer foods, add sauces, cut food up smaller or avoid certain textures)
They have to drink with meals
They have to thicken my drinks
They don't enjoy eating and drinking any more
They are nervous or scared when eating and drinking
Other

Question 21: Which of these signs and symptoms were you aware of first? Select a maximum of three

Question 22: From your perspective, which of these signs and symptoms, are the worst day to day?

Question 23: How long did it take for a health care professional to investigate the swallowing difficulties?

They were investigated for swallowing difficulties before their neuromuscular condition was diagnosed.

They were investigated for potential swallowing problems as soon as I was diagnosed with my neuromuscular condition.

They were asked about swallowing problems sometime after their neuromuscular condition was diagnosed but before they were aware of any swallowing problems.

They were investigated as soon as they had their first sign or symptom of swallowing difficulty.

They were investigated within 6 months of their first sign or symptom of swallowing difficulty.

They were investigated within 12 months of their first sign or symptom of swallowing difficulty.

It took longer than 12 months for their difficulties to be investigated after their first sign or symptom.

They were only investigated for swallowing difficulties after they were admitted to hospital with a chest infection and/or had a severe choking episode.

They have never discussed swallowing difficulties with a health care professional or had them investigated

I can't remember

Other

Question 24: Which person or professional do you think should be responsible for identifying the early signs of swallowing difficulty?

The person living with the neuromuscular condition should be responsible

I (the caregiver) should be responsible

The GP should be responsible

The neurologist should be responsible

It should be the responsibility of a swallowing specialist

I'm not sure

Other

Question 25: How was the swallowing problem assessed? Select all that apply

A swallowing x-ray using a white barium drink (known as a videofluoroscopy)

A camera into the nose and throat (known as a fiberoptic endoscopic evaluation of swallowing or FEES)

A healthcare professional watched them eat and drink

They haven't been assessed

Other

Question 26: Do you think these tests were helpful? Please use the box provided to explain your answer

Yes

No

I don't know/I'm not sure

Question 27: How important do you think it is to have swallowing problems diagnosed early?

- Very important
- Quite important
- Not really important

Question 28: When do you think is a good time to raise awareness of potential swallowing problems that may be associated with a neuromuscular condition?

- At the same time as being given a neuromuscular diagnosis
- After the neuromuscular diagnosis but before swallowing problems occur
- After the first symptom of swallowing difficulty
- After you have had swallowing difficulties for some time
- Only if swallowing problems cause significant problems
- Other

Question 29: How do the swallowing difficulties affect you as a caregiver day to day? Select all that apply.

- I have to prepare special foods and meals for the person I care for
- We can't talk or socialise during mealtimes any more
- I have to cut food up small for the person I care for
- I have to be present at mealtimes to watch them carefully
- I have to remind them to take extra care when eating and drinking
- I have to crush or disperse medications
- I have to give medications for saliva
- I have to provide food and fluids via a gastrostomy
- I have to wipe or clear food debris from the mouth of throat of the person I care for
- I get anxious and stressed when watching at mealtimes
- Other (please specify)

Question 30: Of the answers from the previous question, what is the most difficult or challenging part of caring for somebody with a swallowing problem? Select just one.

Question 31: Have you had any advice on how to manage the swallowing difficulties of the person you care for?

- Yes, from a GP or neurologist
- Yes, from a Speech and Language Therapist
- Yes, from a family member or friend
- Yes, from somebody else with my condition
- No, we've managed them on our own
- No, their swallowing problems are not managed at all
- No, we don't need any advice at the moment
- Yes, from another healthcare professional (please specify)

Question 32: How well do you think the people who provided the advice understood the swallowing problem in relation to the neuromuscular disease?

Very well
Quite well
Not very well

Question 33: Were any of these people part of a specialist neuromuscular team?

Don't know
No
Yes (please state who)

Question 34: What advice was given to you and/or the person you care for? Select all that apply

Eat and drink slow, allowing time for a rest or break
Try to sit upright
Take smaller mouthfuls
Cut food into small pieces
Avoid certain food textures
Change the texture of your foods (for example, choose softer or pureed options or add extra sauces)
Add thickener to drinks
Have a drink with meals
Swallow more than once to get things down
Tuck your chin downwards when eating and/or drinking
Request liquid or dispersible medications
Take liquid food supplements (such as milkshakes)
Use or consider a feeding tube (gastrostomy)
Request home antibiotics to treat early signs of a chest infection
Use coughing or chest clearance techniques
Medications to dry-up saliva
Train friends or family members in first-aid for choking
Change medications to dispersible or liquid forms
Other (please specify)

Question 35: How much did this advice help you and the person you care for?

A lot
A fair amount
A small amount
Not at all

Question 36: Of the advice given to you and/or the person you care, for what was the most useful? Select a maximum of three.

Question 37: How was the swallowing advice given to you? Select all that apply

In conversation (either face-to-face or on the telephone)
Via a leaflet or letter
By demonstration
It wasn't given to me
Other (please specify)

Question 38: Have you or the person you care for found any techniques or strategies of your own that help with swallowing?

Yes (please tell us about your techniques in the box below)

No

Question 39: Is there any advice or information you wish you had been given as a caregiver?

Yes – please explain in the box below

No

Question 40: Has the person you care for been provided with any exercises for their swallowing?

Yes – please specify

No

Don't know

Question 41: Have you or they found these exercises helpful? If you can, please explain your answer in the box below.

Yes

No

Don't know

Question 42: How well do you think the person you care for is managing their swallowing problems?

Very well

Fairly well

Not very well

Not at all

Question 43: Has the person you care for ever had a serious choking event requiring emergency attention?

Yes – just one

Yes – more than one

Yes -regularly

No

Question 44: If food ever gets stuck in the throat, are you ever involved in helping the person try and clear it away? Select one.

No, they cough it up successfully on their own

I help them to cough either with encouragement or a pat on the back

I encourage them to keep swallowing or eating/drinking to push it down

I get them a drink

I do not need to do anything

They won't let me help

Not applicable (they don't experience food getting stuck)

Other (please specify)

Question 45: Has the person you care for experienced a chest infection that you think (or have been told) was related to food and drink going down the wrong way?

Yes - in the last 6 months

Yes - in the last 12 months

Yes – more than one in the last 12 months

Yes – in the last 3 years

No - they haven't experienced any chest infections

They have experienced some chest infections but as far as I'm aware they were not related to swallowing

Unsure – I wasn't aware of the link between swallowing and chest infections

Other (please specify)

Question 46: How was this (or these) chest infection(s) treated? Select all that apply.

They needed admitting to hospital

The GP prescribed a course of antibiotics

They used their breathing and coughing exercises

They didn't need any treatment

Other (please specify)

Question 47: From your perspective, is the person you care for:

Under weight

About right

Over weight

Unsure

Question 48: How anxious or fearful are you about the person you care for and their swallowing problems?

Very anxious

Fairly anxious

A little anxious

Not anxious at all

Question 49: Who do you think is the most concerned about the swallowing problems?

Select just one

Me

The person with the swallowing problem

The doctor or healthcare team

Nobody

Other (please specify)

Question 50: Can you think of anything to help reduce the anxiety or stress you experience due to the swallowing problems experienced by the person you care for? Please provide information in the box below.

Question 51: If you were going to improve services for either for individuals with swallowing difficulties and neuromuscular conditions and/or their carers, which two of the below would be the most important to you? Select a maximum of two. Please do add ideas of your own.

Question 52: Below is a space for you to add any additional comments about any aspect of swallowing difficulties and neuromuscular conditions you would like to share.

Question 53: Thank you for taking the time to complete this survey. Please let us know where you first heard about this survey by selecting an option from below:

Charity newsletter

Charity website

Disease registry

A friend or family member

Hospital, clinic or GP surgery

Social media

Other (please specify)

Supplementary material 3

Indications of dysphagia experienced by participants living with NMD and their caregivers according to i) current, earliest-onset and most troublesome indications ii) life-threatening indications and iii) indications of progression

i) Indications of dysphagia (current, earliest, and most troublesome)											
		Participants living with NMD (plwNMD)					Participant caregivers (pCG)				
Indications of dysphagia¹	Descriptor	All NMD (n=272)	DM1 (n=111)	FSHD (n=56)	SMA 2&3 (n=39)	Other NMD (n=66)	All NMD (n=38)	DM1 (n=23)	SMA (n=6)	IBM (n=3)	Other NMD (n= 6)
Coughing or choking whilst eating	Current	177 (65.1%)	72 (64.9%)	31 (55.4%)	29 (74.4%)	45 (68.2%)	31 (81.6%)	21 (91.3%)	1 (16.7%)	3 (100.0%)	6 (100.0%)
	Earliest-onset	109 (40.1%)	49 (44.1%)	19 (33.9%)	16 (41.0%)	25 (37.9%)	26 (68.4%)	17 (73.9%)	1 (16.7%)	3 (100.0%)	5 (83.3%)
	Troublesome	106 (39.0%)	45 (40.5%)	17 (30.4%)	15 (38.5%)	28 (42.4%)	22 (57.9%)	14 (60.9%)	1 (16.7%)	3 (100.0%)	4 (66.7%)
Coughing or choking whilst drinking	Current	107 (39.3%)	34 (30.6%)	25 (44.6%)	15 (38.5%)	33 (50.0%)	15 (39.5%)	9 (39.1%)	1 (16.7%)	1 (33.3%)	4 (66.7%)
	Earliest-onset	35 (12.9%)	11 (9.9%)	9 (16.1%)	2 (5.1%)	13 (19.7%)	6 (15.8%)	4 (17.4%)	0 (0.00%)	0 (0.0%)	2 (33.3%)
	Troublesome	34 (12.5%)	10 (9.0%)	9 (16.1%)	0 (0.0%)	13 (19.7%)	6 (15.8%)	3 (13.0%)	1 (16.7%)	0 (0.0%)	2 (33.3%)
Feeling food sticking or lodging in the mouth	Current	47 (17.3%)	14 (12.6%)	7 (12.5%)	11 (28.2%)	15 (22.7%)	5 (13.2%)	4 (17.4%)	1 (16.7%)	0 (0.0%)	0 (0.0%)
	Earliest-onset	6 (2.2%)	2 (1.8%)	1 (1.8%)	1 (2.6%)	2 (3.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	Troublesome	5 (1.8%)	3 (2.7%)	0 (0.0%)	0 (0.0%)	1 (1.5%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Feeling food sticking or lodging in the throat	Current	207 (76.1%)	88 (79.4%)	40 (71.4%)	30 (76.9%)	49 (74.2%)	21 (55.3%)	13 (56.5%)	1 (16.7%)	3 (100.0%)	4 (66.7%)
	Earliest-onset	120 (44.1%)	50 (45.0%)	24 (42.9%)	18 (46.2%)	28 (42.4%)	7 (18.4%)	6 (26.1%)	0 (0.0%)	1 (33.3%)	0 (0.0%)
	Troublesome	105 (38.6%)	44 (39.6%)	21 (37.5%)	15 (38.5%)	22 (33.3%)	4 (10.5%)	3 (13.0%)	0 (0.0%)	0 (0.00%)	1 (33.3%)
Feeling of food sticking or lodging in the chest	Current	72 (26.5%)	26 (23.4%)	17 (30.4%)	7 (17.9%)	22 (33.3%)	5 (13.2%)	3 (13.0%)	1 (16.7%)	0 (0.0%)	1 (33.3%)
	Earliest-onset	20 (7.4%)	6 (5.4%)	8 (14.3%)	0 (0.0%)	6 (9.1%)	2 (5.3%)	0 (0.0%)	1 (16.7%)	0 (0.0%)	1 (16.7%)
	Troublesome	25 (9.2%)	9 (8.1%)	8 (14.3%)	1 (2.6%)	8 (12.1%)	2 (5.3%)	0 (0.0%)	1 (16.7%)	0 (0.0%)	1 (16.7%)
Pain or discomfort whilst swallowing	Current	54 (19.9%)	17 (15.3%)	17 (30.4%)	4 (10.3%)	16 (24.2%)	8 (21.1%)	5 (21.7%)	1 (16.7%)	1 (33.3%)	1 (16.7%)
	Earliest-onset	13 (4.8%)	4 (3.6%)	7 (12.5%)	0 (0.0%)	2 (3.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)

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	Troublesome	13 (4.8%)	3 (2.7%)	10 (17.9%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Difficulty swallowing tablet medication	Current	125 (46.0%)	43 (38.7%)	23 (41.1%)	28 (71.8%)	31 (47.0%)	13 (34.2%)	9 (39.1%)	2 (33.3%)	1 (33.3%)	1 (16.7%)
	Earliest-onset	58 (21.3%)	19 (17.1%)	9 (16.1%)	18 (46.2%)	12 (18.2%)	4 (10.5%)	1 (4.3%)	2 (33.3%)	0 (0.0%)	1 (16.7%)
	Troublesome	38 (14.0%)	10 (9.0%)	4 (7.1%)	7 (17.9%)	6 (9.1%)	3 (7.9%)	1 (4.3%)	2 (33.3%)	0 (0.0%)	0 (0.0%)
Drooling, gurgling or coughing on saliva	Current	117 (43.0%)	53 (47.7%)	20 (35.7%)	15 (38.5%)	29 (43.9%)	17 (44.7%)	12 (52.2%)	1 (16.7%)	1 (33.3%)	3 (50.0%)
	Earliest-onset	38 (14.0%)	19 (17.1%)	7 (12.5%)	3 (7.7%)	9 (13.6%)	6 (15.8%)	4 (17.4%)	1 (16.7%)	0 (0.0%)	1 (16.7%)
	Troublesome	41 (15.1%)	26 (23.4%)	6 (10.7%)	4 (10.2%)	6 (9.1%)	6 (15.8%)	4 (17.4%)	0 (0.0%)	1 (33.3%)	1 (16.7%)
Feeling sticky secretions in the mouth or throat	Current	92 (33.8%)	36 (32.4%)	16 (28.6%)	21 (53.8%)	19 (28.8%)	11 (28.9%)	8 (34.8%)	0 (0.0%)	1 (33.3%)	2 (33.3%)
	Earliest-onset	23 (8.5%)	12 (10.8%)	4 (7.1%)	3 (7.7%)	4 (6.1%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	Troublesome	19 (7.0%)	9 (8.1%)	5 (8.9%)	7 (17.9%)	2 (3.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Chest infection(s) requiring hospital admission or GP treatment	Current	52 (19.1%)	23 (20.7%)	8 (14.3%)	12 (30.8%)	9 (13.6%)	11 (28.9%)	8 (34.8%)	0 (0.0%)	1 (33.3%)	2 (33.3%)
	Earliest-onset	18 (6.6%)	9 (8.1%)	3 (5.4%)	3 (7.7%)	3 (4.5%)	3 (7.9%)	3 (13.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	Troublesome	11 (4.0%)	3 (2.7%)	1 (1.8%)	4 (10.2%)	4 (6.1%)	5 (13.2%)	4 (17.4%)	0 (0.0%)	0 (0.0%)	1 (33.3%)
Weight loss	Current	29 (10.7%)	11 (9.9%)	3 (5.4%)	5 (12.8%)	10 (15.2%)	11 (28.9%)	7 (30.4%)	1 (16.7%)	1 (33.3%)	2 (33.3%)
	Earliest-onset	6 (2.2%)	2 (1.8%)	1 (1.8%)	0 (0.0%)	3 (4.5%)	3 (7.9%)	3 (13.4%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	Troublesome	5 (1.8%)	2 (1.8%)	1 (1.8%)	1 (2.6%)	2 (3.0%)	3 (7.9%)	3 (13.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Taking extra care when eating and drinking	Current	187 (68.8%)	74 (66.7%)	33 (58.9%)	34 (87.2%)	46 (69.7%)	29 (76.3%)	17 (73.9%)	4 (66.7%)	3 (100.0%)	5 (83.3%)
	Earliest-onset	29 (10.6%)	11 (9.9%)	2 (3.6%)	10 (25.6%)	6 (9.1%)	8 (21.1%)	4 (17.4%)	3 (50.0%)	1 (33.3%)	0 (0.0%)
	Troublesome	46 (16.9%)	16 (14.4%)	8 (14.3%)	8 (20.5%)	12 (18.2%)	10 (26.3%)	7 (30.4%)	3 (50.0%)	0 (0.0%)	0 (0.0%)
Mealtimes take longer	Current	152 (55.9%)	57 (51.4%)	16 (28.6%)	35 (89.7%)	44 (66.7%)	29 (76.3%)	17 (73.9%)	5 (83.3%)	2 (66.7%)	5 (83.3%)
	Earliest-onset	45 (16.5%)	22 (19.8%)	3 (5.4%)	12 (30.8%)	8 (12.1%)	8 (21.1%)	5 (21.7%)	2 (33.3%)	1 (33.3%)	0 (0.0%)
	Troublesome	45 (16.5%)	16 (14.4%)	4 (7.1%)	14 (35.9%)	13 (19.7%)	7 (18.4%)	4 (17.4%)	2 (33.3%)	1 (33.3%)	0 (0.0%)
Unable to talk/socialise when eating & drinking	Current	87 (32.0%)	34 (30.6%)	11 (19.6%)	17 (43.6%)	25 (37.9%)	12 (31.6%)	7 (30.4%)	0 (0.0%)	3 (100.0%)	2 (33.3%)
	Earliest-onset	16 (5.9%)	8 (7.2%)	1 (1.8%)	1 (2.6%)	6 (9.1%)	1 (2.6%)	0 (0.0%)	0 (0.0%)	1 (33.3%)	0 (0.0%)
	Troublesome	21 (7.7%)	11 (9.9%)	2 (3.6%)	6 (15.4%)	7 (10.6%)	3 (7.9%)	1 (4.3%)	0 (0.0%)	2 (66.7%)	0 (0.0%)
I need to adapt	Current	168 (61.8%)	67 (60.4%)	29 (51.8%)	31 (79.5%)	41 (62.1%)	27 (71.1%)	17 (73.9%)	3 (50.0%)	3 (100.0%)	4 (66.7%)

what and how I eat	Earliest-onset	30 (11.0%)	15 (13.5%)	2 (3.6%)	6 (15.4%)	7 (10.6%)	9 (23.7%)	4 (17.4%)	2 (33.3%)	1 (33.3%)	2 (33.3%)
	Troublesome	43 (15.8%)	21 (18.9%)	7 (12.5%)	4 (10.3%)	9 (13.6%)	10 (26.3%)	7 (30.4%)	2 (33.3%)	0 (0.0%)	1 (16.7%)
I drink with meals	Current	150 (55.1%)	75 (67.6%)	22 (39.3%)	16 (41.0%)	37 (56.1%)	25 (65.8%)	16 (69.6%)	2 (33.3%)	3 (100.0%)	4 (66.7%)
	Earliest-onset	39 (14.3%)	25 (22.5%)	3 (5.4%)	3 (7.7%)	8 (12.1%)	3 (7.9%)	2 (8.7%)	1 (16.7%)	0 (0.0%)	0 (0.0%)
	Troublesome	19 (7.0%)	14 (12.6%)	0 (0.0%)	1 (2.6%)	2 (3.0%)	1 (2.6%)	1 (4.3%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
I thicken my drinks	Current	6 (2.2%)	1 (0.9%)	0 (0.0%)	1 (2.6%)	4 (6.1%)	2 (5.3%)	1 (4.3%)	0 (0.0%)	0 (0.0%)	1 (16.7%)
	Earliest-onset	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	Troublesome	1 (0.4%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (1.5%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
I don't enjoy eating and drinking any more	Current	37 (13.6%)	15 (13.5%)	4 (7.1%)	8 (20.5%)	10 (15.2%)	8 (21.1%)	3 (13.0%)	1 (16.7%)	3 (100.0%)	1 (16.7%)
	Earliest-onset	1 (0.4%)	0 (0.0%)	0 (0.0%)	1 (2.6%)	0 (0.0%)	1 (2.6%)	0 (0.0%)	0 (0.0%)	1 (33.3%)	0 (0.0%)
	Troublesome	7 (2.6%)	4 (3.6%)	0 (0.0%)	2 (5.1%)	2 (3.0%)	5 (13.2%)	1 (4.3%)	1 (16.7%)	2 (66.7%)	1 (16.7%)
I am nervous or scared when eating & drinking	Current	47 (17.3%)	12 (10.8%)	7 (12.5%)	16 (41.0%)	12 (18.2%)	6 (15.8%)	2 (8.7%)	1 (16.7%)	1 (0.0%)	2 (33.3%)
	Earliest-onset	5 (1.8%)	2 (1.8%)	1 (1.8%)	1 (2.6%)	1 (1.5%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	Troublesome	6 (2.2%)	3 (2.7%)	1 (1.8%)	5 (12.8%)	1 (1.5%)	2 (5.3%)	1 (4.3%)	0 (0.0%)	0 (0.0%)	1 (16.7%)
Other ²	Current	7 (2.6%)	0 (0.0%)	2 (3.6%)	0 (0.0%)	5 (7.6%)	4 (10.5%)	3 (13.0%)	1 (16.7%)	0 (0.0%)	0 (0.0%)
	Earliest-onset	6 (2.2%)	0 (0.0%)	1 (1.8%)	0 (0.0%)	5 (7.6%)	2 (5.3%)	1 (4.3%)	1 (16.7%)	0 (0.0%)	0 (0.0%)
	Troublesome	4 (1.5%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	4 (6.1%)	2 (5.3%)	1 (4.3%)	1 (16.7%)	0 (0.0%)	0 (0.0%)

ii) Life-threatening indications of dysphagia (choking, weight loss & chest infections)

		Participants living with NMD (plwNMD)					Participant caregivers (pCG)				
	Descriptor	All NMD (n=272)	DM1 (n=111)	FSHD (n=56)	SMA 2&3 (n=39)	Other NMD (n=66)	All NMD (n=38)	DM1 (n=23)	SMA (n=6)	IBM (n=3)	Other NMD (n= 6)
Choking event requiring emergency or hospital attention	A few	15 (5.5%)	3 (2.7%)	2 (3.6%)	5 (12.8%)	5 (7.6%)	3 (7.9%)	3 (13.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	One	14 (5.1%)	5 (4.5%)	1 (1.8%)	4 (10.3%)	4 (6.1%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	Never	243 (89.3%)	103 (92.8%)	53 (94.6%)	30 (76.9%)	57 (86.4%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)

Weight	Over	94 (34.6%)	44 (39.6%)	23 (41.1%)	9 (23.1%)	18 (27.3%)	12 (31.6%)	9 (39.1%)	0 (0.0%)	0 (0.0%)	3 (50.0%)
	Under	44 (16.2%)	21 (18.9%)	7 (12.5%)	6 (15.4%)	10 (15.1%)	14 (36.8%)	7 (30.4%)	4 (66.7%)	1 (33.3%)	2 (33.3%)
	About right	134 (49.3%)	46 (41.4%)	26 (46.4%)	24 (61.5%)	38 (57.6%)	10 (26.3%)	6 (26.1%)	2 (33.3%)	1 (33.3%)	1 (16.7%)
	Unsure	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (5.3%)	1 (4.3%)	0 (0.0%)	1 (33.3%)	0 (0.0%)
Chest infections related to food & drink	>1 in 12 months	6 (2.2%)	3 (2.7%)	2 (3.6%)	1 (2.6%)	0 (0.0%)	2 (5.3%)	2 (8.7%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	1 in 6 months	5 (1.8%)	0 (0.0%)	1 (1.8%)	2 (5.1%)	2 (3.0%)	1 (2.6%)	1 (4.3%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	1 in 12 months	14 (5.1%)	7 (6.3%)	0 (0.0%)	2 (5.1%)	5 (7.6%)	1 (2.6%)	1 (4.3%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	1 in 3 years	14 (5.1%)	4 (3.6%)	3 (5.4%)	2 (5.1%)	5 (7.6%)	4 (10.5%)	2 (8.7%)	1 (16.7%)	1 (33.3%)	0 (0.0%)
	Never	81 (29.8%)	37 (33.3%)	22 (39.3%)	0 (0.0%)	22 (33.3%)	9 (23.7%)	4 (17.4%)	2 (33.3%)	0 (0.0%)	3 (50.0%)
	Unrelated	142 (52.2%)	58 (52.3%)	26 (46.4%)	28 (71.8%)	30 (45.5%)	12 (31.6%)	9 (39.1%)	0 (0.0%)	1 (33.3%)	2 (33.3%)
	Other/Unsure	10 (3.7%)	2 (1.8%)	2 (3.6%)	4 (10.3%)	2 (3.0%)	9 (23.7%)	4 (17.4%)	3 (50.0%)	1 (33.3%)	1 (16.7%)

iii) Progression of dysphagia

		Participants living with NMD (plwNMD)					Participant caregivers (pCG)				
	Length of time living with dysphagia	All NMD (n=272)	DM1 (n=111)	FSDH (n=56)	SMA 2&3 (n=39)	Other NMD (n=66)	All NMD (n=38)	DM1 (n=23)	SMA (n=6)	IBM (n=3)	Other NMD (n= 6)
Worsened	Total	180 (66.2%)	76 (68.5%)	32 (57.1%)	34 (87.2%)	38 (57.5%)	36 (94.7%)	23 (100%)	5 (83.3%)	3 (100%)	5 (83.3%)
	<12 months	13 (4.8%)	3 (2.7%)	5 (8.9%)	4 (10.3%)	1 (1.5%)	4 (10.5%)	1 (4.3%)	2 (33.3%)	0 (0.0%)	1 (16.7%)
	1-5 years	89 (32.7%)	44 (39.6%)	16 (28.6%)	13 (33.3%)	16 (24.2%)	16 (42.1%)	11 (47.8%)	3 (50.0%)	0 (0.0%)	2 (33.3%)
	6-15 years	51 (18.8%)	18 (16.2%)	8 (14.3%)	11 (28.2%)	14 (21.2%)	13 (34.2%)	9 (39.1%)	0 (0.0%)	3 (100%)	1 (16.7%)
	>15 years	27 (9.9%)	11 (9.9%)	3 (5.4%)	6 (15.4%)	7 (10.6%)	3 (7.9%)	2 (8.7%)	0 (0.0%)	0 (0.0%)	1 (16.7%)
Improved	Total	9 (3.3%)	5 (4.5%)	1 (1.8%)	0 (0.0%)	3 (4.5%)	1 (2.6%)	0 (0.0%)	1 (16.7%)	0 (0.0%)	0 (0.0%)
	<12 months	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	1-5 years	1 (0.4%)	1 (0.9%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)

	6-15 years	3 (1.1%)	1 (0.9%)	0 (0.0%)	0 (0.0%)	2 (3.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	>15 years	5 (1.8%)	3 (2.7%)	1 (1.8%)	0 (0.0%)	1 (1.5%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	Total	83 (30.5%)	30 (27.0%)	23 (14.1%)	5 (12.8%)	25 (37.9%)	1 (2.6%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (16.7%)
Unchanged	<12 months	10 (3.7%)	3 (2.7%)	5 (8.9%)	0 (0.0%)	2 (3.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	1-5 years	37 (13.6%)	12 (10.8%)	13 (23.2%)	2 (5.1%)	10 (15.2%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (16.7%)
	6-15 years	23 (8.5%)	10 (9.0%)	4 (7.1%)	1 (2.6%)	8 (12.1%)	1 (2.6%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	>15 years	13 (4.8%)	5 (4.5%)	1 (1.8%)	2 (5.1%)	5 (7.6%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)

DM1 = Myotonic Dystrophy, FSHD = Facioscapulohumeral Muscular Dystrophy, SMA = Spinal muscular Atrophy, IBM = Inclusion Body Myositis.

Underlined: length of time living with dysphagia not specified

1. Statements have been provided in first person to reflect statements from participants living with dysphagia. The equivalent third-person statements were provided for caregivers (e.g., 'Food sticking or lodging in the mouth' would translate to '*They report* food sticking or lodging in the mouth').

2. **Participant(s) living with FSHD**: I choke 'on nothing,' food falls out of my mouth, I have a very dry mouth. **Participant(s) living with other NMD**: I have a constantly dry throat (*person living with CMT*), I have a gastrostomy fitted (*person living with undiagnosed NM condition*) I have to time when I eat according to my medication (*person living with myasthenia gravis*), I have to clear my throat (*person living with CMT*), my throat clamps up when I swallow (*person living with myotonic dystrophy type 2*).

Participant caregiver for plwDM1: They have a gastrostomy (n=2), they avoid certain foods. **Participants caregiver for plwSMA**: They can't swallow at all, not even their saliva.