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Living with Motor Neurone Disease (MND) and Dysphagia – the personal experiences of people with MND and their caregivers

Volume 2 (2)

Appendices and References

Thesis presented by

Dominika Lisiecka, MSc. in Speech & Language Therapy

2018

List of Contents

Appendix 1: Irish Consistency Descriptors for Modified Fluids and Foods 1

Appendix 2: Functional Oral Intake Scale..... 2

Appendix 3: ALS Severity Scale: Speech 3

Appendix 4: Letter of Invitation to Participate in a Research Project..... 4

Appendix 5: Consent for Participation in Research 6

Appendix 6 a): Interview Template for a Person with MND 10

Appendix 6 b): Interview Template for a Caregiver 12

Appendix 7 a): Data Analysis Table: A PwMND (Sally) 14

Appendix 7 b): Data Analysis Table: A Caregiver (Jackie) .. 20

Appendix 8 a): Mind Map - A PwMND (Sally)……...42

Appendix 8 b): Mind Map – A Caregiver (Jackie)..... 43

References……44

Appendix 1: Irish Consistency Descriptors for Modified Fluids and Foods

Irish Consistency Descriptors for Modified Fluids and Foods

IASLT

Irish Nutrition and Dietetic Institute

Modified Foods

Texture A - Soft

May be naturally soft or cooked/ cut to alter its texture.

Texture B - Minced and moist

Soft, moist and easily mashed with a fork.

Texture C - Smooth pureed

Smooth, moist and lump free

Texture D - Liquidised

Smooth, pouring, uniform consistency

Modified Fluids

Grade 1 - Very Mildly Thick

Steady, Fast flow

Pours quickly from a cup but slower than regular, unmodified fluids.

No effort required to take this thickness via a standard bore straw

Grade 2 - Mildly Thick

Steady, Fast flow

Pours quickly from a cup but slower than regular, unmodified fluids.

Effort required to take this thickness via a standard bore straw

Grade 3 - Moderately Thick

Slow flow

Cohesive and pours slowly

Possible to drink from a cup although fluid flows very slowly

Difficult to drink using a straw, even if using a wide bore straw

Grade 4 - Extremely Thick

No flow

Cohesive and holds its shape on spoon

It is *not* possible to pour this type of fluid from a cup into the mouth

For further information or copies of this poster please refer to: www.iaslt.com (Irish Association of Speech and Language Therapists) or www.indi.com (Irish Nutrition and Dietetic Institute)
With thanks to: The Speech Pathology Association of Australia and the Dieticians Association of Australia.

Appendix 2: Functional Oral Intake Scale

(Crary, Mann, & Groher, 2005)

TUBE DEPENDENT (levels 1-3)

1. No oral intake
2. Tube dependent with minimal/ inconsistent oral intake
3. Tube supplements with consistent oral intake

TOTAL ORAL INTAKE (levels 4-7)

4. Total oral intake of a single consistency
5. Total oral intake of multiple consistencies requiring special preparation.
6. Total oral intake with no special preparation, but must avoid specific foods or liquids items.
7. Total oral intake with no restrictions.

Appendix 3: ALS Severity Scale: Speech

(Hillel et al., 1989)

NORMAL SPEECH PROCESSES

10 – Normal Speech: Patients denies any difficulty speaking. Examination demonstrates no abnormality.

9 – Nominal Speech Abnormality: Only the patient or spouse notices that speech has changed. Maintains normal rate and volume.

DETECTABLE SPEECH DISTURBANCE

8 – Perceived Speech Changes: Speech changes are noted by others, especially during fatigue or stress. Rate of speech reminds essentially normal.

7 – Obvious speech abnormalities: Speech is consistently impaired. Affected are rate, articulation, and resonance. Remains easily understood.

BEHAVIOURAL MODIFICATIONS

6 – Repeats Messages on Occasion: Rate is much slower. Repeats specific words in adverse listening situation. Does not limit complexity or length of message.

5 – Frequent Repeating Required: Speech is slow and labored. Extensive repetition or a "translation" is commonly needed. Patient probably limits the complexity or length of messages.

USE OF AUGMENTATIVE COMMUNICATION

4 – Speech Plus Augmentative Communication: Speech is used in response to questions. Intelligibility problems need to be resolved by writing or a spokesperson.

3 – Limits speech to One-Word Response: Vocalizes one word response beyond yes/no; otherwise writes or uses a spokesperson. Initiates communication nonvocally.

LOSS OF USEFULL SPEECH

2 – Vocalizes for Emotional Expression: Uses vocal inflection to express emotion, affirmation, and negation.

1 – Nonvocal: Vocalization is effortful, limited in duration, and rarely attempted. May vocalize for crying or pain.

Appendix 4: Letter of Invitation to Participate in a Research Project

Living with Motor Neuron Disease (MND) and Dysphagia – the personal experiences of individuals with MND and their caregivers.

My name is Dominika Lisiecka. I am a Speech & Language Therapist and a student in the Department of Speech & Hearing Sciences at University College Cork. I am conducting a research study as part of the requirements of my PhD degree. I would like to invite you to participate in this study. Please read this letter as you have to be fully aware of time commitment and any potential risks and benefits to make an informed decision.

I would like to study the experiences of people living with motor neuron disease (MND), who also have swallowing difficulties. I am contacting you as you have been diagnosed with MND and swallowing problems or you are caring for someone with these problems.

If you decide to participate, I will meet you to get your consent and I will check if you fulfil all criteria to take part in this study. After that, you will be asked to meet me for two interviews. There will be an option of scheduling more interviews if we both feel the need to do so.

The interviews will take place in your home. However, if you prefer to meet me at different location, I can provide an alternative venue.

The time will be mutually agreed and the duration of each interview will be 45 minutes maximum (for a person with MND) and 60 minutes (for a caregiver).

Each session will be audio recorded so that I can accurately reflect on what is discussed. If you use alternative communication I will ask for your permission to video tape the session, but you have right to refuse (and we will audio record only). The recordings will only be reviewed by members of the research team, who will transcribe and analyse them.

Your participation is confidential. Study information will be kept in a secure location at the University College Cork. The results of the study may be published or presented at professional meetings, but your identity will not be revealed.

You may feel emotional during the interview and you can stop the interview at any point. We will also stop when you get tired.

Taking part in this study is your decision. Although you won't benefit directly from participating in the study, we hope that others affected by MND and swallowing difficulties will benefit, as this project should improve our understanding of these problems. The data you will provide will be analysed, the result will be presented in a thesis and shared with relevant professionals. It is hoped that this information will result in improved quality of life and quality of care for both patients with MND and their families.

Your participation is voluntary and you can withdraw at any stage with no consequences. You may also request to have your data destroyed up to two weeks after the last interview.

There is no financial reimbursement for participation in this study.

I will contact you next week to see if you would like to participate. Alternatively, you may contact me at any stage and I will be happy to answer any questions. My phone number is 0861564494 and my email is MNDresearchPhD@gmail.com.

You may also wish to contact my Chief-Investigator, Dr. Helen Kelly at the Department of Speech and Hearing Sciences, School of Clinical Therapies, Brookfield Health Sciences Complex, University College Cork, College Road Cork, Ireland; tel: (0) 21 490 1746; fax: (0) 21 490 1542; email: helen.kelly@ucc.ie

With kind regards,

Dominika Lisiecka

Appendix 5: Consent for Participation in Research

Information Sheet

"Living with Motor Neuron Disease (MND) and Dysphagia – the personal experiences of individuals with MND and their caregivers.

You are being asked to participate in a research study investigating the experiences of swallowing difficulties in Motor Neurone Disease (MND). In order to decide whether or not you want to be a part of this research study, you should understand enough about its risks and benefits to make an informed judgment. This process is known as informed consent. This consent form gives detailed information about the research study, which will be discussed with you. Once you understand the study, you will be asked to sign this form if you wish to participate.

STUDY INFORMATION:

We are doing this study to improve our understanding of swallowing problems in Motor Neurone Disease. We are interested in finding out how people living with MND experience swallowing difficulties. We would like to talk to adults diagnosed with MND and their caregivers.

Interviews

At least two interviews are planned with every person. The duration of each interview will be approximately 45 minutes for the person with MND and 60 minutes for the caregiver. We will voice record all interviews. In some circumstances we may ask you to make a video recording, but you have the right to limit the recording to voice recording only.

Inclusion criteria

We have a list of specific conditions, which you will need to fulfil in order to take part in this project. For example, we will look at the time since your diagnosis, what diet you eat/ prepare, what your thinking processes are like. We will explain all conditions to you at our first meeting. If you fulfil the conditions we will schedule our first interview.

What will happen to your records?

Ensuring that your records are kept confidential is very important to us. We will remove your name and any other information which could identify you. Only the research team may access the original data. The recordings of our talks will be stored on an encrypted laptop / encrypted external drive and kept in a locked filing cabinet in a locked room at the University College Cork.

We will analyse your recordings and results will be presented in a thesis and shared with relevant professionals. Some of the interview (for example, quotations) may be presented at conferences or published in writing, but your identity will never be revealed.

Is the information I share in the interviews confidential?

The information you share in the interviews are considered confidential. However, in some exceptional circumstances it may become necessary to break confidentiality. Exceptional circumstances include:

1. If there is a serious concern that there may be a threat to the safety or life of you or others.
2. In the context of criminal behaviour and disclosures required by legal process.
3. In the context of child protection and elderly protection issues.

If this is required, it will be done with sensitivity and on a need to know basis. Your interviewer will make every effort to discuss this with you before that step is taken.

Potential risks and benefits

You may feel emotional or tired during the interview and you can stop the interview at any point.

Taking part in this study is your decision. Your participation is voluntary and you can withdraw at any stage with no consequences. Your withdrawal will not have any impact on the health services normally available to you. You may also request to have your data destroyed up to two weeks after the last interview.

Although you may not benefit directly from participating in the study, this project may improve our understanding of these problems. It is hoped that this information will result in improved quality of life and quality of care for both patients with MND and their families.

Primary Investigator:

Dominika Lisiecka
Department of Speech and Hearing Sciences, School of Clinical Therapies, Brookfield Health Sciences Complex, University College Cork, College Road Cork, Ireland
Tel: 0861564494
Email: MNDresearchPhD@gmail.com.
Dominika Lisiecka is carrying out this project as part of the requirements for her PhD at University College Cork which has been funded by the Health Research Board. She is being supervised by Dr. Helen Kelly and Prof Jeanne Jackson.

Chief-Investigators:

Dr. Helen Kelly, Department of Speech and Hearing Sciences, School of Clinical Therapies, Brookfield Health Sciences Complex, University College Cork, College Road Cork, Ireland
Tel: (0) 21 490 1746
Email: helen.kelly@ucc.ie
Prof. Jeanne Jackson, Department of Occupational Sciences and Occupational Therapy, School of Clinical Therapies, Brookfield Health Sciences Complex, University College Cork, College Road Cork, Ireland
Tel: (0) 21 4901536
Email: j.jackson@ucc.ie

AGREEMENT TO CONSENT

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason.

3. I agree to take part in the above study

4. I agree to the interview being audio recorded

5. I agree to the interview being video recorded (if appropriate)

6. I agree to the use of anonymised quotes in publications

7. I understand that in exceptional circumstances where a significant risk of safety of life has been identified it may be necessary to break the confidentiality. This will be discussed with me before any action.

I have received a copy of this consent form for my records. I understand that if I have any questions concerning this research, I can contact the persons listed above.
After reading the entire consent form, if you have no further questions about the study and wish to participate, please sign where indicated.

I, the undersigned, hereby consent to participate in the above described project conducted at University College Cork.
Signature of participant:_____
Date and time: _____
Witness: _____
Date and time:_____

Appendix 6 a): Interview Template for a Person with MND

Name: _____

The following background / demographic questions will be asked following the interview in an open-ended manner (as far as possible)

DOB: _____

Address: _____

GP: _____

Neurologist: _____

Medications:_____

_____

Member of IMNDA: Yes □ No□

Current diet: Oral □ Non-oral □ (NG□ PEG □ PEJ □ REG □) both□

Current liquid consistency: _____

Current food texture: _____

Self-feeding: Yes □ No □

Occupation: _____

Lives with: _____

Interviewer introduction:

Hi, my name is Dominika and I am a student at UCC. As part of my PhD I am conducting a research project and as part of that I will be interviewing you today. I am very glad that you gave your consent to participate in my project. You can stop the interview at any point. As discussed before, I will record your voice to help me analyse our interview. Please let me know if you feel tired and need to take a break.

Main questions	Additional questions
I am interested in getting information about you and your life. Can you tell me a little bit about you and your family? If I followed you throughout a typical day, what would I see you doing? Some people say that they have good days, days when they have good energy and are able to do more, and bad days, days when the energy is lower and they are not as active. What about you?	Do you work? (if appropriate) How is work?
We are going to talk about food and eating now. Can you tell me about your typical breakfast, lunch and dinner? I would like you to go back to the past. Can you recall any meal that you really enjoyed? What was it like? Some people love food and food is very important in their lives. Others eat to keep going, but don't really pay much attention to food. What about you? What place does food have in your life? In the last few months has anything changed in the way you eat or drink? Can you tell me more about this? Can you tell me how did you discover that your swallow had gotten weaker? What knowledge did you have about the swallowing before you became sick? How do you understand swallowing problems now?	Can you elaborate on that? That's helpful. I'd appreciate more details. When was it? Where were you? Who were you with? How did the food taste/ smell/ look? Alternative: How has the way you eat and drink changed in the last few months?
What is it like to have swallowing problems and MND? If you had any questions related to your swallowing, who would you ask? What do you think about the services you received for your swallowing problem? If you had a power to make any changes to the services you and your family received so far, would you change anything?	Suppose I was someone who never heard of swallowing problems and MND, how would you explain these to me? (If yes) What would you like to change?
Conclusion of interview Would you like to add anything else? Were you surprised by the questions I asked? Did I leave anything out that you thought I would ask?	

Appendix 6 b): Interview Template for a Caregiver of a Person with MND

Name: _____

Date: _____

Address: _____

Member of IMNDA: Yes □ No □

Occupation: _____

Relationship with the person with MND _____

Introduction of interviewer:

Hi, my name is Dominika and I am a student at UCC. As part of my PhD I am conducting a research project and as part of that I will be interviewing you today. I am very glad that you gave me your consent to participate in this project. You can stop the interview at any point. As discussed before, I will record your voice to help me analyse our interview. Please let me know if you wish to take a break.

Main questions	Additional questions
I am interested in getting information about you and your life. Can you tell me a little bit about you and your family?	Do you work? How is work?
If I followed you throughout a typical day, what would I see you doing?	
I would like to talk about X (person with MND) now.	
Can you tell me how you care for X?	
What is it like to look after X?	
Suppose I was someone who is just about to start caring for someone with MND. How would you help me to prepare for this role?	
When you care for X, is there anything you find particularly hard?	(if yes) Is there anything that you find the hardest?
I would like to talk about eating now.	
Can you describe X's typical breakfast, lunch and dinner.	
How exactly do you help X with eating and drinking?	How do you prepare food for X?
I understand that X has some swallowing problems. Can you tell me how it all started?	Can you take me through what happened?
In the last few months, has anything changed in the way X eats and drinks? Can you tell me more about that?	Alternative: How exactly has the way X eats and drinks changed in the last few months?
What is it like to look after someone with swallowing difficulties?	
What knowledge did you have about the swallow before X became sick?	
How do you understand swallowing problems now?	
If you had any questions related to X swallowing, who would you ask?	
What do you think about the services you received for X's swallowing problem?	
If you had a power to make any changes to the services you and X received so far, would you change anything?	(If yes) What would you like to change?
Conclusion of interview	
Would you like to add anything else? Were you surprised by the questions I asked? Did I leave anything out that you thought I would ask?	

Appendix 7 a): Data Analysis Table: A PwMND (Sally)

Superordinate theme	Subordinate themes	Emergent themes	Quotations	Line
1. Living with dysphagia	**1.1 Pre-gastrostomy experiences**	"I thought I was going to die"	**What did you feel? [when the swallow problems started]** I thought I was going to die.	16-17
		Swallow deterioration	**So Sally, can you remember when the swallow problems started?** Ehm (pause)… I don't know. About 4 weeks before the tube.	12-14
		Losing weight	(…) all my clothes got too big.	115-116
		Choking	**And can you remember the first time when the choking happened to you?** I can. **What was happening? Can you describe?** I couldn't get my breath. **What were you eating?** I can't remember. **Were you on your own?** Maybe? It was nothing. Got worse.	18-26
		Unable to eat	**And were you advised not to take anything by mouth?** I can't…couldn't… (body language indicating no ability to swallow at all)	84-85
		Determined to look for explanations	**What were you thinking before? Did you have anything in your mind what was happening to you?** I was thinking we have the money to go anywhere in the world to get help.	31-32
		No previous knowledge of dysphagia	**And what knowledge did you have about the swallow before?** No.	95-96
		Diagnosis as a relief	**Can you remember your first visit to [hospital]?** Yes **How was that for you?** It was such a relief to know at last what was wrong with me.	27-30

Comments:

This was a very stressful time. The time of not knowing what was happening with her body. Her speech started to slur and she became unable to swallow. She was not able to eat anything at all for about 2 weeks before she was diagnosed. She thought she was dying, but she didn't give up. She wanted to find out what was wrong with her. She was prepared to travel and pay a lot of money to get some answers. There were delays between visits with consultants. Finally, Sally's daughter rang the IMNDA and she got an appointment within two weeks. Sally went up to the MND clinic and got her answer: MND. Not many people would say that they felt relieved when they heard the diagnosis. For Sally, the diagnosis explained

her symptoms and gave her access to medical management and support. Maybe she felt understood and reassured. *Sally has a good insight into her swallowing status. She is not denying the problem. She admits it. She remembers her first choking experiences but that was only the beginning. The swallow deteriorated with time to the point where Sally became unable to swallow anything. Even a taste of food was not possible. Her own saliva became a serious risk and could potentially choke her.* *Would it have helped Sally to have had some previous knowledge of dysphagia? Would this have helped her to find the answers quicker? It must have been so exhausting and hard. She continued her house-hold routines, such as shopping and cooking and she was trying to eat but it was becoming harder and harder. She did not suspect MND. In fact, she did not suspect anything. She had no clue. She couldn't understand what was happening to her and she was convinced that she was dying.* *When I think about Sally's life before she got the diagnosis and the gastrostomy tube (which was almost simultaneous), I feel that she escaped death in the last moment. Prior to non-oral feeding she was already unable to eat and lost much weight. Paradoxically, as how can you say that someone has escaped death by being diagnosed with a terminal disease… but this was the case for Sally. In her circumstances, the diagnosis of MND opened the door to the medical services that she required. Although Sally could not be cured, her symptoms could be managed, ultimately prolonging her life.*				
	1.2 Living with non-oral feeding	Acceptance of gastrostomy	**And was it [doctor] who talked to you about the tube?** Hmm [yes] **Can you remember that moment?** [nod] **What did you think of it?** I was willing to do it.	38-43
		Non-oral feeding as a relief	**What was your impression when you saw the tube for the first time?** [vocalisations] **Is that nervous?** [Vocalisation]. [wrote]: Relived.	50-53
		Feeding regime	We are working on it now.	113
			And I understand the feeding takes a long time now. Hmm (yes). 16 hrs.	67-70
		Position	Liam cleans the RIG and I come out and sit for the rest of the food to finish.	68-69
			I would like to be able to sleep on my side and put my arm around Liam. **Is that not possible because…** The pillow is very high and I have to sit up. **Has that changed the way you sleep?** Yes.	117-121
		Husband's support	**If I followed you through you typical day what would I see you doing from the moment you wake up?**	65-68

		Liam takes out the food thing and I have a shower… Liam cleans the RIG (…)	
	Problems	**So what happened today? You had to go to the doctor…** I broke the tube. My tube came loose.	4-5

Comments:
Sally was willing to be fed non-orally. She was willing to live and she had no other option. Her swallow had failed completely. It was a life and death choice for her. Her initial reaction when she saw the RIG for the first time was the feeling of being relived. The procedure was successful. The gastrostomy tube was there. In her stomach. A small piece of plastic which could prolong her life. She had just managed to get it on time. This was due to her daughter who contacted the IMNDA. Although Sally had been seen by various medical professionals the progression of MND was so much faster than the delays in the health service. Sally tried to get help. She was told to wait. Each time. Her symptoms were classic and although the diagnosis could not have been confirmed without undergoing specific tests, the doctors must have had some suspicions. How was she left starving for 2 weeks before seeing a doctor, who decided to perform a gastrostomy, (as reported by her husband)?Sally had been seen by many professionals for many weeks, yet when her dysphagia progressed dramatically leaving Sally unable to eat and drink, no one was around to help her.

Although the feeding tube prolonged Sally's life, it came with specific problems and demands. The feeding regime took time to establish. It was a trial and error approach where various types of feeds were given to see how Sally's digestive system reacted. She still requires to be fed very slowly. Although she is being fed all night it is not sufficient. Her feeds take 16 hours to be administered. Sally needs her husband's support to look after the "food thing". She has lost a lot of independence.

Re: position. It is known that non-oral feeding increases the risk of reflux and subsequently chest infections or pneumonia. Having to be fed overnight requires a person to be in an upright position to minimise the occurrence of reflux. This is the medical perspective. For Sally, having to be upright at night affected her sleep in many ways. It prevented her from being able to "put her arms around" her husband. She missed that. Sally was medically safe at night but emotionally unsafe.
Professionals often consider and recommend sleeping position for patients. Should they look beyond the medical reasons and consider how an altered sleeping position affects the person holistically?

Problems with the gastrostomy tube: When I arrived one morning Sally was not at home despite asking me to call to her. There was an emergency – the tube became loose and they had to rush to the doctor. Sally was hoovering and maybe bending caused the tube to dislodge a bit. When she said "I broke the tube" I thought she felt guilty about it. She knows that the tube extended her life and maybe she felt that she should be more careful with it. She is confined to the house due to the long feeding time and she wants to stay active. She attempts to participate in her house chores, but the tube is there to stop her a bit. It is there to remind her to slow down and be mindful of herself. The tube is a gift of life and wants to be respected.

	Social impact	We used to go for meals out and have friends in but never I cannot do that.	59-60
	Missing food	I would love to have a rasher sandwich but I … cannot take any by mouth.	82
	Food as a means to socialise	**And in the past would you say the food was important in your life?** Yes.	89-92

		How important was it? Well it was always good to socialise.	
	Changed participation in celebrations	I was 80 last week. All the children come and we were all together. Lidia had a nice meal just the … but I could not eat. Or have a glass of champagne.	125-127

Comments:

Sally's life used to evolve around food. She was a lively housewife who cooked a lot and invited people for meals "while Liam was making the money". That's how they shared their duties: Liam was working outside the house and provided finance for the family, Sally looked after the house and family's social life. Food was important to her mainly as a way of socialising. Now she has lost her ability to swallow and she has lost her social life.

In our culture celebrations involve food. The food becomes symbolic: we expect a cake for someone's birthday or wedding, we cook turkey for Christmas, and buy chocolate eggs for Easter. We celebrate occasions with champagne. It becomes so difficult when a person is unable to swallow. What to do? Although Sally is being fed non-orally, other family members continue to eat in the natural way. When they meet together to cerebrate various occasions, there really is no way to avoid eating and drinking. What can be a substitute for Sally who is unable to even taste the food or drink? Her daughter made a meal for Sally's birthday, but it was not for Sally. They celebrated Sally's 80s with a glass of champagne, but she could not participate. What could have been done to help Sally celebrate her birthday and to have something special that day? What would she like?

The family will meet in Sally's house this year as she feels unable to go to her daughter's house as before. This is because of non-oral feeding. It is still new to them and Sally does not use it outside her house. Sally will cook Christmas dinner. I am sure she has everything well planned. When she said "some dinner" it sounded like she is not so excited about the food anymore, she cannot be. It is not for her. She will make an effort to cook well for others, because she loves them. There is nothing she can make for herself, nothing that she could try at the Christmas table. Maybe she had engaged in the process of detaching from food. It was never going to be a part of her life again.

When you have severe dysphagia you are not able to participate in the celebrations as before. It is a fact. We can look for substitutes but it will not be as before.

	1.3 Lost independence	Lost skills	I would not be able to do all myself. The not being able to talk. Or go out myself …	115-116
		Requiring constant support	**So how has your life changed now since the diagnosis?** Well I cannot even do shopping without Liam. I have to have Liam all the time.	59-60
		Being a burden	I have to have Liam all the time and he gets very tired because of me.	60

Comments:

Sally lost her independence despite being fully mobile and having fully preserved limb functions. She has no speech and no swallow and she knows that the MND can cause further deteriorations at any time. She does not go out by herself due to her inability to communicate and she needs a lot of help with non-oral feeding

at home. It shows how people' circumstances differ. Other participants with bulbar onset of MND reported that they were still very independent. Sally cleans and cooks at home. She can dress herself and shower. She is independent in self-care except for non-oral feeding. I am not sure why she has not attempted to manage it herself. From the beginning it was Liam who looked after it. He was trained in the hospital and he continues to manage non-oral feeding, although Sally's fine motor skills are perfect.

Sally is living a different life with MND. No food or drink. No social life. Participation in family cerebrations/ occasions are not the same. No independence. So vulnerable. Unable to hug her husband at night. Unable to chat to him. Maybe her self-worth suffered too? She says that buying new clothes would be a waste. Is it that she is not worth them as she is not leaving the house or having many visitors, or is it that she feels her life can come to an end soon?

	1.4. Professional attitude	Empathy	Ann [therapist] was very nice but Jane [another therapist] was more understanding	37
	1.5 Making sense of own suffering	Approaching death	and I think if I bought new clothes it would be a waste (…)	115
		Appreciation of life pre-MND	We have had a good life and I was going to offer any pain or discomfort to God in thanksgiving for all.	54-55
		Suffering as thanksgiving	We have had a good life and I was going to offer any pain or discomfort to God in thanksgiving for all.	54-55
		Offering discomfort to God	We have had a good life and I was going to offer any pain or discomfort to God in thanksgiving for all.	54-55
		Importance of religion	**Okay. How important is religion for you?** Very.	56-57

Comments:

Sally's life is very hard for her. It changed a lot. She lost a lot. However, Sally decided to do the best she can. She continued being involved in her house duties including cleaning and cooking. She consented for non-oral feeding; she was not ready to die. Sally contrasted her life with MND to the "good life" before. She feels grateful for her past and she offers her current suffering to God as a thanksgiving for what she had got/ experienced before. This altruistic approach helps her to cope with MND. It added sense to her suffering. It made it easier to accept it. Religion helped her to focus on "doing the best she could" instead of thinking about ending her life and giving up. "The not being able to talk" is particularly hard for her. Sally uses a lot of body language to communicate.

Sally is so busy at home, she moves so fast. She used to exercise and she is still very fit. Her baking and cooking is perfect. There is no hesitation, no mess. Everything seems to be well planned. Years of experience. But when I look into her eyes it feels like the spark is gone from her. There is no voice and there is no independence. She is doing her best given her circumstances, but I don't feel she is very happy. She is trying to use her time well, but she feels insecure. She is also aware that her husband gets tired looking after her, she is a burden for him now. He is older and she used to care for him all their lives. I don't think she regrets her decision to commence non-oral feeding as she was not ready to die, especially to die of

something unknown and unexplained. She wanted to continue living and she accepts the consequences. There is a price you pay for everything in life. She is pragmatic and realistic. In the past, Sally was able to stay at home with her children as the husband provided for the family. She travelled around the world. She had hobbies. She raised four children and is very proud of them. She has her grandchildren and she loves them all. Towards the end of her life she says THANK YOU by accepting her suffering. Her memories are still alive and no one can take them away from her. They help her to keep going. The religion adds sense to her changed life and it provides some sense of peace when thinking about the end.

After this interview was completed I posted Sally a notebook with follow-up questions:

1. *How have you been since I saw you? How is Liam?*
2. *How did you spend Christmas?*
3. *How is the RIG going?*
4. *How does your swallowing feel now?*
5. *What do you think about the services you received for your swallowing?*
6. *Is there anything else you would like to add?*

When I did not receive the notebook by the suggested deadline I presumed she was unable/ not willing to continue (there had been changes in the family's circumstances which prevented me from calling Sally's relatives to find out about her willingness to complete the study).
On the 13th of April (2016) I received a phone call from Sally's husband. He apologised for not sending the notebook back to me. Sally had completed it within the specified deadline, but he misplaced it. We scheduled another interview, as per Sally's wishes.

There was almost a 5 months gap between the interviews and (after consulting my Supervisory Team) I therefore decided not to include the 2nd in the further stages of this study. I validated the findings from my first interview. Sally reported that she got used to not eating and it "does not bother her" to see food anymore (so she does not desire to have her bacon sandwich anymore). I also perceived a change in her relationship with Liam. I feel he is becoming increasingly less able to look after Sally due to his own health issues. Sally appeared worried that he may die first and what would happen to her. She also provided information about Liam becoming less tolerant of her disabilities, for example, he continuously asks her to close her mouth while she is not even aware that her mouth is open.
She also said that the sleeping is going well and there was no mention of wanting to hug Liam at night anymore. So there were changes in the emerging themes which could change the overall interpretation of her experiences. However, the information pertaining to perceiving the diagnosis as a relief, offering suffering to God, and lost independence was still confirmed.

After the first interview my personal overall theme describing Sally's life was: the experience of love in MND. After the second interview this theme would change to: how progression of MND killed love.

Appendix 7 b): Data Analysis Table: A Caregiver (Jackie)

Superordinate themes	Subordinate themes	Emergent themes	Quotations	Line
1. Desire to prolong her husband's life	**1.1. Supporting her husband all the time**	Prioritising Chris's needs	That's what we did, you know, we make the most of every day and make sure that anything Chris wants to do he can do it.	653-655
			We went to a healing mass last night now. Yeah it was kind of a healing ceremony. My brother rang and said it was on so we dropped everything and we went, em, like Chris will want to go to the match this evening, so we will make sure that Chris goes to the match whoever else goes everywhere else.	80-83
		"We're all running around him"	And usually we're racing (laughs), running around. Well Chris isn't. He spends all of his time sitting here now but we, em, we're all running around him so like going, here, there, doing everything but when you go now the match will have to be sorted	521-523
		Determined to protect Chris	I saw a fella going for his pocket and he did (laughs) and I was very bold. I just pushed the crowd in front of me, the whole lot of them onto the tube because I could see this fella aiming at Chris. I just gave a big push and nobody was going to get injured like. I just pushed the crowd like, you know, because he was two ahead of me and I pushed the crowd and we got onto the train and he was giving out mad. Who was pushing us and I said nothing and then, eh, and we were all just on the train then and everybody was pushing and the door was just about to close and the fella who did try to steal the thing ran off like a bat. He definitely because I was saying did I imagine that? No I didn't. He was just gone.	595-603
		Ready to give up work for Chris	I would give work up in the morning like if Chris wanted me and that is the situation. I said	173-175

		Chris when you want me to stay at home say so and I'll stay at home	
Comments: *She may be delicate and softly spoken. She may be fragile and heart broken. However, when it comes to protecting her husband she gathers her powers and becomes unstoppable and fearless. She has a clear priority: to protect her family. Chris is vulnerable now due to MND so she does her best to mind him and to ensure his safety all the time. She wants him to live as long as possible. They are both young (early 50s) and they have (…) children. I feel that prolonging his life is her goal and she is doing her best to achieve it. She knows that Chris doesn't have much time left therefore his needs and wants are the priorities.* *When I was in their house I could feel the strength of this family. The way they communicated with each other, the way they spoke with me. I met two of Jackie's (…) children. They were not only so kind and nice but also appeared to be strong, mature, and very independent.*			
	Ensuring appropriate diet	I might make the soup but I'd put a lot of cream in Chris's, you know, to keep the calories because like I was told to maintain his weight. On day one the first thing, one of the nurses she says just keep the weight on.	218-221
Comments: *Jackie looks after Chris's diet as she knows that maintaining his weight means longer survival. She is also aware of his swallowing difficulties, therefore, she ensures that food consistencies are safe for Chris. She is modifying food to help him stay as healthy as possible, not because she was advised by a SLT. She has a clear understanding of the relationship between food and Chris's health status. Extra calories are required to maintain his weight (can you really battle this with muscle wasting?) and soft food means less choking. Her main motivation is to keep Chris alive and well as long as possible.*			
	Looking after husband's mental wellbeing	I suppose like obviously Chris isn't working at the moment and I suppose the only reason we're keeping on the cows at all and working hard is to keep state of mind good (upset)	175-177
Comments: *Jackie knows her husband well and she respects and acknowledges his needs (also psychological). I think she is trying to keep Chris's spirit up to give him more motivation to live and keep adapting to what MND requires from him (non-oral feeding, mobility aids, losing independence, etc.). I think she hopes that by ensuring that Chris is as happy as possible she can motivate him to live longer (to want to live longer). She tries to continue their "normal" (previous) life style. Chris worked on [anonymised] all his life and she knows that selling [it]m would come as a huge shock to him. She took on Chris's duties and she gets some help from her children. This is to avoid this shock (the shock of selling the [anonymised]) for as long as they can. I feel that if Chris loses his motivation to live he may not consent to having a gastrostomy or any other support. She wants him to see the point in living, despite his progressive disabilities.*			
	Spending time with her husband as much as possible	I'm last in the door to work so I just stay at home until then and have breakfast with Chris and then go to work at nine and, em, I work until three o'clock and I come home	50-54

			straight at three as well. Again I used to stay in work until four	
			So, I don't know. I was there [at dysphagia training] that day now without Chris and I didn't feel any better. (…) I felt it was a waste of my time being away from Chris to be honest.	424-426
Comments: *Jackie's routines have changed. She is so focused on being with her husband as much as she can that everything else is secondary. She spends her time at home with Chris as much as possible. She goes to work at the "last minute" and she drives home straight after. She needs to have a good reason to go somewhere without him. She doesn't sleep as well or as long as before.* *I feel her pressure – unstoppable, constant, and exhausting.* *Jackie's holiday routine has changed too. They used to be so active when travelling. They used to go abroad annually in recent years. This is not possible anymore. The way they plan has changed for her. "It is more day by day". This must influence her perspective on life. She doesn't appear to have anything to look forward to. She is constantly worried and stressed. Even if they were to book a holiday now "for the sake of the children" Jackie would worry whether Chris would be able to go. MND is like an unwanted shadow. It is there all the time and it follows you, your movements. You may not be able to see it on a very bright day, but it is always there.* *Although Chris has always been a good driver (and he still is according to her), Jackie noticed that people are becoming more nervous about him driving as they see his inability to talk. She realised that when "last day now one of the neighbours said she'd go with him because I couldn't go I had to milk the cows and she, em, she sat in with him to go somewhere and I'd say he doesn't know what to think now (…) He's was an excellent driver always and he still is. I suppose people begin to get nervous of him so I don't know what's happening". This is upsetting for Jackie. For her, people could potentially stop Chris from doing what he has been doing for a long time and what he loves doing. This must be so upsetting for him too. There are things he is unable to do anymore and it is hard enough to live like that. There are other things that he can still do, but society doesn't trust his skills anymore. This is so cruel, yet somehow I can understand it. The nature of MND is to blame here. People may know the disease will progress, but no one knows when. People may fear that Chris may became unwell when driving their kids to the match. Jackie feels confused ("I don't know what's happening") and she finds it hard to understand why people are nervous about Chris's driving. She is convinced his driving skills are perfect especially when it was confirmed by an OT. I think she will do her best to be in the car with Chris all the time so he is not being joined by neighbours who don't trust his skills. This would bring an additional burden for her as, for example, she would have to milk the cows at a later time or get someone else to do it (so having to pay for it while she is the only earner in the house now). She may do it as she is focused on Chris's needs and she want to support him to do what he still enjoys. This is all contributing to his willingness to live and you need that to try to adapt to MND.*				
	1.2. Non-oral feeding as life prolongation	PEG as a "good thing"	**What made him decide [for gastrostomy] do you think?** Well, em, it was getting harder to eat like. I suppose I did say to him Chris we want you around as long as possible because we had heard like that it will prolong life, you know, at this stage it will prolong life. Chris what do you think and one day… I didn't really push it hard. I didn't	355-363

			really push it and I didn't push it at all but I did say it will prolong life and its good for, em, to keep all your body strong and em, and I said we want you around as long as possible. **(…)**And one day he said okay I'll go for the tube.	
		Anxious for Chris to undergo gastrostomy	But like I did ring and suppose I be ringing again today. I didn't ring now yesterday but it is on my mind. (Long pause). I thought really when he made the decision like because there was so much, people saying to us like you should get the tube, you should get the tube. I thought that when he decided that he would get the tube. And here we are now six weeks later and after coming to this monumental decision in our lives we're still waiting.	444-450
		Aware that Chris may become too unwell for gastrostomy	And I'm also very aware of the fact that after a certain stage you can't get the tube like. So I actually, I don't know. I worry sometimes is he still alright to get it but I hope he is.	440-442

Comments:

Jackie sees the PEG tube as the opportunity of have her husband alive for a longer time. She believes "it will prolong life" and that the feeding tube is "a good thing". She really would like Chris to undergo a gastrostomy as she knows it may become necessary in the future. When I was leaving her house one day she told me about Chris's (…) who died of MND. "He really died of starvation" she said.

Jackie knows there is no cure for MND and there is very little that can be done for her husband. Possibly the only hopeful news she heard from the professionals was in relation to the gastrostomy tube. This may be the only / one of the few ways of taking some control over the progression of MND. This is not a cure, but it matters. It is a solution for her. She remembers that:

"So then eight weeks ago, Chris's uncle came down and he spoke quite forcibly about it and I said and then a dietician had said it to us as well and the speech therapist said it to us"…

Some professionals recommended the PEG for Chris and Jackie heard "it may prolong life". At the same time she wanted Chris to decide for himself as she doesn't feel it would be respectful and appropriate to influence his decision.

"One day coming down in the car then I said like the speech therapist took out the tube again to Chris and I said what did she say about the tube Chris and he said leave it all back there (laughs) and I said no more."

Jackie is also aware of specific conditions that Chris needs to fulfil to be medically safe for the tube insertion.

"So Easter, Holy Thursday then I rang again because Chris was finding it tough to eat and I was afraid the time would pass because there's only a certain amount of time, you know, you can get it so I rang again and I rang again last week and left a message again and then we went up yesterday".

She is anxious that it may be too late for Chris to get the tube. She was hoping to get some help from professionals to convenience Chris to go for the tube, but not everyone was helpful to her in this regard:

"I thought going up that day that, em, oh great now she'll [the doctor] tell him get the peg and all will be great and but anyway no she wasn't… She didn't push the peg at all". *According to her priority (willingness to have her husband alive as long as possible) Jackie changed her behaviour from "I said no more" to verbalising her opinions. There was no time to remain silent anymore. It was hard for her: feeling the urge to influence Chris's decision while strongly believing that the choice should be purely his. She noted the deterioration of Chris's swallow and she could not hide her feelings anymore:* *"It was getting harder to eat like. I suppose I did say to him Chris we want you around as long as possible because we had heard like that it will prolong life, you know, at this stage it will prolong life". She saw the tube as a tool to support her main priority: having Chris alive for as long as possible".* *Jackie is almost explaining her behaviour to me and trying to justify it:* *"I didn't really push it hard. I didn't really push it and I didn't push it at all but I did say it will prolong life and its good for, em, to keep all your body strong and em, and I said we want you around as long as possible".* *She is justifying that her words were not to push Chris to decide, but she really wanted him to get the tube and she attempted to influence his decision at the same time.* Note: More on the PEG under Dysphagia theme				
2. Internal conflict	**2.1. Maintaining a positive attitude**	No choice but to accept MND	(…) I suppose you come to live with it a bit then. Well you just have to accept it and try and go on.	138-139
		Trying to be positive	We try to stay positive.	79-80
			Even though I can see the changes myself like but at the same time I'm hoping things aren't too bad.	412-413
			But it's not easy seeing Chris the way he is but then I suppose it could be worse. I don't know.	94-95
			(…) and at the same time I always try that, em, we all try that… Usually we try to be in good form, the kids and all that.	78-79
		"Be positive and make the most of everyday" "Carry on as normal"	**So let's say if I was someone who's just starting to look after a person with Motor Neuron Disease, would you have any advice for me? What would you say to help someone else to be prepared for this role?** Just to be positive and to get up every day and make the most of every day and to carry on as normal. (…) I would say carry on as normal once you get over the initial shock and make the most of every day and don't let anything pass by that you could do.	625-638

		Appreciation of the "golden time"	And don't be, don't be sad over it. Like be sad, okay you'll cry and cry but generally make the most of it, make the most of it. A cousin of mine said to me I don't want to see you crying. This is your golden time. You enjoy it and she said you've plenty time for crying after. (Sounds upset).	640-643
		Hope for slow progression of MND	I just kind of hope that like when he does the breathing there's so many different things that they'll be kind of… I just hope that there won't be, dis-improve too much. Doctor usually like examines his lungs and I just hope like that he doesn't, they don't have anything too bad to say to us.	405-410
		Separated MND from her home life	I found nothing like but and I asked everybody, everyone I ever met questions, loads of questions and questioned everything. **Do you mean like…?** The experts. **The experts, yeah.** And but then I put it behind me when I'd come home again and I'd just carry on as normal.	639-640
	2.2. Seeing deterioration	Hard to be positive	(…) we just tried to stay positive and we still do but it's harder because Chris is deteriorating.	143-144
		Aware of upcoming deterioration	(…) even though it would be a huge shock to change our lifestyle as well as Chris's but long-term we won't be able to do the cows because the kids will have to go to college (…)	177-179
		Noticing changes	Like he went to Vienna last summer and he walked Vienna like (laughs). He couldn't walk Vienna now.	210-211
		Uncertain of her perception	(…) before Christmas again I thought he took a step back and then he'd kind of go steady for a while and I don't know whether that's it or not. I don't know. Maybe its because I'm at home and I see it all the time in front of me rather than when I'm at work I mightn't see it. You don't know. I don't know but definitely there is a change whether its progressive or whether it's	203-209

			sudden I don't know. He's not as well as he was like.	
		Monitoring deterioration	I'm getting more worried about Chris all the time so I take out my phone and I take down the results of the snip test that they do and, em, I suppose I like to keep my own record of how he's doing, in my own mind. I don't know but maybe other people wouldn't be like that now. Wouldn't want to do that but I was sorry I didn't keep a record of how well he was last, you know, how he does in these little tests that we do when we go up. That's all I can think of but I have started doing that now myself that I keep the results of the tests now, how he's improving, dis-improving, em, oh sure I can't really say.	319-331
		From being a leader to being cared for	He was always the leader on the holiday. That was a big change [having to be cared for]	607-609
		Living day by day	**Are you planning to go somewhere this year?** We have no plans. I don't know. Its more day-by-day this year definitely. **Yeah.** Because there's bigger changes and it will depend on this tube and lots of things like.	610-613
	2.3 Emotions and feelings	Frustration	We always meet the same answer that they can do nothing for us like basically, you know, I don't know there doesn't seem to be any answer	332-341
			You're hitting a brick wall the whole time like but, em, it doesn't make any difference. It doesn't make any difference because nobody can suggest the slightest thing that's of help. That's why we gave up going to [name a service] because nobody can do anything.	
		Lack of help for her husband	I don't mind going anywhere that will help him like but I don't see the point of course.	430
		Worry	I suppose I'm getting more worried about Chris all the time	1004

		Financial pressure	I suppose financially I'm bringing in the money at the moment because there isn't any profit in [husband's work] at the moment.	179-181
		Future as "huge shock"	(…) even though it would be a huge shock to change our lifestyle as well as Chris's but long-term we won't be able to do the cows because the kids will have to go to college (…)	177-179
		Constant awareness of MND	I am conscious of the background all the time but I still enjoy very much what I do [her work] but, em, I suppose it a… I don't know.	171-172
		Self-blame	I suppose I could feed him better too. (…) sometimes I'd be beating myself up for that [low intake] but sure, you know, he has very good food.	475-478
		Coping	Well I suppose I find I can kind of cope away with Chris and life but then when something else happens anyone that's when it knock you big time. If you understand? I don't know (…)	144-146
		Constant rush	And usually we're racing (laughs), running around. Well Chris isn't. He spends of his time sitting here now but we, em, we're all running around him so like going, here, there, doing everything but when you go now the match will have to be sorted	521-523
		Being busy all the time	(…) I just watch Fair City and that's just purely for a break I suppose because it's always very busy (…)	75-76
		Being completely immersed at home	(…) when I'm at home I live just totally separate lives when I'm at home. I'm completely immersed in home. Then when I go to work.	169-170

	Proudness	And all the children are brilliant. They just, anything at all done. They're just… And they were never like I read somewhere that God they'll be ashamed and embarrassed about it. They're never ashamed or never embarrassed. They just go with it. When you live with someone you have a very clear, you can really see like how difficult things are and they're very good. They make every effort to, em, to help him.	659-661
	Desire to protect her children	I don't know should we be talking more about it with them. I don't know because you can't hide it like and I know that they, they know everything about it like more or less. The children don't know about the tube yet.	644-646 330-331
	Loving her work	**How do you enjoy your work?** Yeah I love my work. I love my work life. That's just it. I love my work. (Laughs).	19-21

Comments:

Jackie tries to maintain positive feelings and hope. She would like to protect her family from various consequences of MND as much as she can. She tries to bracket the disease from her family life by "carry on as normal". She tries to be positive (note that she uses the word "try" a lot here). She may be aware that this is not fully achievable and all she can do is "try". She knows that her husband will not live for a long time and she feels she should appreciate every moment spent together. She knows that the grief should be left for after her husband is gone. Now is the time to enjoy life (try to enjoy). It seems like a struggle between emotions and pragmatic reasoning. It may sound logical to use the time to enjoy life and not to get upset while Chris is still alive and reasonably well. However, she knows that Chris's death in unavoidable and that she will be left alone with children and a [anonymised], which she would have to sell at some stage. It is worrying – seeing her so emotionally drained and exhausted now while she is trying to be positive and strong. How will she be when she is alone? How will she be when she lets her grief out? One can only hope that her love for their children will keep her going and give her strength.

MND is the only disease known to me that "by right" you should have no hope. There are treatments for many other serious diseases (cancer). They may/ may not work, but they are available. Other progressive neurological diseases can have periods of remission (MS) or can progress over a long time (Parkinson's disease). MND is cruel, rapid and has no cure. This is typically made clear to any patient at the time of the diagnosis. However, Jackie still has hope. Her main hope is for the slow progression of MND. She knows her husband is going to get weaker but she wants to delay this as much as possible. She is accepting the way he is now and wants him to stay like that forever. She seems happy with what he can still do and the fact that his mobility is still functional and he is independent. When they go for medical appointments Jackie hopes to hear good news, which for her would be little or no deterioration from the previous visit.

This is a very challenging role to play and emotionally draining. Jackie carries a lot of hidden emotions and it can be exhausting. She burst into tears the minute she sat down to talk to me and it

didn't stop. She kept saying: "I am fine normally. It is only when I talk about it. I don't usually talk about it. I am fine".

While trying to be positive and carry on as normal Jackie can see the deterioration of her husband. He is physically weaker and unable to participate in family life as he used to. She cannot deny it as it is happening in front of her eyes. MND is visible to everyone. This is very hard: to produce a smile on her face while her heart is breaking with pain. There are changes in their life caused by the progression of MND and Jackie may be attempting to hide them or to make them less significant/ impactful by trying to be in good form. This must come at a high price.

At the same time Jackie is full of frustration. "You're hitting a brick wall the whole time like but it doesn't make any difference". All the medical appointments achieve nothing for her. No one can help her husband to recover. She is trying to keep him well but she know it makes no difference in the end. MND always wins. She looked for answers herself (by checking the web sites) and she asked the experts. She got no answers.

In relation to the swallowing: Jackie tries to do her best to ensure the food is high in calories and safe in consistency. She spends time thinking about what to buy and how to cook it. At the same time she knows no consistency is fully safe, so her efforts are failing (He, em, like when he eats, even like if you have everything mashed up he, em, like he'd caught, it gets caught and it's not easy). She is not giving up, but she is blaming herself for not being able to do better (I suppose I could feed him better too. I don't know).

All above factors place Jackie on edge. She can barely cope with her everyday life. If something additional happens it "knock her big time". (Well I suppose I find I can kind of cope away with Chris and life but then when something else happens anyone that's when that it knock you big time. If you understand? I don't know (…).

Jackie is also physically exhausted. She is not sleeping well, she works full time, she has additional [anonymised] duties, she has four children and a sick husband. She is neglecting her own needs to look after other members of her family. She gets no break. She also is the only earner in the family now, since Chris is unable to do the work. Although she is ready to give up work for Chris she knows that this would put financial strain on the family. Jackie is worried about her future. The [anonymised] would have to be sold at some stage although she is going to delay it. She is going to be left with the kids. The family is so important for her and for Chris. Now MND is going to damage that forever. The kids are going to start college and soon she will be living alone. This would be a massive change for her, something she would never have wanted to have.

Jackie's priority is her family. This is her source of happiness and pride. She admires the children for the way they accept their father and how they are trying to help her every day. She would like to protect them from additional stress and she is not sure how much information to give them. MND cannot be hidden so the kids can see the problem, but still they may not be as aware. It is hard to know how much information to disclose and when. Jackie is a part of her family and almost doesn't feel her own identity (She says "we" a lot). Jackie is completely immersed in her home life. She loves her job and she acknowledge that it is a break for her too (although the MND is all the time in the background). However, she is ready to give work up in the morning at Chris's request. I see this as another example of neglecting herself – not only does she need work for her mental wellbeing and sense of satisfaction, but she is the only person bringing money to the house. Giving up work may mean getting loans which she would have to pay back in the future (unless they sell the [anonymised] which may be a solution, but even at that she would sacrifice herself. There will be no distractions from MND anymore). Jackie's priorities are clear. At the moment she has two separate lives and that helps her to cope. She is ready to change that to be with her husband as much as possible and as much as he requires.

I think it is very important for Jackie to have her two separate lives. Even though she is aware of MND all the time, work brings her many positive aspects (joy, satisfaction, fulfilment). "It is a break" she says. A break from frustration, injustice, pain, grief, and no hope. It seems important to have that second life, a moment of disconnection, a time when she is surrounded by her old colleagues and where MND is not the most important part of the day.

3. Dysphagia	**3.1. The visibility of dysphagia**	Different diet	(…) and it would all have to be, em, like it would, yeah, obviously it would be different to everybody else's on the table.	244-246
		Signs of dysphagia	**How did you notice that the swallow was off a little bit?** Oh he wasn't able to eat it like. You notice like if somebody couldn't eat it like.	278-283
		Children able to see signs of dysphagia Visible signs of dysphagia	**Okay, okay and were you talking to the kids about the swallow at all?** Well they can see that. **They can see that.** They know, they can see that because Chris eats slowly number one, and number two he, em, can kind of gag on his food at times, and he can get dreadful coughs trying to bring up stuff and they can see that his dinner is soft and that his potatoes are mashed up with butter and they can see.	125-135
		Coughing during meals	**And what does he do if he's eating and if he starts coughing?** It depends. It depends sometimes he'll go outside the door for air and if he's here we'll open the window for air or sometimes he'll just take it out of his mouth and put at the side of his plate if it comes up. **Does he continue eating then?** He continues eating.	313-314
Comments: *It is interesting to note how Jackie and her children see swallowing problems. They are focused on how Chris eats so they can see that his mealtimes are longer, that his food looks different and sometimes he coughs up/ gags on food. He may need to open the window to get more air when eating. They are focused on him so they can see that. This was not as evident in any family so far.*				
	3.2 Managing dysphagia at home	New approach to food	I approach the food differently.	222
		Concerned about nutrition	Definitely yeah. When I go shopping I think of calories most of the time Well I buy cream and double cream on a very regular basis. **That's for calories, is it?** Yeah for calories yeah.	218-220 213-217

	Having unhealthy food at home	**And would you keep it different now for the kids or do they all have the same?** No, he has his own food. They're very health conscious the four of them. **Are they?** They are very, they are. They all play sport and they wouldn't dream of eating any rubbish.	943-947
	Eliminating unsafe foods	**Is there any other food like that that he's not… that is off the list at the moment?** Well anything hard (laughs). **Anything hard, okay. So it could be meat, it could be fruit, yeah.** Oh fruit, apples and all that is gone. **Okay.** Yeah, yeah, unless stewed apples but…	270-272
	Modifying food textures	Yeah dinner then would come then. I would basically, em, we have mince now today. Well basically then I would mash the, I did mash Chris's potato with butter and make it butter and creamy and the vegetables would be mashed up with plenty butter (laughs) added as well and the meat would be obviously soft. Em, it would all be very soft (…)	239-244
		White sauce, we'd use white sauce and gravy and he has ketchup. He used never eat tomato ketchup much or we'd have YR sauce but he always has sauce yeah and I'd buy new products like, you know, bacon and ham, you know, a different sauce that I could put over something yeah…	929-932
	Supplements	Well I suppose I know he's having the Fortisips so that gives me assurance.	1158
	Thickened liquids (Preparation)	Thickener alters the taste **What way…? Do you just mix it with a spoon or what way do you do it?** I put it in and mix it with a spoon for twenty seconds as it says on the tin. Well it went lumpy at the bottom so I obviously didn't mix it enough that day and he tasted but he didn't get	274-277

		far in the cup. Like he didn't get as far as the lump in the bottom to taste it. (Laughs). (Laughs). He knew sooner. He knew straightaway. He said the milk is gone off and I said no it's not but anyway…	
	Husband's dislike	He doesn't like the thickener, he just doesn't like it. He can taste it. **Has he tried it for a bit?** He's tried it yeah. Maybe I put in too much. (Laughs)	269-273
	Adding thickener covertly	I must kind of cut it down again and put in a little bit and maybe he mightn't notice it. **So do you put it in yeah?** Sometimes I put it in but he has told me when I put it in. (Laughs).	281-284
Comments: *Jackie's attitude to food has changed and she is admitting it. Her food choice is now dictated by high calories and soft consistency. This is all new for her as they used to eat very healthy. Now she has "rubbish" food at home and it is unusual. All healthy eating priorities are not important as MND has its own rules. I remember people in the clinic worrying about raising their cholesterol.* *MND wins with that. You have some changes i.e. longer survival when you eat a lot and keep your weight up (this again is a fight you are not able to win anyway). Jackie seems very proficient at modifying food consistencies. She does it by longer cooking, chopping, mashing, adding extra sauces. Jackie is very aware of various ways of modifying food consistencies to make them easier to swallow. She provided information clearly and it was almost effortless. The diet modification techniques are an integral part of her life now. I wonder if her attitude towards food has changed for her.* *Chris dislikes thickener but Jackie feels she must keep adding it in. She blames herself for his reluctance to take thickened fluids ("Maybe I put in too much"). She thinks about adding the thickener behind Chris's back. She must know it is there to protect him from aspiration. Although she respects Chris's decision and choices her main priority is to keep him alive, so would do anything to achieve that.*			
	3.3 Chris' changed approach to food	Decreased appetite	It was mince and vegetables and em, for tea now tonight he might have lasagne or he might have, em, actually there are more and more things he doesn't like. He used to like fish pie and he doesn't like that anymore (laughs). **So that's changed as well yeah.** He doesn't like as many things like.	270-274
			Is it harder now to find something to cook? It's harder to find things yeah and before he goes to bed then he'll have crackers or biscuits again so biscuits and tea or coffee, a latte.	275-277
			How's his appetite? It can be good some days but generally he doesn't have anything	255-259

			like the appetite he had before. I'd say he eats for the sake of eating, you know. He feels he has to eat.	
		Becoming a "fussy" eater	Yeah, I would always think of what's soft and like I'd put down, em, often put, em, if it was lamb chops or I was looking for something nice, you know, he's not, he was never a fussy eater but he's a bit more fussy now so like I'd put the chops into the oven at a low heat for a very long time and I would totally change everything.	909-912
		Variable intake	I suppose he's better some days than other days.	948
	3.4 Understanding of dysphagia	Dysphagia is like "every issue in life"	**How aware do you think people are, generally in society, of swallowing problems?** Unaware (laughs). Well I suppose like I was unaware of [confidential] or anything until it happens to yourself. That's the way with every issue in life. Like parents in work they're unaware of things until it comes to their own door. Everybody has something. And you have to go down… So it's swallowing. Yeah that's the way it is.	454-463
		Awareness of the progressive nature of dysphagia	**You cook the same meal yeah you just add more butter and cream to Chris's.** Yes and have it mashed. I wouldn't say pureed because it's just mashed at the moment with a fork	251-253

Comments:

Dysphagia in MND is progressive. Every disability in MND is progressive. You may attempt to solve a problem but every solution is temporary. Jackie adapts to Chris's changing needs. His appetite has dis-improved and he does not take pleasure from eating anymore. She tries to solve that by researching new foods, new cooking ideas. She gets a sense of security from having nutritional supplements at home. This is one of her aims to keep her husband alive (ensuring adequate intake). She knows that dysphagia will progress and she feels prepared to manage that. She knows how to adapt food consistencies and use supplements. She will not be looking for professional help as she believes the services don't really offer any solutions.

Jackie respects Chris's choice regarding food. He stopped eating bread after a bad choking experience. However, when they went away he attempted to eat bread in a restaurant and she didn't stop him. instead, she accommodated his wish by:

"I just cooked one side of it and em, I put a lot of butter on it and put a bit of marmalade on it and he'd try it and he didn't anything, like the crust and all were cut off but he had a bit of it that day".

I think Jackie is doing outstanding work in relation to the management of dysphagia. She is realistic and pragmatic, yet accommodating and gentle. She has no previous experience of dysphagia at all: ***Did you have any knowledge of swallowing before Chris …?*** *No.* ***No.*** *(412-414)* *Jackie seems not to be particularly focused on dysphagia. This is just one of the steps to help her achieve her goal: keeping Chris alive. She says that dysphagia is like "every issue in life". You will be unaware of it "until it comes to your own door". She accepts it as an unavoidable feature of MND and she feels able to manage it. "Everybody has something" she says.* ***Yeah.*** *And you have to go down… So it's swallowing. Yeah that's the way it is."* *There is not much emotion associated with talking about dysphagia in particular. Dysphagia is another problem she needs to manage, but she is looking beyond the swallowing in order to achieve her main goal.*				
	3.5 Non-oral feeding	"Monumental decision"	And here we are now six weeks later and after coming to this monumental decision in our lives we're still waiting.	449-450
			He took his time with us [a doctor] and I suppose, it's up to yourself to make the decision but it's a very tough decision.	97-98
		Consulting others	I suppose that should be the next step now. When you talk you kind of get ideas yeah because Henry [other man with MND and PEG] did email him two or three nights ago but he didn't mention the tube.	118-119
		Conflicting opinions from professionals	The nurse was here then and, em, she said you should go up to see our doctor. She's always dealing with the tubes. So we went up there. That didn't… Oh I suppose you make up your own mind like basically on things. We were down at his physiotherapist and em, we were telling her and what did she think of the tube? We were asking her and she said yeah. Oh look there's one nurse in here, now she constantly deals with the tube. I'll bring her out. She came in and she doesn't want to commit either way but they weren't coming out very strongly in favour of it as I would like, you know, so kind of Chris said no.	335-344
			And how much do you know about looking after the tube then and the whole feeding thing?	422-428

			I don't know anything much about it. They say it's… Well it depends who you speak to. Some say it's very straightforward, others say it's not at all straightforward. One person says it's as easy to get a chest infection from a tube as it is to get from swallowing. **Okay.** So I don't know. I don't know really…	
		PEG recommended by professionals	**And how did he decide to go for it?** How did he decide? Em… **Like has he seen the tube before or how…?** No, they all recommended it. They recommended it. The [anonymised] seemed to be very much in favour of it like. They seem to be in favour of it.	327-330 78-81
		Feeling confused	**So do you feel you're getting kind of contrasting messages or is it that it's just so complex?** I don't know. I really don't know because it's been brought to up, it has been brought up to us a lot in the past for the peg and now when we're kind of going about it like we don't know what we're doing.	82-86
		It's Chris's decision	A lot of people were saying it to me, do you know that it probably would be better if he got it (…) but Chris wasn't in favour of it so we left it.	26-30
			So it's basically back to Chris whatever he decides.	76
			Well its Chris's decision. I left it to Chris. I can't decide whether he gets a peg or not. It's whatever Chris wants	86-87
			It's up to Chris. I hope he'll get the strength to make his own decision because I wouldn't push it.	103-104
		Husband not anxious to get the PEG Respecting husband's choices	How it happened, em, well, em, about this time last year the subject was first broached with us that maybe he should go for a peg and I think it might have been said in [hospital] first and then we went to [another hospital] and it was said in [there] as well and then, em, Chris	20-24

			wasn't anxious for it and I would go with whatever he wanted.	
		Husband slow to decide about the PEG	They recommended the tube and em, he was very slow to accept it or to take it on board that he might need it or want it so he said no for a long time and em, we looked up a lot about the tube.	333-335
		Attempted to talk to the husband about the PEG	One day coming down in the car then I said like the speech therapist took out the tube again to Chris and I said what did she say about the tube Chris and he said leave it all back there (laughs) and I said no more.	344-347
		Husband had negative experiences with other types of tubes	Chris's father died last year and I know it's totally different now. He had, em, oh he was continually getting urinary tract infections so he had a tube inserted down there and oh infection, infection, infection from the time he got the tube to the day he died. So he was allergic to tubes. He didn't want to hear tubes at all. I suppose Chris was his primary carer even though Chris was very sick, he was the only person that his father, you know, he wanted Chris around all the time.	348-354
		Would like him to get the PEG to prolong his life	So then eight weeks ago we, Chris's aunt came down and she spoke quite forcibly about it and I said and then a dietician had said it to us as well and the speech therapist said it to us in [hospital] like, well Chris what do you think about the peg like? It would prolong your life and it's a good thing and that so then anyway about eight weeks ago we decided that, well Chris decided, he said that I think I will email [hospital] about the peg, so we did.	30-35
			Oh look there's one nurse in here, now she constantly deals with the tube. I'll bring her out. She came in and we knew her because she used to be a neighbour that lived here before. I didn't really know her but Chris knew her and em, a very nice person and obviously she doesn't want to	343-348

			commit either way but they weren't coming out very strongly in favour of it as I would like, you know, so kind of Chris said no.	
			A very hard decision. She gave, I thought going up that day that, em, oh great now she'll tell him get the peg and all will be great and but anyway no she wasn't… She didn't push the peg at all.	71-73
		Torture of waiting for gastrostomy	**What's happening with the peg tube?** I don't know. Its five weeks now since we broached that subject. I rang Holy Thursday. **So you're waiting to have it done?** Yeah, yeah. Its five-and-a-half weeks now. Today is Tuesday again. Now is it six weeks today? Yeah its six weeks. (…) We had emailed them two weeks prior to that that, em, please put everything in motion.	322-326 368-9
		Aware that husband may become too unwell to get the PEG	And I'm also very aware of the fact that after a certain stage you can't get the tube like. So I actually, I don't know. I worry sometimes is he still alright to get it but I hope he is.	440-442
		Anxious to get the PEG	But like I did ring and suppose I be ringing again today. I didn't ring now yesterday but it is on my mind. (Long pause). I thought really when he made the decision like because there was so much, people saying to us like you should get the tube, you should get the tube. I thought that when he decided that he would get the tube. And here we are now six weeks later and after coming to this monumental decision in our lives we're still waiting.	444-450
		Told that PEG can be problematic	She says it brings as much problems as solutions. You can get infections, chest infections from having the peg as well as from having it and the food can go up as well as go down and she wasn't pushing it at all as was the man yesterday.	73-72
			Yesterday he said that it will not prolong life.	52-62

		The trauma of unexpected appointment	It might ease your situation but it will not prolong life. He spoke of the ethical side of it as well. **And what did he say about that?** Well he just said he gave us his own background. That he's written a… I haven't read them but he's written a lot of papers and things from the ethical side like, like of people, I suppose. He would be quite willing to give Chris the peg like with older people and things like that, you know, but, em, we would have been aware of all that side of things. We would have discussed that with people. We would be aware of that and we had met another nurse and she spoke about ethical issues as well (laughs).	
			It's whatever Chris wants but like that was only yesterday. It's only sinking in. I haven't spoken to him today.	87-88
		Having to re-consider	**Right and how did it go yesterday?** Em, well there were no answers, you know, it's up to Chris to decide again now.	732-734
		"crossing a line"	He feels it's crossing a line and he's well educated and he knows a lot about everything (…)	418-419
		PEG as additional duty PEG as support (dilemma)	He took his time with us and I suppose, it's up to yourself to make the decision but it's a very tough decision. **Hmm…** Very tough in many ways because like you, okay Chris's walking around and he doesn't have to flush out anything or do anything every day to himself like he's and at the same time then if you get sick when you need something to feed you, it's just tough. I don't know. I didn't…	97-104
		Fear of the future with PEG	I'm hoping this operation, now this big operation won't set him back.	415
		Feeling unsure	I don't know is it a good or a bad thing we're waiting. I don't know. I	467-475

			don't know what's coming down the track like. **Hmm… Would you change anything?** I don't know. I don't… Like I don't know. I just don't know what to expect. He can just have it there and not use it but also like he would be so tired, you know, he was told he'll have to be sitting. He can't use at night unless he's… **Sitting upright or…?** He was saying he might use it during the day preferably, em,	
Comments: *It was exhausting to listen to Jackie talking about the gastrostomy tube. For her, it was the hardest decision ever. It was a process of consulting others and getting conflicting advice, being aware that it is a way of prolonging Chris's life (so achieving her main goal) while at the same time wanting Chris to decide for himself (respecting his decisions). Consulting others made the process particularly complex and confusing for Jackie. She was hoping for everyone to encourage Chris to get the gastrostomy tube, but not everyone did. She stayed silent for as long as she could, but when she noticed further deterioration of Chris's swallow she gently started to talk to him about non-oral feeding. She couldn't wait and see him wasting away and missing the opportunity of having the gastrostomy tube (while she believed it will help him to live for longer time). The decision was huge. Monumental. Chris had some bad experiences with other types of tubes, which caused him to dislike tubes in general. However, one day he said yes and Jackie acted immediately. She rang and emailed the hospital a number of times and… nothing happened. For over 6 weeks they were waiting for an appointment. The time was long enough for Chris to change his mind or to deteriorate beyond the point where he would be still a candidate for this procedure. Jackie was stressed out. Unexpectedly, a doctor who was supposed to call them for the gastrostomy procedure called them for a consultation instead. He was not in favour of non-oral for Chris. He gave his reasons. He quoted his own research. He smashed Jackie's hope ("It will not prolong life he said"). He asked Chris to re-consider it for two more weeks. Like he hadn't considered it for over a year. Moreover, the team of MND clinicians seemed to be in favour of non-oral feeding too. Jackie was traumatised and exhausted after that appointment. There was less animation on her face, less emotions in general. She was completely overwhelmed and concerned. She was delighted when Chris consented for gastrostomy and now the process of deciding was to start again.* *I felt absolutely shocked after hearing that story. These were not naive people hoping to win with MND or people who were not aware of the consequences of living with non-oral feeding. They were aware of the ethical side and every possible medical complication. That doctor hadn't met them before. He knew the disease, but not how the disease affected Jackie and Chris and how they coped with it, adapted to it, lived with it. Looking at Chris's type of MND and his stage, the choice is to either get the gastrostomy now or to not get it and stop being able for any oral intake soon. This could kill Jackie. This will become a problem for all when the medication can't be swallowed or when Chris is dehydrating. There would be nothing that Jackie could do to ease the situation as the oral route will not be an option anymore. She needs the security of the PEG, although she is aware that it is "crossing the line" and it is like a symbol of losing his independence / losing their "normal life" forever.*				
	3.6 Professional Services	**MND Clinic**	**And how happy are you to go in the room and have a few professionals sitting there?** It's fine. (…) its better.	307-309

			Yeah, I think it's nice. (…) I would have no issue with that. It's probably better actually. I think it's actually better that they're all… They all know everything about you together. I don't like, em, I think it's a good system. I don't like to be critical. I don't like to be critical so I don't like saying anything bad but I know in (…) now it's a bit more one-by-one and I think it's better together because they're all informed about everything.	
		Training "Came home upset"	I just go to the workshop, like the MND swallowing workshop around that. I was on my own. **And what did you think of it?** It was fine. I suppose I had already been to the swallowing, you know, I'd spent three quarters of an hour above with Chris so I don't think I learnt anything new. (…) Because I had listened to it all and been through it all. **(…)** They went through the four types of food like, you know. **All the diets.** The diets and they went through the thickening, the thickener and they went through… They had cups, you know, and they had different cups you can hold. I suppose I wouldn't have been aware of those now to be honest (laughs) and we hadn't got to that stage yet. **Hmm…** And, em, (short pause) well to be honest most of it I felt I hadn't learnt much new there because I had been, I spend an hour; I had been with Chris the previous week or two. I had been above there on an individual basis and I kind of…	332-345
		Didn't identify with other caregivers at the workshop	There were only two others (…) I just felt I hadn't much in common with them. **Right.** I hadn't much in common.	346-367

		Waste of time	So, I don't know. I was there that day now without Chris and I didn't feel any better. I felt it was a waste of my time being away from Chris to be honest. **(…)** Yeah, next question (laughs).	382-405

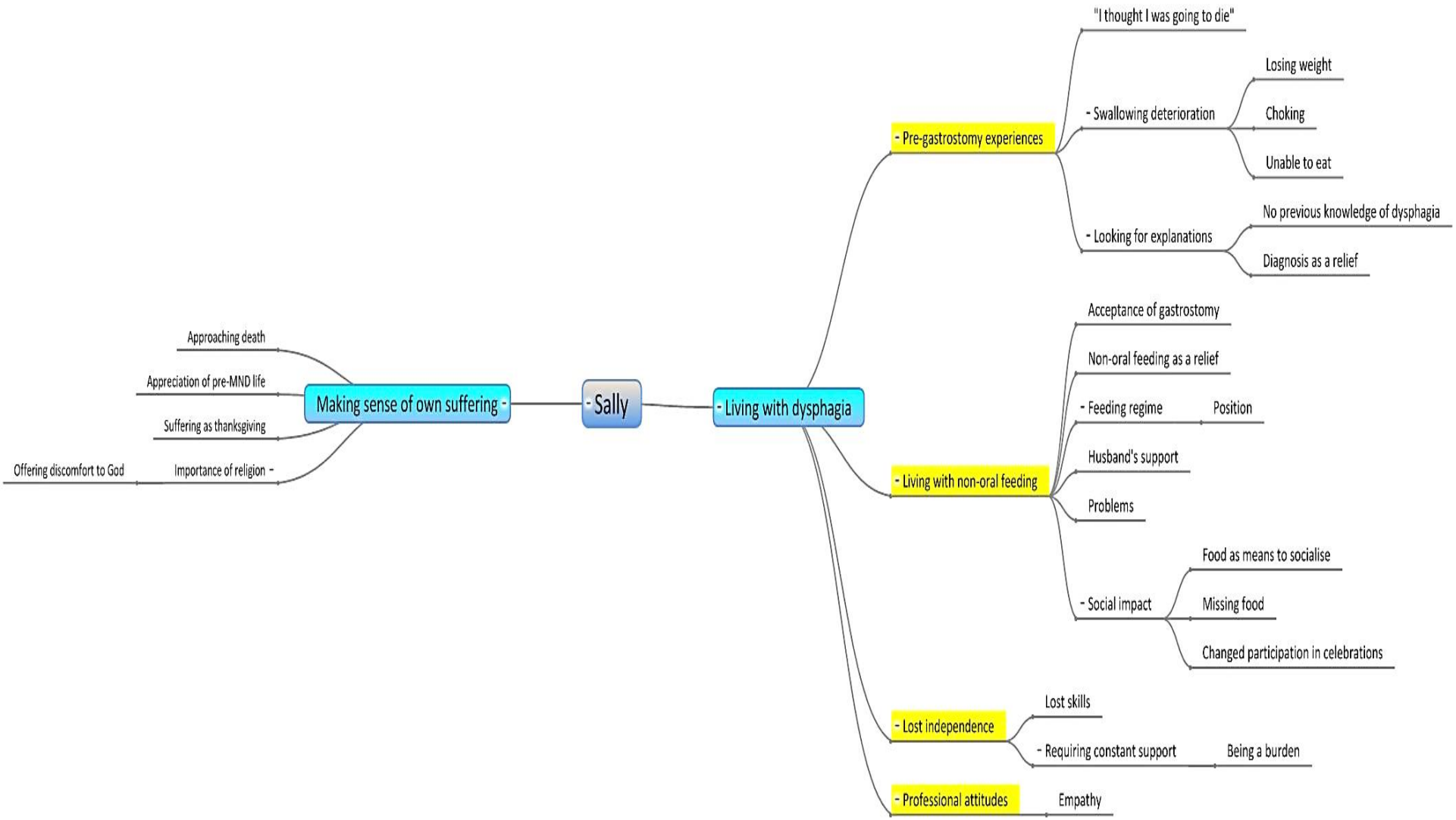
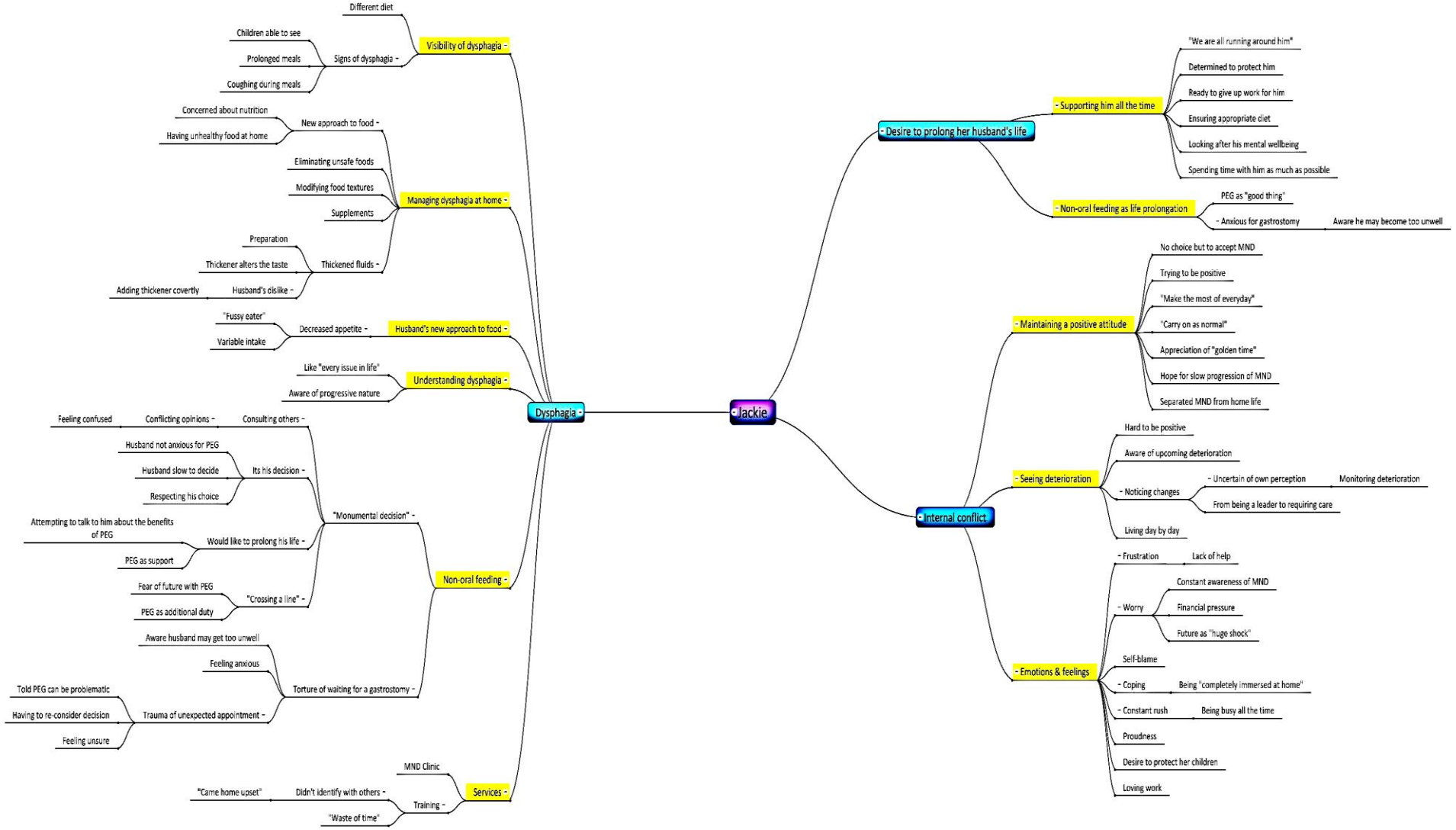
Comments:

Jackie's relationship with the health services is interesting. She attends them with Chris but she doesn't believe that they can offer any help. She attends them to monitor Chris's deterioration as she is unsure of her own observations. She prefers to be seen by the team together, this experience does not seem to intimidate her. She sees it as a better usage of her time.

The swallow workshop she attended was not a positive experience. First of all it was a repetition of the knowledge she was already given at the SLT consult. That was the way she perceived it anyway. She noticed various drinking utensils and she knows that Chris may need one in the future. This was new knowledge for her and maybe there were other examples which she didn't report to me. What really complicated the experience for Jackie was hearing the experiences of other caregivers, some very traumatic for her. She came home upset and she felt she "wasted her time being away from Chris". Was that something the SLT should/could anticipate? It is still possible that Jackie feels so confident in managing dysphagia due to attending consultations and the workshop and getting a good understanding of dysphagia from the professionals involved? It is simply not possible to ignore the emotional side of her life. She was unable to appreciate hearing about various cups while at the same time she also heard that someone similar to Chris was almost dead.

It looks like work is the only place where Jackie immerses herself for 90%. When she is shopping, eating out, going on holidays and attending workshops the MND is in front of her eyes all the time. It changes the way she perceives and experiences the world around her. Only work allows her to escape.

APPENDIX 8A: Mind Map – A Person with MND (Sally)



Appendix 8b): Mind Map – A Caregiver (Jackie)