

# Positivity within the lived experience of Motor Neurone Disease: A qualitative approach

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# Research aims and objectives

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## Aim

- To identify and explore the positive coping strategies that are utilised by people with MND

## Objectives

- To identify what influences a positive perspective when living with MND.
- To explore how people with MND build on the positives.
- To investigate how clinicians can influence the 'up's' during intervention.

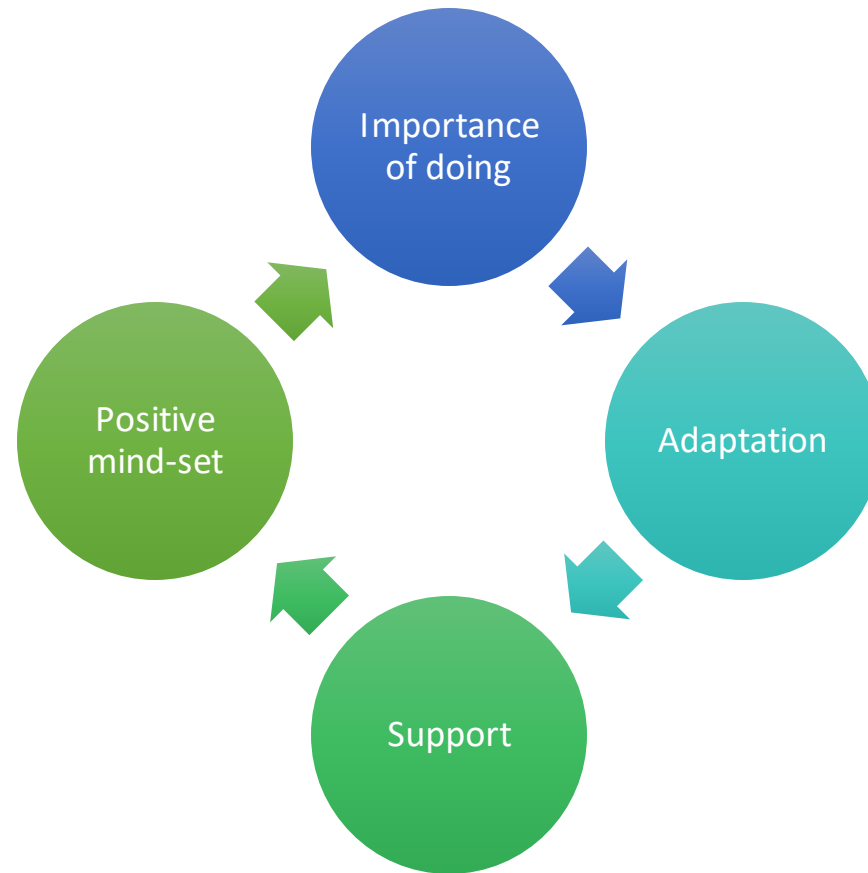
# Methodology

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- Qualitative study exploring the lived experiences of people with MND.
- Purposive sampling.
- Five participants.
- Semi-structured interviews.
- Braun and Clark's (2006) approach to thematic analysis applied.

# Finding - Four themes

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# Theme One

## Importance of doing

### Enjoyment

- “I love being outside and doing family things...we try and have days out and weekends away as often as we can” (Eleri)

### Personality

- *“The prof said no way will I give you a note, and I was up and about with a brace...I had an appointment the week before we were due to go on holiday...and we went” (Gloria)*

### Planning

- *“I try and plan what I am going to do...I go to bed and think well tomorrow I am going to do this...you always have to have something to look forward to” (Frank)*

# Theme Two

# Adaptation

## Activity adjustment

- *“I enjoy fly fishing...I went last summer, it was not very good...so I had my rod adapted to use it double handed...and I managed...didn't catch a bloody thing...but I coped and felt positive” (Michael)*

## Equipment and adaptations

- *“My electric wheelchair goes up and down, I can make a meal so that's good...and an electric bed and I can do everything myself” (Gloria)*

## Independence

- *“I can get my wheelchair outside on my own and then go and meet my friends...I can do everything myself...I like to do me on my own”(Gloria)*

Theme Three

Support

# Theme Four

## Positive mind-set

### Acceptance

- *“To accept it is to be able to move on from the diagnosis...at least when you know and even though there isn’t a treatment or a cure it is being able to move on from there” (Eleri)*

### Positive thinking

- *“I try not to dwell...I try and think about something else, what I am going to make in my shed” (Frank)*

### Positive interpretation

- *“A little girl said, Daddy why is that lady in a push chair? And the dad took her off, but I would have liked to have said something...I tell my grandchildren they think it is hilarious”(Gloria)*



# Implications for practice

Consider people beyond their physical disability

Encouragement people to remain 'doing'

Focus on strengths

Maintain a message of hope

Empower people

Support continuous adjustment

Multi disciplinary team working

Acceptance / Denial

# Conclusion

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- How patients face the disease impacts on their quality of life and adjustment.
- Understanding factors which impact on positivity can improve patient care.
- 4 main themes - importance of doing, adaptation, support and positive mind-set.
- Range of problem focused and emotional focused strategies.
- Despite the relentless progression and loss, people with MND can lead a good and meaningful life.
- Not forgetting the uniqueness of the individual - Not all strategies are possible for everyone.