

Topic Guide: 1 month post implantation

The DiPALS Trial.

Diaphragm pacing in motor neurone disease

Study information

- Overview of the study
- Details of funder
- Overview of who is being selected for interview
- Explanation of dissemination strategy and how the study will inform local services

Aim of discussion

- Informal discussion
- Views and opinions
- No right or answers but interested in views and experiences

Confidentiality

- Recording of interviews
- Information will remain anonymous
- Review of information sheet with an opportunity to ask questions
- Signing the consent form

Background Information about the patient/carer

Participant information including name (and how long they have been carer for the individual with ALS)

Awareness of the surgical procedure

- What the surgery involved
- Expectations of what the equipment would do
- Size of equipment and wires involved

Experience of surgery

- Any concerns they had prior to surgery
- Expectation versus reality
- If they were to tell someone else about the procedure what would they tell them
 - Fears, anxiety
 - Pain, discomfort
 - General anaesthetic

Use of equipment in hospital

- Information provided
- Who provided it and when
- Was any of the information provided before the surgery
- Format – written or verbal
- Was it easy to understand
- Was it enough of was there anything else you wanted to know
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Transition to use at home

- Support available at home
- Did they know who and how to contact them
- Any problems or complications using the equipment
- Who manages the equipment, ensuring it is working properly, dealing with it at home
- How easy is this to do and confidence to take on this role
- Any early impacts on QoL apparent on
 - Individual
 - Carer
 - Family members
 - Friends

Topic Guide: 6 month post implantation

The DiPALS Trial.

Diaphragm pacing in motor neurone disease

Although previously interviewed repeat early information as a reminder and to ensure participants still wish to participate

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Background Information about the participants

Participant information including name and age

Impact on Quality of life

- Describe any changes that have occurred as a result of having the equipment fitted
- Changes to behaviour both positive and negative
- Does it interfere with certain activities such as dressing, washing etc
- Is there anything that you dislike about the equipment

Experience of using the equipment

- Explain what it's like to use the equipment
- How often and for what duration have you used this (overnight use)
- Any adaptations made to how you were told to use it?
- Barriers to using the equipment
- Follow up at the clinic
- Frequency of support and if any further support is required
- Support from the ALS team
- Any ways the support / information could be improved / adapted
- Support from family and carer
- In the past 6 months how have things changed