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**End-of-life decisions and advance  
care directives in ALS/MND:  
Evidence-based guidelines for best  
practice in Ireland.**



# Background

The clinical management of ALS/MND is palliative from the time of diagnosis and is focused on symptom control and adjustment to the progressive loss of neurological function with the certainty of early death.

As treatments are limited, inevitable decisions regarding accepting or forgoing life-sustaining therapies should be made.

The failure to address advance care planning leads to unplanned interventions, particularly mechanical ventilation.

Decisions to withhold or withdraw life-prolonging treatments are among the most difficult for patients, carers and health-care professionals.

Formal guidelines for advance care directives are currently unavailable in Ireland.



# Aims of the Study

- To identify the attitudes, understandings and experiences of patients with ALS/MND, their carers and their health-care professionals to end-of-life decisions and advance care directives
- To determine the concordance between the participants
- To make recommendations for the formulation of advance care directives and end-of-life decisions in the ALS/MND population in Ireland



# Methodology

- **Hermeneutic phenomenology was the chosen methodology for this study as it illuminates the meaning and understanding of the lived experience of contemplating end-of-life decisions and advance care directives for patients with ALS/MND, their carers and their health-care professionals**
- **Purposive sampling was used. The fourteen participants selected had experience pertaining to the phenomena under investigation**
- **Participants included patients with ALS/MND their carers and their health-care professionals, including nurses, Palliative Care Consultants and Consultant Neurologists**



# Inclusion and Exclusion Criteria

## Inclusion Criteria for patients:

- Possible, Probable or Definite ALS/MND as defined by the El Escorial Criteria
- Patients >18 years of age
- Patients diagnosed > twelve months
- Patients had a nominated carer
- Patients without cognitive impairment

## Exclusion Criteria for patients:

- Patients < 18 years
- Patients without a nominated carer
- Patients diagnosed < 12 months
- Patients with cognitive impairment



# Inclusion and Exclusion Criteria

## **Inclusion criteria for health-care professionals:**

All the health-care professionals had experience of the phenomena under investigation. In Hermeneutics it is the lived experience that is required and not just an opinion.

## **Exclusion criteria for health-care professionals:**

Health-care professionals who had no experience of discussing end-of-life issues and advance care directives with ALS/MND patients.



# Participants

**Table 1: Profile of Patient Participants**

Pt. no.	Gender	Age	Occupation	Date of Diagnosis	Religion	Religiosity	Education	Limb / Bulbar	ALSFRS-R
1	Female	62	Nurse	2008	COI	S/W	Third level	Bulbar	32
2	Female	64	Teacher?	2003	R/C	S/W	Secondary	limb	31
3	Male	65	CEO	2002	R/C	V/R	Third level	limb	11

**Table 2: Profile of Carer Participants**

Carer no.	Gender	Age	Occupation	Religion	Religiosity	Relationship	Education
1	Male	67	Factory worker	R/C	Not practising	Husband	Primary Level
2	Female	65	Radiographer	R/C	Very Religious	Wife	Third Level
3	Female	65	Nurse	RC	Somewhat Religious	Friend	Third Level



# Participants

**Table 3: Profile of Health-Care Professional Participants**

Profession	Gender	Age	Time in Position	Religion	Religiosity	Formal ACD
P.C.C.	Female	58	12 yrs	Atheist	N.A.	No
P.C.C.	Male	36	3 yrs	Atheist	N.A.	No
P.C.C.	Male	49	8 yrs	Atheist	N.A.	No
C.N.	Male	61	20 yrs	C.O.I.	Somewhat Religious	No
C.N.	Male	38	5 yrs	R/C	Not Practising	No
P.H.N.	Female	57	20 yrs	R/C	Somewhat Religious	No
H.P.C.N.	Female	35	2 yrs	R/C	Somewhat Religious	No
C.P.C.N.	Female	41	6 yrs	R/C	Somewhat Religious	No



# Advance Care Directives

For the patients and carers that participated in this study, contemplating end-of-life decisions and having advance care directives were profound undertakings which were approached in a unique and individualized way.

For some patients there are worse things than death, for others long term invasive ventilation may be their preferred choice.

The realistic medical options and interventions available will determine and influence these decisions.

As health-care professionals we are constantly attempting to understand illness from the patients' perspective, to advocate on their behalf and to promote autonomy.

Advance care directives are increasingly recognised as important tools for safeguarding autonomy. However, not all patients wish to make advance care directives.



# Autonomy

*“Autonomy is not just a status, but a skill, one that must be developed.*

*Health-care interactions rely upon assent, rather than upon genuinely autonomous consent.*

*Throughout most of their medical lives, patients are socialised to be heteronomous, rather than autonomous.*

*At the worst possible time – when life and death consequences are attached to the choices, the paradigm shifts and real consent is sought, even demanded, making an often traumatic situation even harder.”*

*C. Myers 2004.*



# Key findings

**An interpretative methodology was used and significant themes central to the participants emerged to illuminate the research.**

## **Central Themes:**

### **Patients/carers:**

Individualised impact of illness  
Difficulties discussing E-o-L issues  
Support and consensus within families  
Religiosity  
Burden of responsibility for implementing ACD  
Legal issues  
Public awareness

### **Health-care professionals:**

Difficulties discussing E-o-L issues  
Conflict of interest  
Resources affect the decision making process  
Clinical supervision and guidance  
Burden of responsibility for implementing ACD  
Legal issues  
Public awareness  
Palliative care: advantages and disadvantages



# End-of-Life Issues

**Difficulties discussing end-of-life issues:**

**There needs to be an acknowledgement that death, while not imminent, will be the likely outcome of the illness.**

**One of the major problems is trying to plan for something that is abstract.**

**Patients are requesting that they remain in control and make decisions about their death, just as they did throughout their lives.**

**For some their end-of-life wish is not to die!**





# Burden of responsibility for Carers

- There were concerns and anxieties expressed as advance care directives are not legal, would there be difficulties implementing them?
- Would there be a battle with some health-care professional at the end of a difficult and painful disease process to have their wishes respected? *“I hope the end of his life, will not result in an argument with an official”*
- The carers reported that they had great difficulty discussing end-of-life issues and feared family recriminations if they supported or participated in the patients’ decision to request or refuse treatment.
- Many of the participants identified the importance of family support throughout the disease trajectory but highlighted the importance of family consensus regarding end-of-life decisions and advance care directives.
- The carers reported their reluctance to revisit E-o-L discussions, once a decision was made, fearing that revisiting these issues would cause upset or that the decisions made would be revoked.
- Not all patients may wish to make ACD and this adds to the burden of responsibility for their carers.



# Burden of Responsibility for Health-Care Professionals

The responsibility of ensuring that their patients are fully informed about the likely disease outcome.

That the patients understand the implications of their decisions. That they understand that their decisions may influence the treatments they receive, the services that are available to them and may determine their place of death.

Many reported the difficulties they encountered in dealing with different multidisciplinary teams and how the lack of communication and personal beliefs resulted in patients' wishes not being respected.

All the health-care professionals agreed that attendance at the ALS/MND clinic ensured that E-o-L issues and advance care planning would be discussed in a timely and appropriate manner. However, their concerns emanated from their experience that although patients had ACD these were not respected in local hospitals.



# Ethical Dilemmas

Many health-care professionals believe it appropriate to respect and implement ACD. However, there are some who feel that life should be preserved at all cost.

The anaesthetist who refused to implement the ACD of a patient with ALS/MND stating that *“we don’t polish off patients in the I.T.U. setting”*

The I.T.U. nurses who said that *“if having a baby you would have an expected date of delivery, are we now being asked to have an expected date of death”*

Health-care professionals have a right to their autonomy. It is not obligatory for health-care professionals to respect an ACD, they may not know the patient and they may have concerns that the directives may not actually reflect the current situation.



# Palliative Care

All the participants identified the importance of including Palliative Care services and how vital their skills are in dealing with the complexities of end-of-life issues.

There continues to be a stigma attached to including Palliative Care. Patients believe that their “days are numbered” if referred. Health-care professionals tend to back off, withdrawing their service, believing that if Palliative Care services are involved, there is nothing left to be done.

Many believed that the palliative care team should be introduced, earlier in the disease trajectory and that their services should be available for symptom management throughout the illness, not just in the terminal phase.



# Legal Issues

Some of the participants expressed concern that ACD are not legal, they hoped that legislation would provide clear guidelines and therefore ensure that they would be respected.

Others believed that even if they are not legal, by presenting an ACD you are alerting a healthcare professional to the expressed wishes of the patient.

All the participants agreed that their preference was for a disease specific advance care directive.

Amongst the health-care professionals that participated, there was ambivalence regarding the legislation of ACD and a view that a combination of having a verbal directive and having a nominated proxy would work very well.



# Recommendations

- **End-of-Life issues should be discussed earlier**
- **These discussions should be initiated by the health-care professionals**
- **The nurses believed there should be more clinical supervision and the doctors that there should be clear guidance from the Medical Council**
- **There needs to be improved communication between the tertiary hospital and the local community service**
- **There should be increased public information and awareness regarding end-of-life decisions and advance care directives whereby it does not have to be a sentinel event before these issues are discussed**
- **We have an obligation to create an atmosphere that encourages patients to discuss the specific concerns and worries they have regarding end-of-life issues**



# The Challenge

***“Death, like the sun, cannot be looked at steadily or directly.***

***We cannot, as conscious human beings, easily contemplate***

***our non-existence”***

*Francois de la Rochefoucauld 1613-1680.*