

# The Respiratory Decision Making Process in ALS/MND

*“It is your decision”*

Three Short Informational Videos

A Package for ALS/MND Patients, Families, and  
Professionals

The ALS Association

The Les Turner Foundation

The Forbes Norris ALS Research Center

2013

# First Video: 16 minutes

- Introduces Status of ALS
- Importance of Developing a Care plan
- Importance of staying informed about progression
- Why you WILL have to make a decision or a decision will be made for you
- Assurance you can always change your mind

## Second Video: 15 minutes

- Briefly explains ALS respiratory failure; some diagrams
- Answers some early common questions
- Introduces some patients who tell their story and why they made their decisions

## Third Video: 17 minutes

- Explains that progression continues
- Discusses different respiratory options
  - Non Invasive Ventilator Support Options
  - Tracheotomy Ventilation: Major factors to consider, including option to quit;
  - Hospice Care with refusal of all interventions
- Emphasis on “It is your decision”

# Short Video Trailer

# Final thoughts

- Ready for Release Soon
- To be made available on-line: link via our websites
- CDs: to Support Groups, Neuro Clinics, ALS organizations, chapters, etc.
- In English; no translations planned yet

Questions?