Withdrawal of non-invasive ventilation – how can we help all involved?

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Respiratory failure and ventilatory support

- Wider discussion
- Awareness of symptoms
  - Dyspnoea
  - Respiratory failure
- National Institute of Clinical Effectiveness
  Clinical guideline 105
  July 2010
Issues with ventilation

• Deterioration
  – Disease still progresses
  – Increasing risk of reduced communication

• Emergency situation
  – Sudden deterioration
  – Tracheostomy placed as an emergency
  – Possibility of becoming “locked in” with tracheostomy
Issues with ventilation

• Stresses on family
  – Quality of life may be affected adversely for families, even if not for patient

• Consideration of withdrawal of ventilation
  – Ethical dilemmas
  – Advance statement / advance decision to refuse treatment
  – Practical considerations
  – Stresses on
    • Patient
    • Family
    • Professional staff
Withdrawal of NIV

- Patient not 24 hour dependent
  - May choose not to use NIV
  - May lead to breathlessness
  - May require medication for symptoms

- Patient is 24 hour dependent
  - Withdrawal may lead to death in short period of time
  - Increased breathlessness
Issues - patients

• Decision
  – When to discuss
  – When to consider
  – Alternatives of symptom management if NIV not started

• Fears
  – Symptoms

• Symptom management
  – Dyspnoea
  – Anxiety
Issues - family

- Decision
  - When the discussion may be needed
- Finality
  - Irrevocable decision
- Conflict
  - Mixed feelings
    - Not wanting person to suffer
    - Not wanting person to die
Issues - professionals

• Ethical factors
  – When to discuss
  – Is it ethical?
  – Knowing the ethics but fearing the action

• Practical factors
  – What medication to give
  – Where / how / when

• Feelings
  – Need for support
  – Challenge to own values
Issues - professionals

• Multidisciplinary Team
  – Conflicts
  – Uncertainty
  – Anxiety
    • Team involved
    • Primary care team

• On going support
  – Supervision
  – Debriefing
  – Opportunity to express their concerns
Future developments

• Increased discussion
  – As NIV is commenced
  – As NIV dependency occurs

• Increased awareness
  – Of issues involved
  – Multidisciplinary discussion
Cognitive change

• Possible reduced ability for decision making later in disease progression
  – Frontal lobe dysfunction

• Need for discussion earlier in disease progression
  – May be difficult for patient / family to face discussion
  – If no discussion may lead to emergency situation, without time for discussion
NICE Guideline

- Multidisciplinary team care
  - Coordinating and providing care
- Discussion
  - Patient and family
- Information
  - On issues
  - On NIV use
- End of life care
NICE Guideline

• Multidisciplinary team
  – Leader with specific interest in MND
  – Neurologist
  – Respiratory physician
  – MND specialist nurse
  – Respiratory physiotherapist
  – Respiratory physiologist
  – Palliative care specialist
  – Speech and language therapist
NICE Guidelines - Information

• Withdrawal
• Palliative care as alternative
• Involving patient and family
• End of life care discussions
NICE Guideline

• When to discuss ventilatory support
  – Soon after diagnosis
  – At monitoring
  – When deterioration occurs
  – When patient asks
Discussion of end of life care

- When monitoring starts
- When NIV discussed
- Increasing dependency on NIV
- Patient asks
The future

• Better communication
• Increased discussion at all stages
  – On starting NIV
  – With increased dependency
  – At end of life
• Support for all involved
  – Patient
  – Family
  – Professionals
The future

• Research projects
  – On experiences of withdrawal
  – On effects on wider multidisciplinary team
  – Longitudinal study of how people cope with NIV and with discussion of withdrawal
  – What happens to patients who do not use NIV and how their symptoms are managed