

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
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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