

Amyotrophic lateral sclerosis – what can patients expect from palliative care?

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ALS

Progressive disease

Disabling

No curative treatment

Treatments may slow progression

Patient fears of ALS

- The unknown
 - No information at all
 - Misinformation
- “A terrible disease”
 - Symptoms
 - Distress
- “A terrible death”
 - Choking
 - Pain

What can palliative care offer?

- Assessment
 - Physical Psychosocial Spiritual
- Listening
- Support
 - Patient
 - Family
 - Carers
- Advance care planning

Palliative Care

An approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering, early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual

W.H.O. 2002

Assessment of ALS

Physical

symptoms

positioning / mobility

communication

Psychological / emotional

Social

Spiritual

Symptoms

Dysphagia	87%
Dyspnoea	85%
Weight loss	84%
Speech problems	74%
Pain	73%
Constipation	53%
Drooling	23%
Emotional lability	23%

Oliver 1996

Pain

Musculoskeletal
 Joint pain
 Stiffness
Muscle cramp

Physiotherapy
Non-steroidal anti-inflammatory drugs
Muscle relaxants

Skin pressure pain

Discomfort
Position unchanged

Positioning
Opioid medication

Dyspnoea

Respiratory muscle weakness
Diaphragm weakness

Respiratory failure

- Ventilation
 - non-invasive
 - invasive with tracheostomy





Respiratory failure

- Ventilation
 - non-invasive
 - invasive with tracheostomy
- Opioids

Opioids in ALS

Oral morphine

Mean dose 96mg/24 hours

Median dose 60mg/24 hours

Mean duration
of use 95 days

Oliver 1998

Dysphagia

Weakened muscles in chewing, moving
bolus of food and swallowing

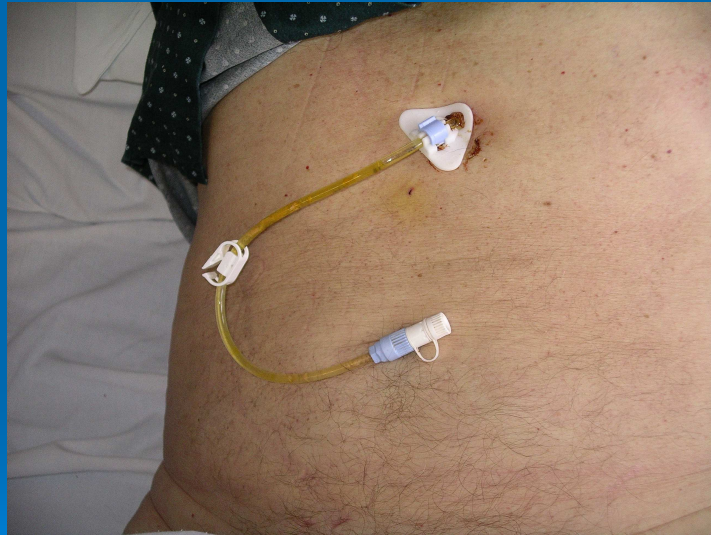
Careful feeding

Alteration of consistency of foods

Time to eat carefully

Percutaneous endoscopic gastrostomy

Radiologically inserted gastrostomy



Patient concerns

Diagnosis
Symptoms
Disability
Dependence
Death and dying

Family concerns

Diagnosis

Communication

physical problems

interpersonal communication

Isolation

Sexuality and intimacy

Family concerns

Finances

Death and dying

Spiritual aspects

“Why me?”

Fears of dying

Fears of death

Team assessment

Multidisciplinary

Multiagency

Increased need to ensure
co-ordinated approach
not overwhelming patients
carers supported

Team Assessment

Facilitating and enabling
patient
family
carers

Patient and family focussed
Family involvement





End of life care

Anticipation

Advance care planning

Communication

patient

family

carers

Support of all involved

Symptom control

Fears of dying

Choking

Pain

Dyspnoea

Management of crisis

Preparation

Anticipation

Calm approach

Injection

Morphine

Midazolam

Glycopyrronium bromide /

Hyoscine hydrobromide

Bereavement

Counselling

Support

Family

Carers

Ambivalence

Relief

Guilt

Palliative care in ALS

Symptom control

Psychosocial care

Support

patient

family

carers

Co-ordination of care

