Breaking the news in neurology: Lessons learned from patients

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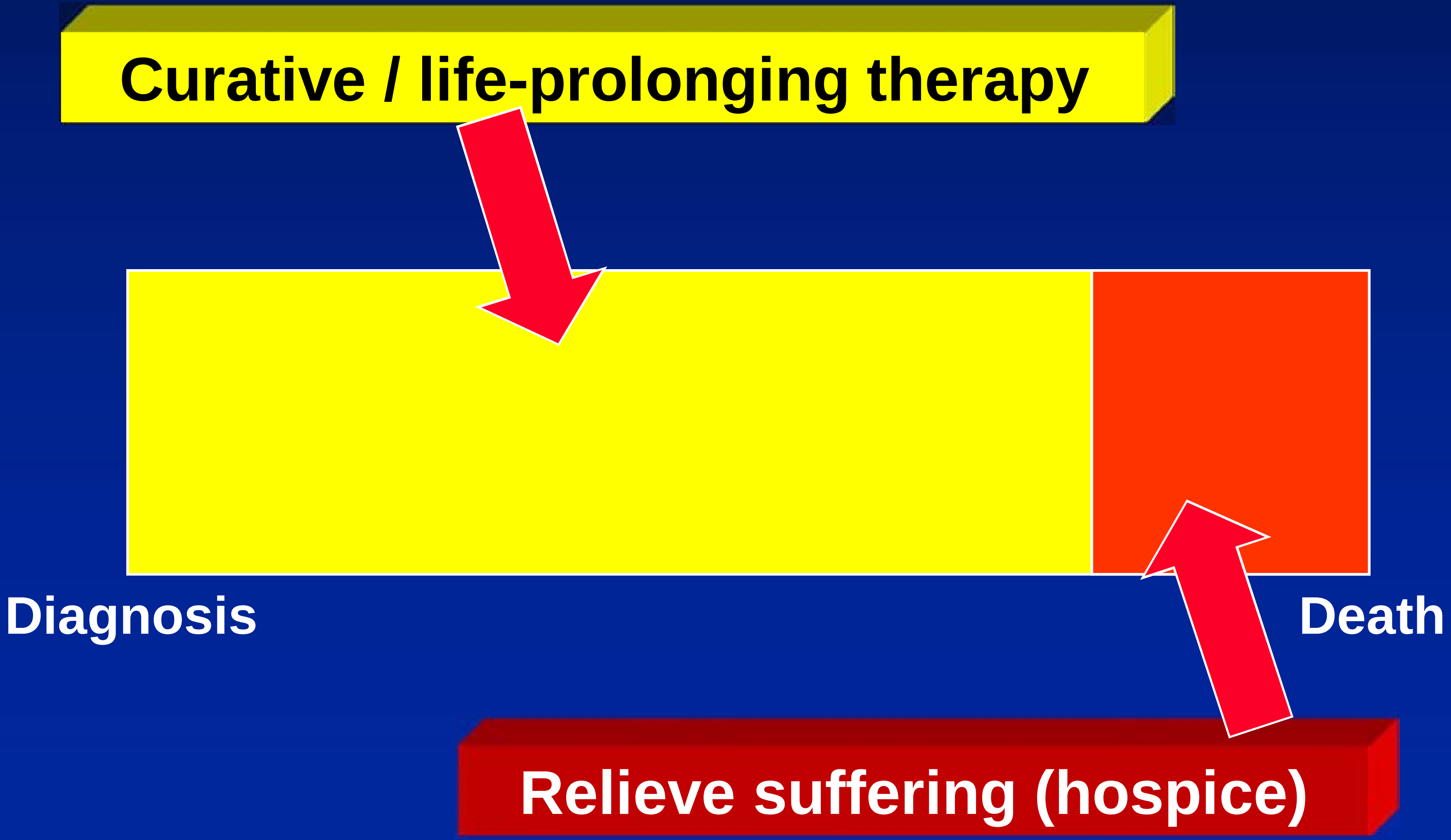
No conflicts of interest are present with regard to this presentation

Learning objectives

- To understand the basic principles underlying the breaking of bad news in Neurology
- To understand the importance of active listening
- To know the steps of the SPIKES protocol
- To conceptualize the communication of the diagnosis as the first step in advance care planning

Palliative Care: Historical Beginning



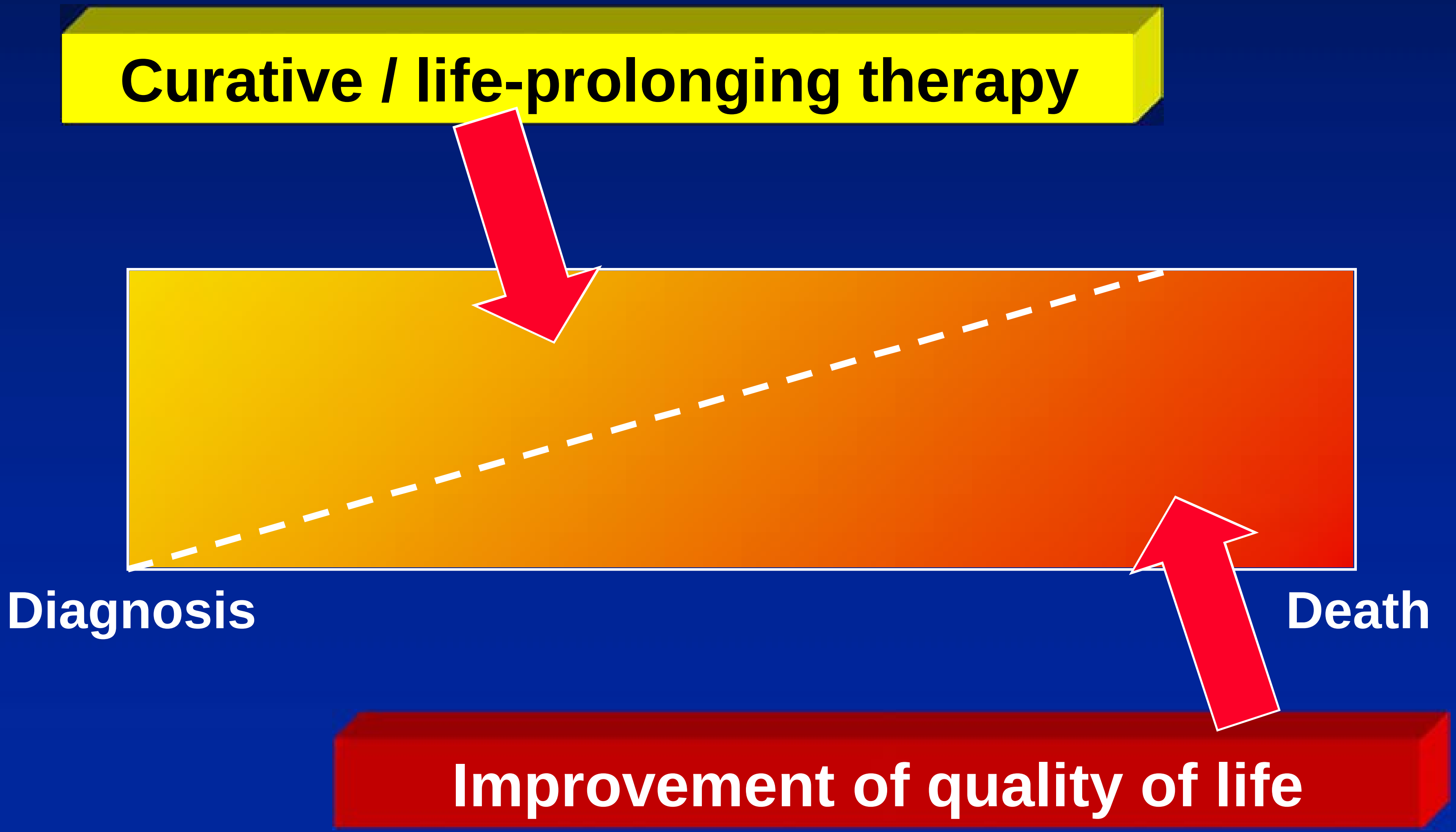
Curative / life-prolonging therapy

Diagnosis

Death

Relieve suffering (hospice)

Palliative Care: Evolution of a Concept



Curative / life-prolonging therapy

Diagnosis

Death

Improvement of quality of life

Palliative Care
is care for the end of life,
not just at the end of life.

Amyotrophic Lateral Sclerosis

- degenerative disease of the first (central) and the second (peripheral) motor neuron
- progressive paralysis of all voluntary muscles
- no major deficits in sensation
- mostly mild cognitive changes of the frontotemporal type

Epidemiology of ALS

incidence	1.5-2 / 100,000 / year
prevalence	6-8 / 100,000 (increasing tendency)
gender distribution	m : f 1.5 : 1
average age at onset	58 years

Clinical Course of ALS

- constant progression, different speeds
- rarely phases of stabilisation
- virtually no remissions
- no abrupt deteriorations
- median life expectancy: 3 years (10% >10yrs)
- death through respiratory insufficiency

Amyotrophic Lateral Sclerosis: a chronic illness?

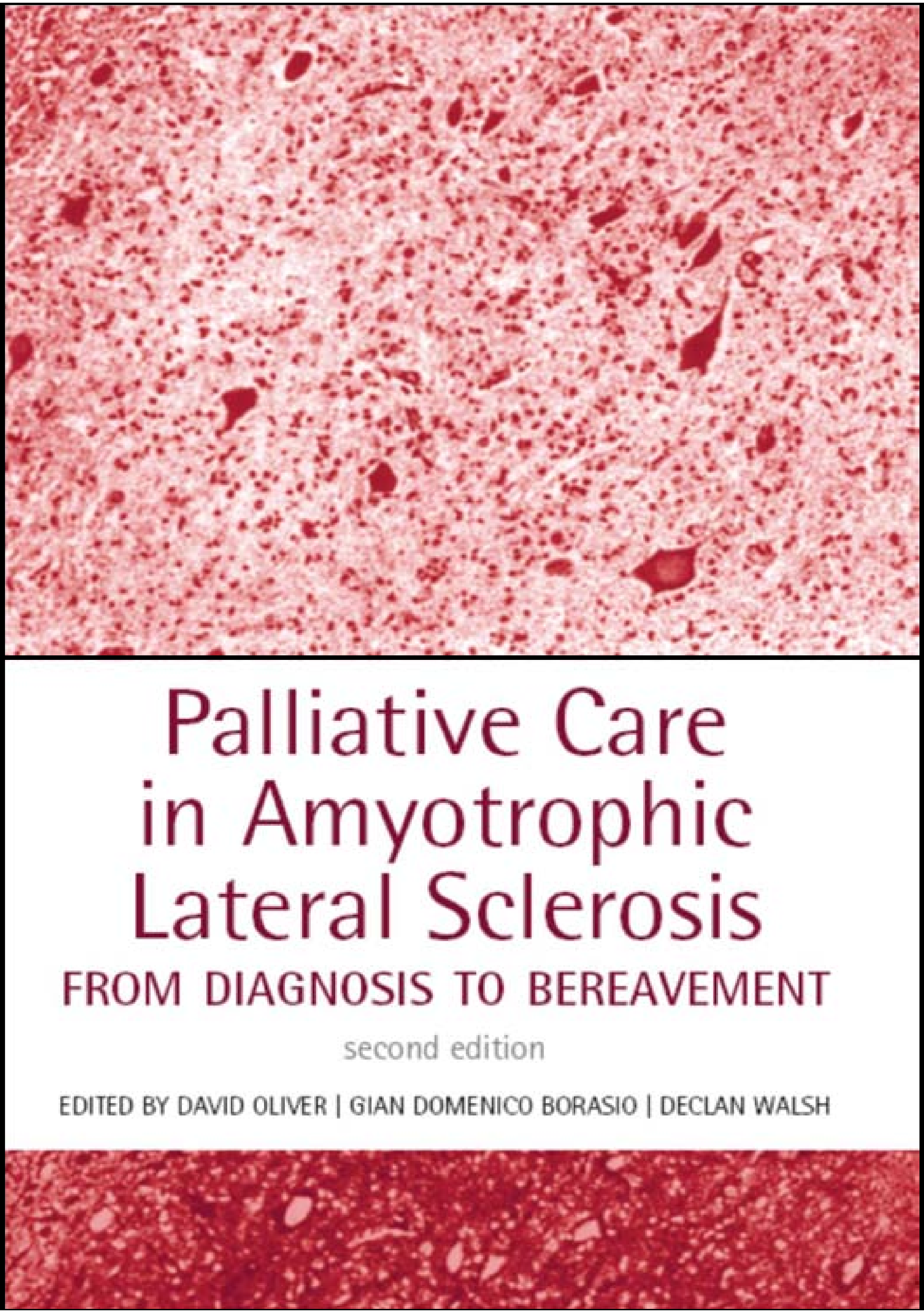
- Loss of ambulation
- Loss of manual dexterity
- Loss of writing
- Loss of driving ability
- Loss of working ability
- Loss of self-care ability
- Loss of ability to swallow
- Loss of speech
- Loss of breathing ability
- Loss of all communication (locked-in)
- Loss of emotional control
- Loss of independence
- Loss of social role
- Loss of family role
- Loss of intimacy
- Loss of dignity
- Loss of hope
- Loss of faith
- Loss of meaning in life

“When you think that you've lost everything, you find out you can always lose a little more.”

Bob Dylan, *Trying To Get To Heaven*

Symptoms of ALS

Direct	Indirect
weakness and atrophy	psychological problems
fasciculations and muscle cramps	sleep disorders
spasticity	constipation
dysarthria	drooling
dysphagia	thick mucous secretions
dyspnea	symptoms of chronic hypoventilation
pathol. laughing/crying	pain



Palliative Care in Amyotrophic Lateral Sclerosis

FROM DIAGNOSIS TO BEREAVEMENT

second edition

EDITED BY DAVID OLIVER | GIAN DOMENICO BORASIO | DECLAN WALSH

Palliative Care in ALS

breaking the news → psychological support →

sympt. treatments → PEG, noninv. ventilation →

end-of-life decisions → terminal phase and death

→ bereavement counselling

Survey on breaking the news

(Borasio et al, J Neurol Sci 1998)

- >50% of ALS patients were unsatisfied with the way the diagnosis was told
- Reasons for dissatisfaction:
  - unclear explanation of the diagnosis
  - no open discussion of course and prognosis
  - no information on where to find help
  - lack of empathy

Breaking the news in ALS

- integral part of palliative therapy
- not standardisable
- early, frank and open
- with relatives
- stepwise
- repeated

Goals

- telling the diagnosis
- preventing fears and anxiety
- providing information for life planning
- discussion of forthcoming palliative measures
- establishment of a mutual trust relationship

Standards of palliative care for patients with ALS: results of a European survey

(Borasio et al., Amyotr Later Scler 2001)

Telling the diagnosis

- 15% do not inform in the presence of a relative
- 24% do not inform on existing ALS associations
- 31% do not tell the diagnosis of ALS to all patients
- 37% take <30 min (4% <10 min)
- 12% have a counsellor available

Cultural sensitivity

- Different communication patterns in different cultures
- Migration background: often different cultures within the same family
- Never take anything for granted
- Do not use relatives as translators if at all possible

Why breaking bad news is difficult for doctors

(after Buckman, 1996)

- Fear of the messenger getting blamed for bad news
- Perceived lack of time
- Lack of training
- Fear of causing distress
- Fear of being asked difficult questions
- Fear of not having all the answers
- Invoking fears of one’s own mortality

Three basic rules

(after Maguire et al., 1986)

- do not withhold information if the patient wants it
- do not impose information if the patient does not want it
- gauge and respond to the patient’s reaction to the news

The stages in breaking bad news

(after Maguire et al., 1986)

- Setting
- Finding out what the patient already knows or suspects
- Finding out how much more they want to know
- Firing the warning shot
- Hierarchy of euphemisms
- Observing and responding to the patient's reactions at each step
- Contract for the future

SPIKES

- S – Setting up the interview
- P – assessing the patient’s Perception
- I – obtaining the patient’s Invitation
- K – giving Knowledge and information
- E – addressing the patient’s Emotions with Empathic responses
- S – Strategy and Summary

Baile et al, Oncology 2000

Initial information

- usually after an inpatient workup
- stepwise offering of information over several days
- final discussion with:
  - relatives
  - social worker
  - ALS clinic physician

Minimal information

- name of the disease
- progressive disease of the motor nerves
- emphasis on positive aspects and palliative measures
- discussion of ongoing research and drug studies
- discussion of available drug options

Additional information

- beginning of the disease: long before onset of symptoms
- no sudden worsening to be expected
- patient organisations (ALSA, MNDA...)
- second opinion
- prognosis: no reliable prediction possible

Therapies

- approved therapies
  - realistic expectations
  - known side effects
- "alternative" therapies
  - no concerns regarding e.g. homeopathy or acupuncture
  - warning about health and financial risks

Possible or suspected ALS

- careful approach, depending on the degree of clinical certainty
- discussion of possible differential diagnoses and planned diagnostic workup
- if ALS is strongly suspected: information about palliative therapy and available medication

„If we want to help somebody, we must first find out where he stands. This is the secret of all caring. Those who cannot do this, are stuck with an illusion if they think they can help others. In order to really be able to help somebody, I must understand more than he does – but first and foremost I must understand what he understands. If I do not, then my greater understanding won‘t help him at all.“

(cont.)

„If I still want to assert my greater understanding, then it is because of my vanity, or my pride, so that my goal actually, instead of helping him, is to be admired by him. But: **Every real act of help starts with an act of humility**; the helper must understand that helping does not mean ruling, but serving, and that helping also implies the willingness to accept that one may be wrong, that one may not understand what the other understands.“

Søren Kierkegaard


THE PATIENTS KNOW MORE ABOUT THEIR DISEASES THAN ME. I MUST GET FASTER MODEM, HIGHER SPEED INTERNET ACCESS THAN THEM
©Morgagnia.

When should communication about end–of–life issues be initiated in ALS?

Information on respiratory failure, ventilation and terminal phase

- at the onset of
  - dyspneic symptoms
  - symptoms of chronic nocturnal hypoventilation
  - rapid decrease of vital capacity
- description of hypercapnic coma
- discussion of ventilatory options
- advance care planning

Movie „Death on request“

(The Netherlands, 1994)

- Documentary on the euthanasia of an ALS patient
- >10 untreated symptoms (incl. pain, dyspnea, depression and anxiety)
- Two physician state that, without euthanasia, he will „choke to death“
- Patient asks for, and receives, euthanasia

- **The information was wrong!**

The terminal phase in ALS

(Neudert et al, J Neurol 2001)

- 171 patients (Munich 121, Rochester 50)
- causes of death: respiratory insufficiency 86%, cardiac failure 6%, pneumonia 5%
- 91% peaceful deaths (USA: 90.4%)
- **no patient choked to death**

Triggers for end of life discussions in ALS

- The patient or family asks – or “opens the door”
- Severe psychosocial and/or spiritual distress
- Pain requiring high doses of analgesics
- Dysphagia requiring feeding tube
- Dyspnea, symptoms of hypoventilation, FVC <50%
- Loss of function in two body regions

Mitsumoto et al., RWJ report 2003

End-of-Life decisions in ALS

- Patients‘ QoL priorities and EoL preferences change over a 6-month period (Silverstein et al. 1991; Neudert et al. 2001)
- Religiousness and spirituality influence EoL decisions (Murphy et al. 2000; Robbins et al. 2001)

Breaking the news:
Starting Advance Care Planning

- Several neurological disorders show a progressive loss of cognitive functions
- „Window of opportunity“ for advance directives, health care proxy, ACP
- Responsibility of the neurologist

Ethics of dialogue: Expression of care

References

Baile WF, Buckman R, Lenzi R et al (2000) SPIKES-A six-step protocol for delivering bad news: application to the patient with cancer. Oncologist 5:302-11

Borasio GD, Sloan R, Pongratz DE (1998) Breaking the news in amyotrophic lateral sclerosis. J Neurol Sci 160 (Suppl.1): S127–S133.

Brewin TB (1992) Three ways of giving bad news. Lancet 337:1207–9.

Buckman R (1996) How to Break Bad News. Papermac, London.

Chiò A, Borasio GD (2004) Breaking the news in amyotrophic lateral sclerosis. Amyotr Later Scler 5:195-201

Doyle D, O'Connell S (1996) Breaking bad news: starting palliative care. J Royal Soc Med 89:590–1

Johnston M, Earll L, Mitchell E, Morrison V, Wright S (1996) Communicating the diagnosis of motor neurone disease. Palliat Med 10: 23–34

Kidd J, Patel V, Peile E, Carter Y (2005) Clinical and communication skills: Need to be learnt side by side. BMJ 330: 374–5

Maguire P, Fairburn S, Fletcher C (1986) Consultation skills of young doctors. BMJ 292: 1573–8

Maguire P, Pitceathly C (2002) Key communication skills and how to acquire them. BMJ 325: 697–700