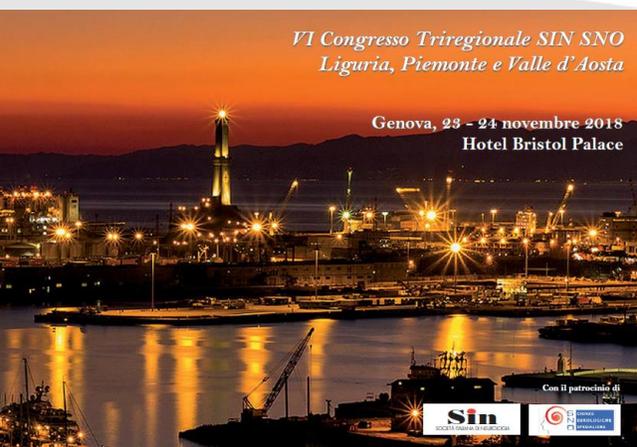




Cure palliative in neurologia

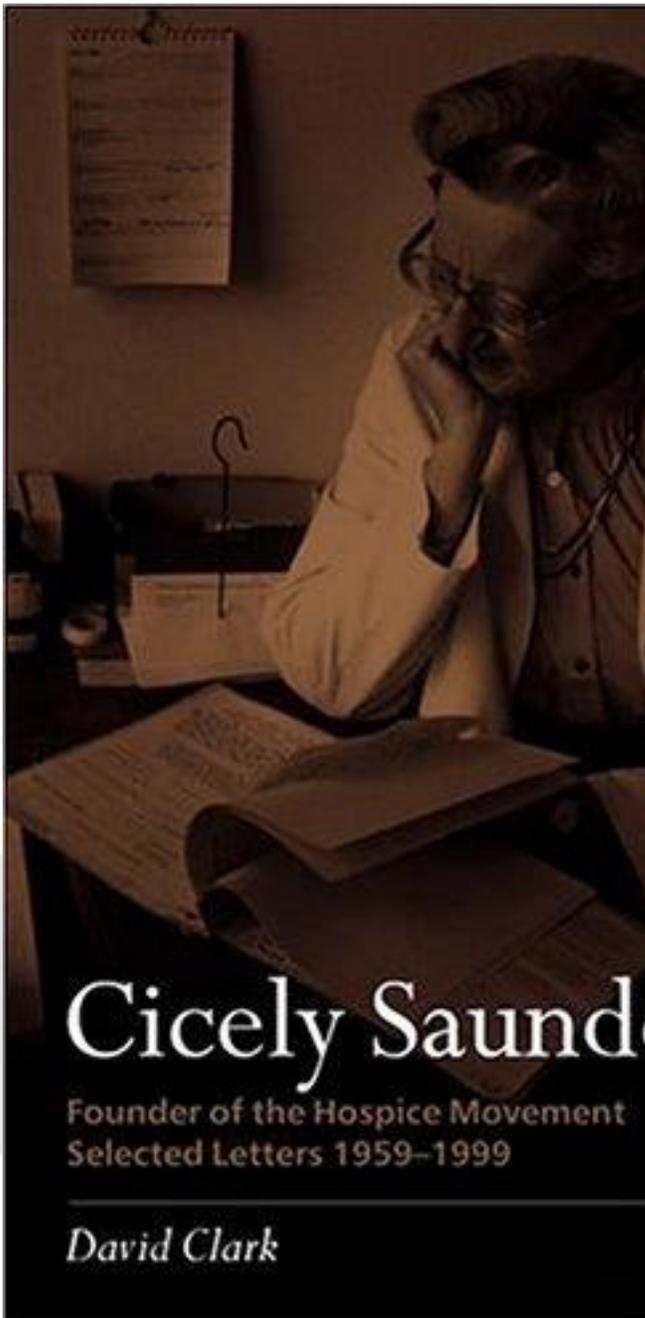
S. Veronese Fondazione FARO, Torino
GdS di Bioetica e Cure Palliative SIN
EAPC Reference group on Neurology



EAPC Reference Group on Neurology
European Association for Palliative Care
Non Governmental Organisation (NGO) recognised by the Council of Europe

- uses a team approach to address the needs of patients and their families, including bereavement counselling
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, and includes those investigations needed to better understand and manage distressing clinical complications
- will enhance quality of life, and may also positively influence the course of illness





- Disease related symptoms
- Comorbidities
- Treatments

Physical

- Fear of suffering
- Past experience of illness
- Anxiety – depression
- Feeling burden

Psychological

TOTAL PAIN

Social

- Isolation
- Loss of job – role
- Financial concerns
- Dependency
- Worries for family

Spiritual

- Anger
- Finding meaning
- Regrets
- Loss of faith
- Fear of the unknown

Legge 15 marzo 2010, n. 38 "Disposizioni per garantire l'accesso alle cure palliative e alla terapia del dolore" G.U. n. 65 del 19 marzo 2010.

*Cure Palliative per qualunque patologia evolutiva durante tutto il suo decorso,
per ogni età ed in ogni luogo di cura*



e homes

c) «malato»: la persona affetta da una patologia ad andamento cronico ed evolutivo, per la quale non esistono terapie o, se esse esistono, sono inadeguate o sono risultate inefficaci ai fini della stabilizzazione della malattia o di un prolungamento significativo della vita, nonché la persona affetta da una patologia dolorosa cronica da moderata a severa;

- ✓ There is a gap between medical, legal and ethical guidelines for the care of dying patients and the beliefs and practices of many neurologists, suggesting a need for graduate and postgraduate education programs in the principles and practices of palliative care medicine

End-of-life care: a survey of US neurologists' attitudes, behavior, and knowledge. Carver AC, et al. *Neurology*. 1999 Jul 22;53(2):284-93.

- ✓ Neurologists have a duty to provide adequate palliative care
- ✓ Neurologists should encourage improved physician education on palliative care
- ✓ Patients have the right to refuse life-sustaining treatment
- ✓ Neurologists do not have a duty to provide assisted suicide or active euthanasia

The neurologist and the dying patient. Bernat JL, Goldstein ML, Viste KM jr. *Neurology*. 1996 Mar;46(3):598-9. Editorial

- **Neurologists receive little formal palliative care training yet**
 - Often need to discuss prognosis in serious illness
 - Manage intractable symptoms in chronic progressive disease
 - Alleviate suffering for patients and their families
- **Because patients with neurologic disorders often have**
 - major cognitive impairment
 - physical impairment, or both,
 - with an uncertain prognosis,
- **their palliative care needs are particularly challenging and they remain largely uncharacterized and often unmanaged**

Neurologists as primary palliative care providers

Claire J. Creutzfeldt CJ et al Neurology: Clinical Practice Jan 2016,

GENERAL INTEREST [◇ EAN CONGRESS NEWS](#)

Lisbon 2018: Report on Symposium 4: EAN/EAPC: Palliative care and neurology

June 17, 2018

EAN/EAPC Symposium 4: Palliative care and neurology

Chairpersons:

Paul Boon, Ghent, Belgium

Philip Larkin, Dublin, Ireland

Palliative care from a neurologist's perspective: the evidence

David Oliver, Canterbury, United Kingdom

Guidelines in progress across Europe

Raymond Voltz, Cologne, Germany

What can a neurologist learn from palliative care specialists?

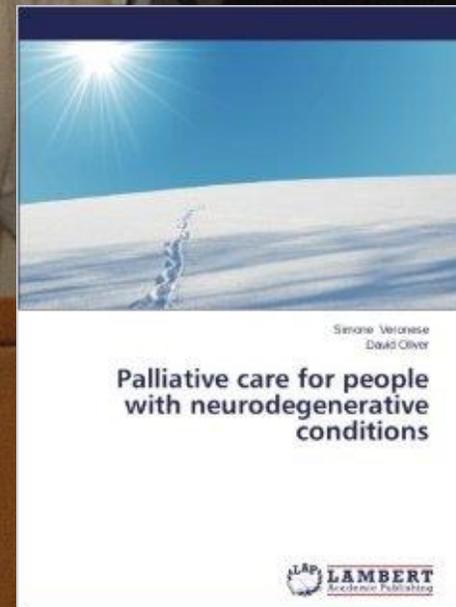
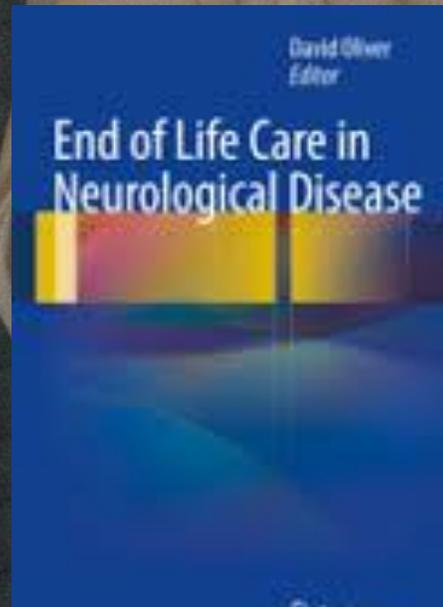
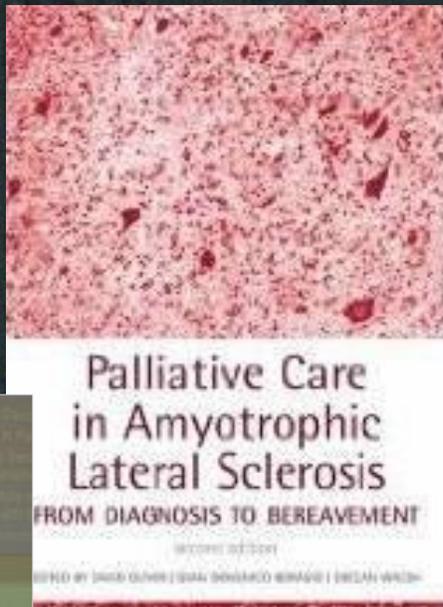
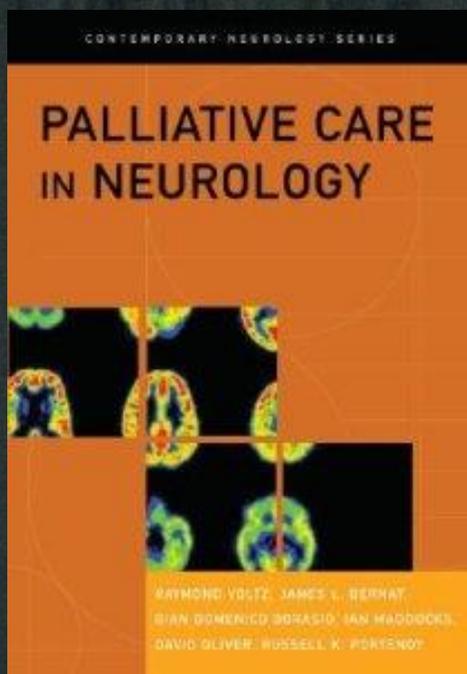
Simone Veronese, Torino, Italy

1. Development of a Core curriculum on palliative care for neurologists and neurologists (Medical Specialists) - 2017
2. Congress sessions in 2017 at the EAPC World Congress in Madrid and the EAN
3. Development of research ideas developed - by end of 2017
4. To consider a European wide research project in 2018



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Cure palliative in neurologia: sindromi

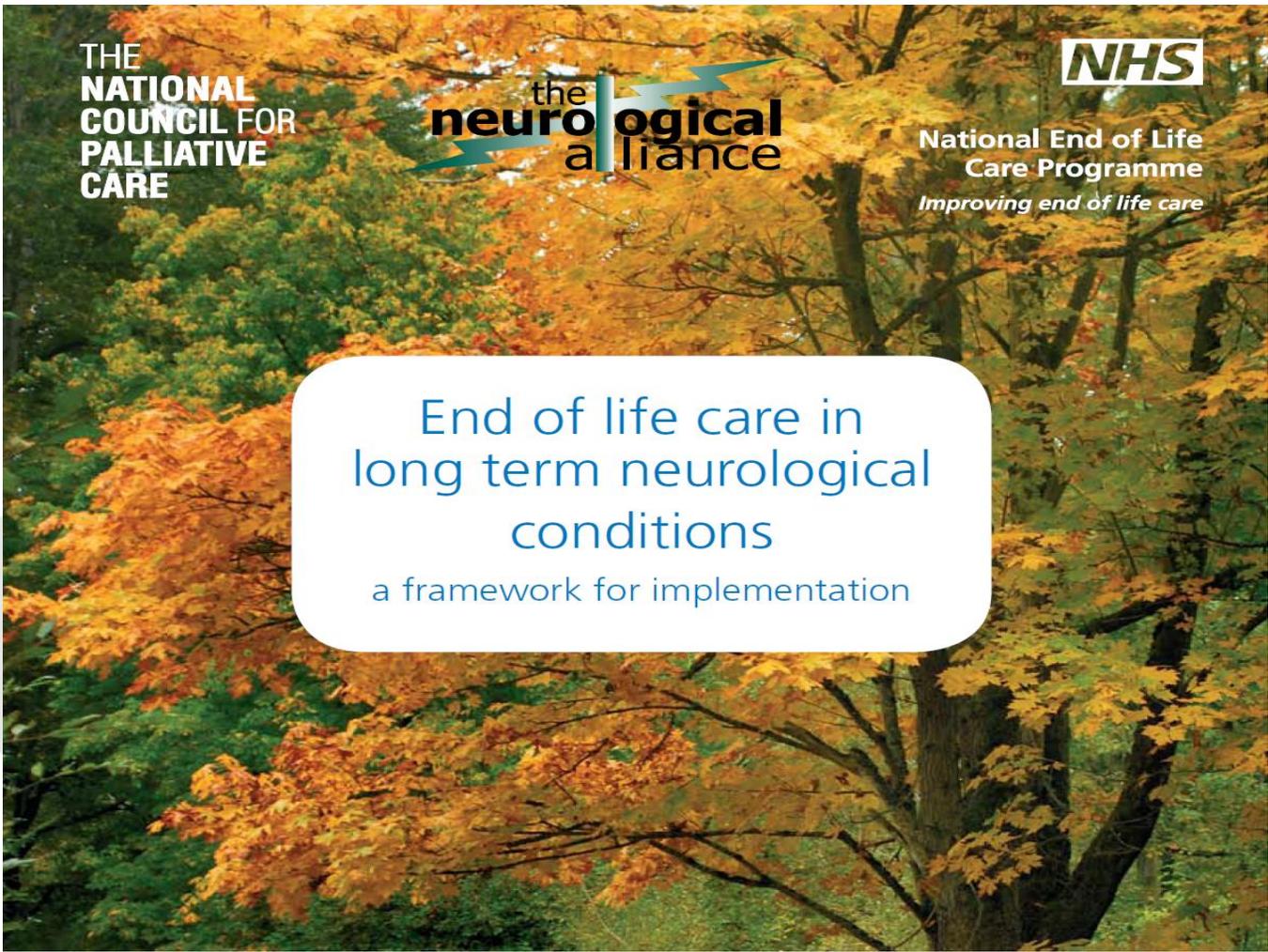
- Malattie del motoneurone (SLA)
- Stroke
- Malattie demielinizzanti (SM)
- Tumori cerebrali
- Parkinson's (PD) e disordini correlati (MSA-PSP)
- Demenze
- Malattie infettive (CJ, HiV)
- Distrofie muscolari
- Epilessie
- Malattie neurologiche pediatriche

Cure palliative in neurologia: sintomi

- Spasticità
- Disfagia-cachessia
- Disturbi della comunicazione
- Convulsioni e miocloni
- Dolore
- Nausea e vomito
- Perdita di mobilità
- Fatigue
- Stati confusionali acuti
- Sintomi respiratori
- Sintomi intestinali
- Sintomi urologici
- Sintomi psichiatrici
- Fasi avanzate-terminali
 - Dispnea grave, crisi asfittiche
 - Infezioni ricorrenti
 - Lesioni da pressione
 - Stato epilettico
 - Locked in syndrome

Cure palliative in neurologia: aspetti etici e multidisciplinari

- Perdita di identità personale
- Alimentazione ed idratazione
- Sedazione palliativa
- Bisogni psicologici
- Bisogni sociali
- Direttive anticipate
- Bisogni spirituali
- Rifiuto o sospensione dei trattamenti
- Aspetti culturali
- Suicidio medicalmente assistito
- eutanasia
- Formazione professionale
- Consenso informato



THE
**NATIONAL
COUNCIL FOR
PALLIATIVE
CARE**



the
**neurological
alliance**



NHS

National End of Life
Care Programme
Improving end of life care

End of life care in
long term neurological
conditions

a framework for implementation



DH Department
of Health

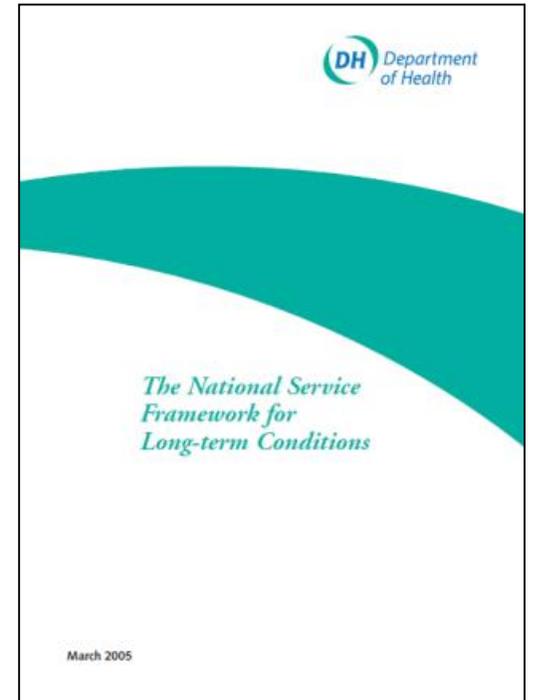


*The National Service
Framework for
Long-term Conditions*

March 2005

The National service framework for long term conditions (2005)

- ✓ Include un requisito di qualità per la fine della vita (QR 9)
- ✓ Riconosce come tuttora siano scarsamente affrontati i temi di fine vita in queste condizioni (EoLC) con questi malati.
- ✓ Riconosce come spesso non siano riconosciuti i cambiamenti cognitivi e quindi suggerisce che le decisioni di fine vita vengano affrontate più precocemente.
- ✓ Evidenzia come le Cure Palliative possano migliorare la QoL durante tutto il decorso delle malattie
- ✓ Sottolinea come un approccio olistico ai bisogni dei malati sia necessario.
- ✓ Invoca il coinvolgimento delle cure specialistiche multidisciplinari nelle fasi terminali delle patologie



The quality requirements (QRs)

Quality requirement 1: A person centred service

Quality requirement 2: Early recognition, prompt diagnosis and treatment

Quality requirement 3: Emergency and acute management

Quality requirement 4: Early and specialist rehabilitation

Quality requirement 5: Community rehabilitation and support

Quality requirement 6: Vocational rehabilitation

*The National Service
Framework for
Long-term Conditions*

March 2005

Quality requirement 7: Providing equipment and accommodation

Quality requirement 8: Providing personal care and support

Le persone affette da patologie neurologiche in fase avanzata hanno il diritto di ricevere un ampio spettro di servizi di cure palliative per ottenere un buon controllo dei sintomi, in particolare sollievo dal dolore, ed essere aiutati nei propri bisogni personali, psicologici, sociali e spirituali, in linea con i principi delle cure palliative.

Quality requirement 10: Supporting family and carers

Quality requirement 11: Caring for people with neurological conditions in hospital or other health and social care settings

CONCISE GUIDANCE TO GOOD PRACTICE

A series of evidence-based guidelines for clinical management

Long-term neurological conditions: management at the interface between neurology, rehabilitation and palliative care

NATIONAL GUIDELINES

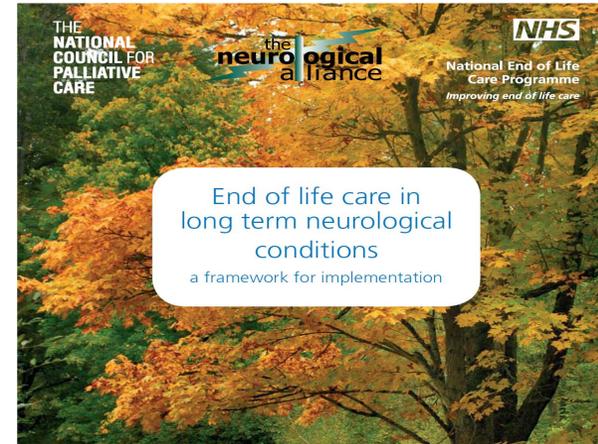
March 2008



THE
NATIONAL
COUNCIL FOR
PALLIATIVE
CARE



- Lunga durata delle malattie
- Morte improvvisa (SLA, MSA)
- Difficoltà di previsione del decorso, fluttuazioni (malattia di Parkinson)
- Cure multidisciplinari complesse (sclerosi multipla)
- Trattamenti specialistici (stimolazione cerebrale profonda nel Parkinson, pompe intratecali al baclofen nella SM)



- Problemi neuropsichiatrici complessi (cambiamenti umorali e comportamentali)
- Le patologie rapidamente progressive possono richiedere cure palliative già dalle prime fasi
- Molti malati muoiono non a causa della patologia neurologica, ma per le complicanze o comorbidità
- Le patologie hanno decorsi variabili e diversi tra loro rendendo difficile l'organizzazione di programmi di cura di fine vita

Prevalenza e Mortalità in UK

	Prevalence	Estimated numbers+	Annual deaths*
Parkinson's disease	110-180/100,000	120,000	7700
Multiple sclerosis	110-140/100,000	100,000	1500
Motor neurone disease	6/100,000	5,000	1500
Huntingtons' disease	6-10/100,000	5,000	240
Multiple Systems Atrophy	5/100,000	4,500	200
Progressive Supranuclear Palsy	6/100,000	5,000	310

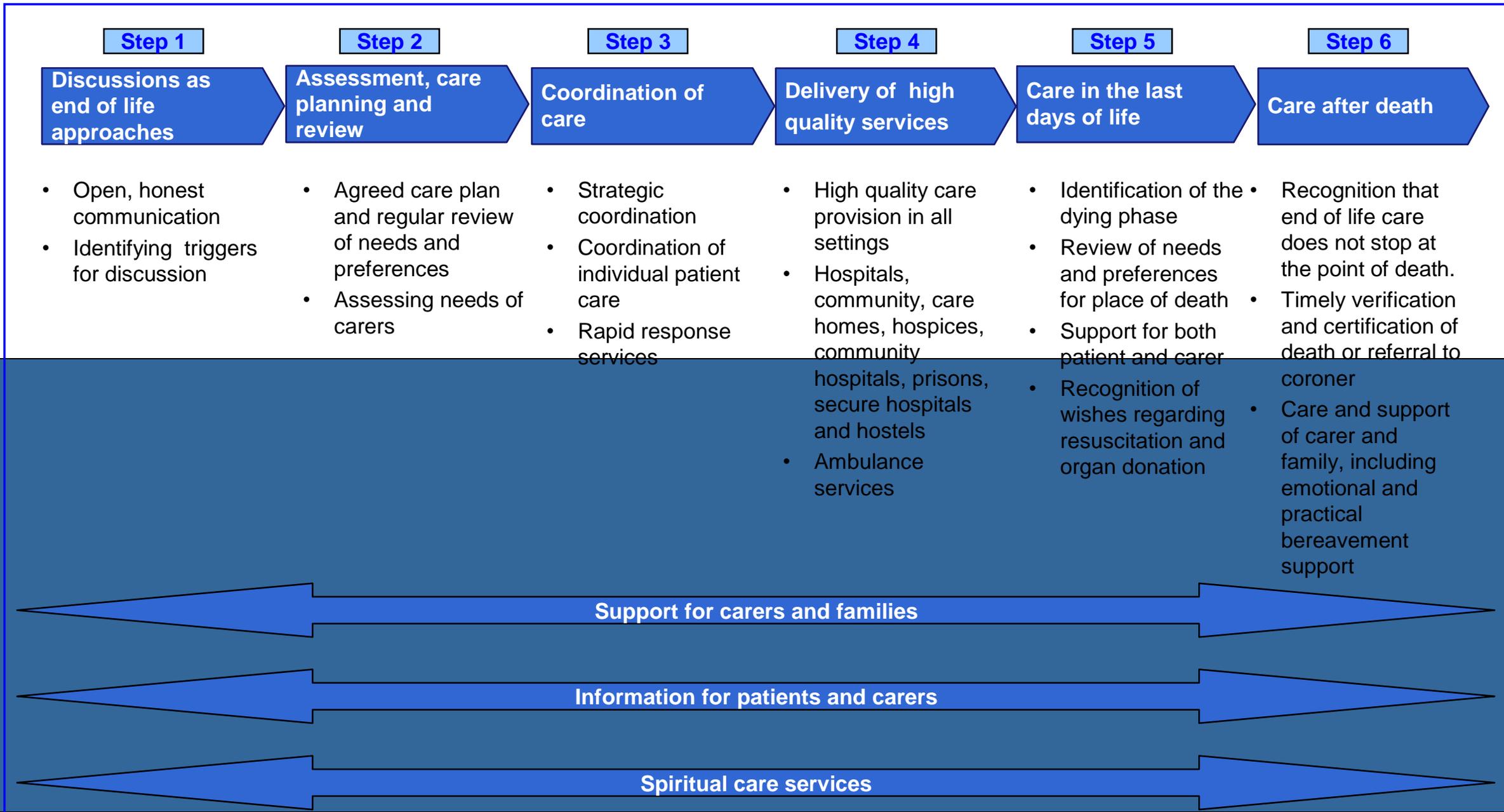
+ Assuming a England of population 50 million

*The condition is mentioned on the ONS return from the death certificates during the period 2002-2010.

Deaths from neurodegenerative diseases in England 2002-2008
www.endoflifecare-intelligence.org.uk

Strumenti utili

- Liverpool Care Pathway for the Dying patient (LCP)
- Gold Standards Framework (GSF)
- Advanced Care Planning
- Preferred Priorities for Care
- Necesidades Paliativas Programme (NECPAL)
- **Supportive and Palliative Care Indicators Tool (SPICT)**
- **Grandi insufficienze d'organo "end stage": cure intensive o cure palliative? SIIARTI**

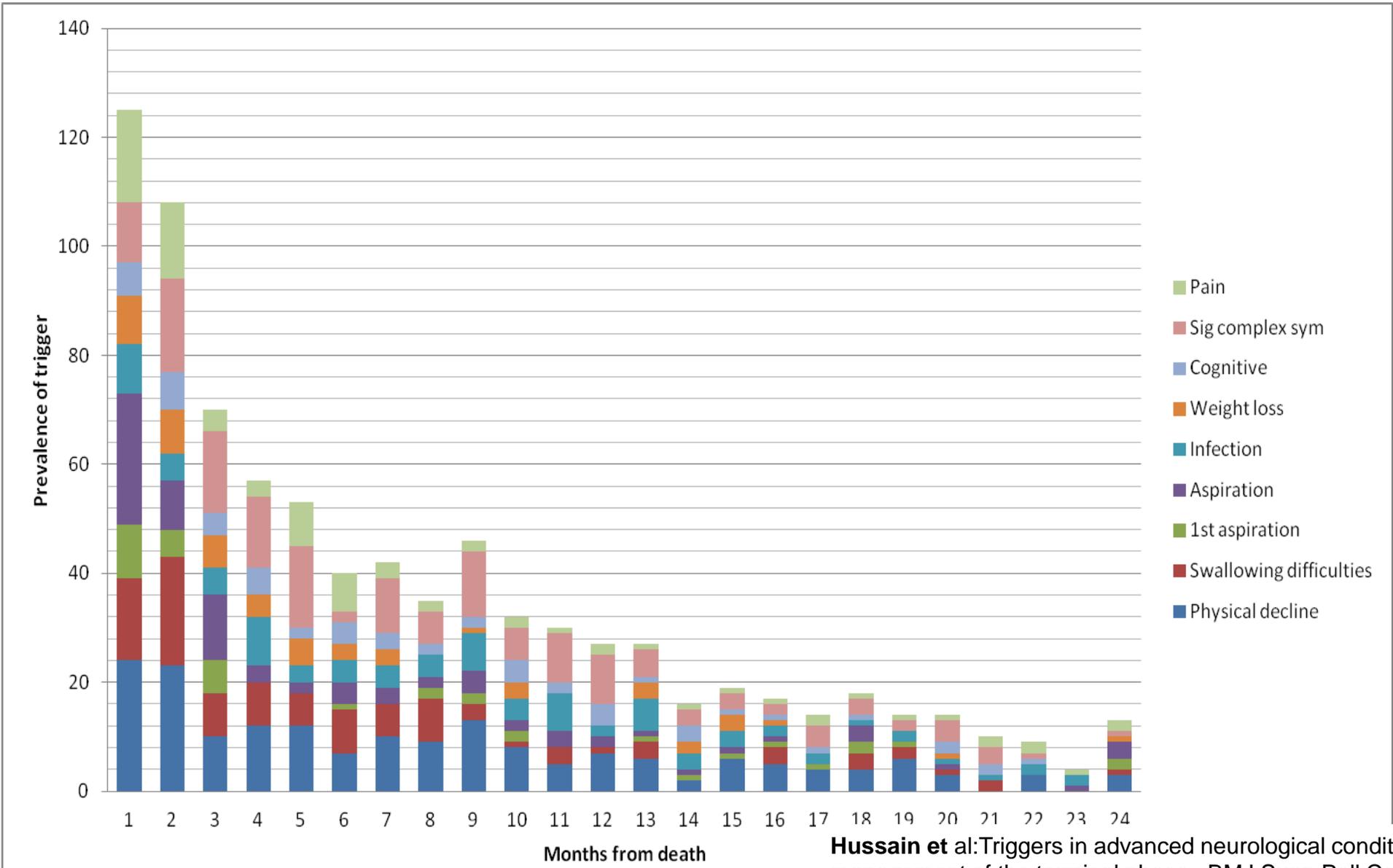


“Triggers” for end of life care

Generali per le patologie neurologiche

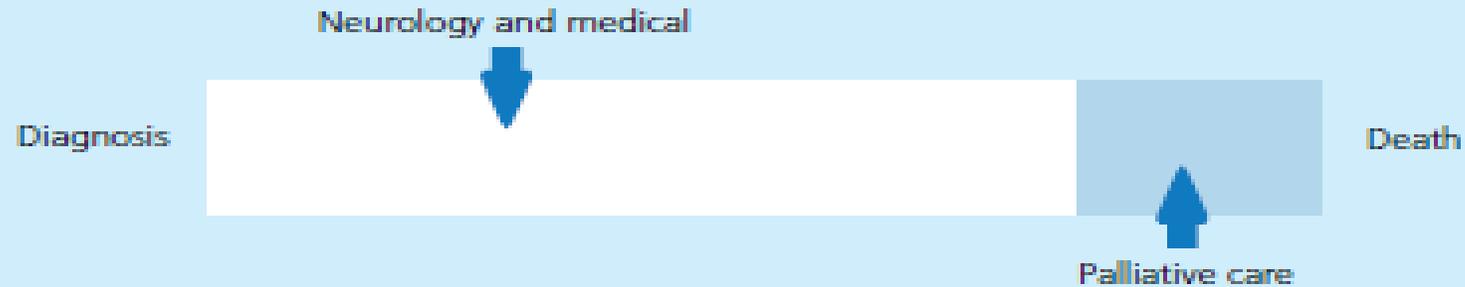
- Richiesta dei pazienti
- Richiesta dei familiari
- Disfagia
- Declino cognitivo
- Dispnea
- Infezioni ricorrenti e ricoveri non programmati
- Perdita di peso
- Marcato scadimento delle condizioni generali

Triggers in months prior to death

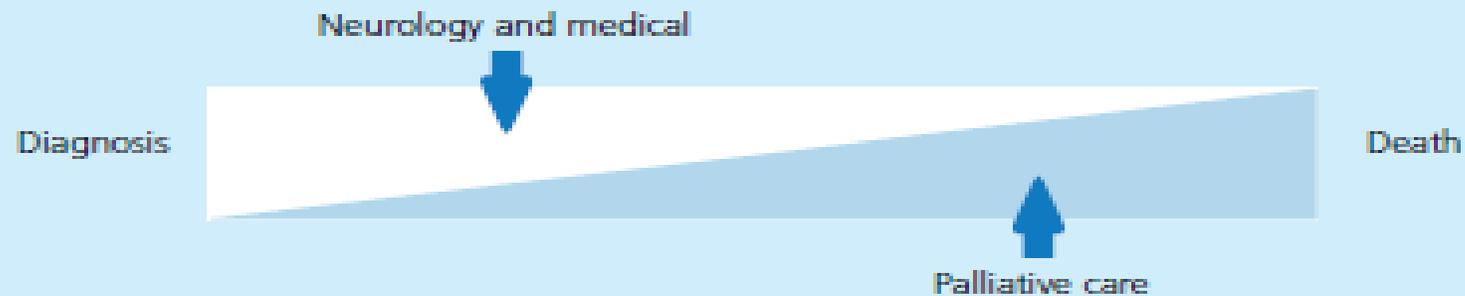


Quando coinvolgere le cure palliative?

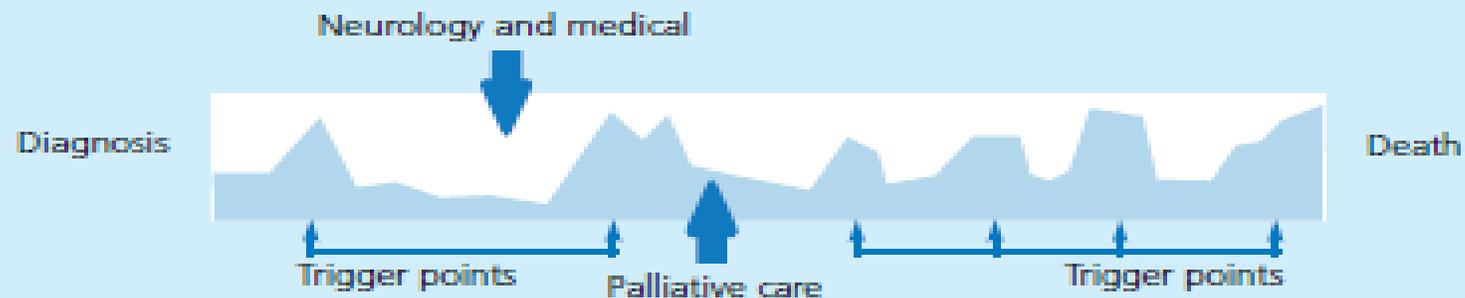
A. The traditional model of late involvement of palliative services



B. The model of early and increasing involvement of palliative services



C. The model of dynamic involvement of palliative services based on trigger points



A consensus review on the development of palliative care for patients with chronic and progressive neurological disease

D. J. Oliver^{a,b}, G. D. Borasio^c, A. Caraceni^{d,e}, M. de Visser^f, W. Grisold^g, S. Lorenzi^h, S. Veroneseⁱ and R. Voltz^{j,k}

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Keywords: collaborative care, consensus, end of life, palliative care, progressive neurological disease

Received 11 February 2014
revision requested 10 July 2014
Accepted 2 September 2015

European Journal of Neurology 2016, **23**: 30–38

doi:10.1111/ene.12889

Background and purpose: The European Association of Palliative Care Taskforce, in collaboration with the Scientific Panel on Palliative Care in Neurology of the European Federation of Neurological Societies (now the European Academy of Neurology), aimed to undertake a review of the literature to establish an evidence-based consensus for palliative and end of life care for patients with progressive neurological disease, and their families.

Methods: A search of the literature yielded 942 articles on this area. These were reviewed by two investigators to determine the main areas and the subsections. A draft list of papers supporting the evidence for each area was circulated to the other authors in an iterative process leading to the agreed recommendations.

Results: Overall there is limited evidence to support the recommendations but there is increasing evidence that palliative care and a multidisciplinary approach to care do lead to improved symptoms (Level B) and quality of life of patients and their families (Level C). The main areas in which consensus was found and recommendations could be made are in the early integration of palliative care (Level C), involvement of the wider multidisciplinary team (Level B), communication with patients and families including advance care planning (Level C), symptom management (Level B), end of life care (Level C), carer support and training (Level C), and education for all professionals involved in the care of these patients and families (Good Practice Point).

Conclusions: The care of patients with progressive neurological disease and their families continues to improve and develop. There is a pressing need for increased collaboration between neurology and palliative care.

Early integration of care

Palliative care should be considered early in the disease trajectory, depending on the underlying diagnosis

REVIEW ARTICLE

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Multidisciplinary team

Assessment and care should be provided by multidisciplinary approach

- At least three professions
 - Physician
 - Nurse
 - Social Worker
 - Psychologist / counsellor

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Communication and planning

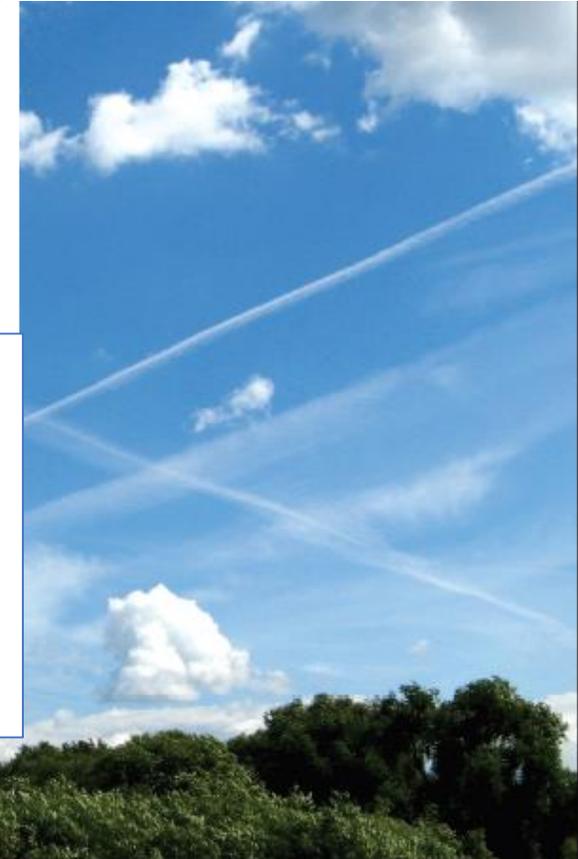
- Communication should be
 - Open
 - Set goals and therapy options
 - Use structured models, SPIKES
- Early advance care planning encouraged
Especially if expectation of
 - Impaired communication
 - Cognitive deterioration

Effect of a Patient and Clinician Communication-Priming Intervention on Patient-Reported Goals-of-Care Discussions Between Patients With Serious Illness and Clinicians

A Randomized Clinical Trial

J. Randall Curtis, MD, MPH; Lois Downey, MA; Anthony L. Back, MD; Elizabeth L. Nielsen, MPH; Sudiptho Paul; Alexandria Z. Lahdya; Patsy D. Treece, RN, MN; Priscilla Armstrong; Ronald Peck, MBA; Ruth A. Engelberg, PhD

This intervention **increased** the occurrence, documentation, and quality of goals-of-care communication during routine outpatient visits and **increased** goal-concordant care at 3 months among patients with stable goals, with no change in symptoms of anxiety or depression.



Ethical relevance of patients' capacity

Capacity to decide for yourself

Weight of decisions



t – trajectory of disease

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Symptom management

1. Physical symptoms
 - a. Diagnosis
 - b. Pharmacological and non-pharmacological management
 - c. Regular review
2. Proactive assessment of
 - a. Physical issues
 - b. Psychosocial issues
3. Principles of palliative care symptom management should be used

A consensus review on the development of palliative care for patients with chronic and progressive neurological disease

D. J. Oliver^{a,b}, G. D. Borasio^c, A. Caraceni^{d,e}, M. de Visser^f, W. Grisold^g, S. Lorenzi^h, S. Veroneseⁱ and R. Voltz^{j,k}

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Keywords: collaborative care, consensus, end of life, palliative care, progressive neurological disease

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European Journal of Neurology 2016, **23**: 30–38

doi:10.1111/ene.12889

Background and purpose: The European Association of Palliative Care Taskforce, in collaboration with the Scientific Panel on Palliative Care in Neurology of the European Federation of Neurological Societies (now the European Academy of Neurology), aimed to undertake a review of the literature to establish an evidence-based consensus for palliative and end of life care for patients with progressive neurological disease, and their families.

Methods: A search of the literature yielded 942 articles on this area. These were reviewed by two investigators to determine the main areas and the subsections. A draft list of papers supporting the evidence for each area was circulated to the other authors in an iterative process leading to the agreed recommendations.

Results: Overall there is limited evidence to support the recommendations but there is increasing evidence that palliative care and a multidisciplinary approach to care do lead to improved symptoms (Level B) and quality of life of patients and their families (Level C). The main areas in which consensus was found and recommendations could be made are in the early integration of palliative care (Level C), involvement of the wider multidisciplinary team (Level B), communication with patients and families including advance care planning (Level C), symptom management (Level B), end of life care (Level C), carer support and training (Level C), and education for all professionals involved in the care of these patients and families (Good Practice Point).

Conclusions: The care of patients with progressive neurological disease and their families continues to improve and develop. There is a pressing need for increased collaboration between neurology and palliative care.

Carer support

1. Needs of carers assessed regularly
2. Support of carers – before and after death
3. Professionals should reduce emotional exhaustion and burnout by
 - a. Education
 - b. Support
 - c. Supervision

A consensus review on the development of palliative care for patients with chronic and progressive neurological disease

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Conclusions: The care of patients with progressive neurological disease and their families continues to improve and develop. There is a pressing need for increased collaboration between neurology and palliative care.

End of life care

1. Continued and repeated discussion
As continual changes
 - a. Physical
 - b. Cognitive
 - c. Preferences
2. Encouragement of open discussion about dying process
3. Encourage open discussion about the wish for hastened death

A consensus review on the development of palliative care for patients with chronic and progressive neurological disease

D. J. Oliver^{a,b}, G. D. Borasio^c, A. Caraceni^{d,e}, M. de Visser^f, W. Grisold^g, S. Lorenzi^h, S. Veroneseⁱ and R. Voltz^{j,k}

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Keywords:

collaborative care, consensus, end of life, palliative care, progressive neurological disease

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Conclusions: The care of patients with progressive neurological disease and their families continues to improve and develop. There is a pressing need for increased collaboration between neurology and palliative care.

Training and education

1. Palliative care principles should be included in the training and continuing education of neurologists.
2. The understanding and management of neurological symptoms of patients in the advanced stages of neurological diseases should be included in the training and continuing education of specialist palliative care professionals.

2010

Research Paper

Multiple
Sclerosis

Multiple Sclerosis
16(5) 627–636
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msj.sagepub.com



Palliative care for people severely affected by multiple sclerosis: evaluation of a novel palliative care service

Polly Edmonds¹, Sam Hart², Wei Gao², Bella Vivat³,
Rachel Burman¹, Eli Silber⁴ and Irene J Higginson²

Abstract

Multiple sclerosis results in both physical and psychological disability but some patients have needs that are not adequately met by existing services. Our objective was to explore whether a new palliative care service improved outcomes for people severely affected by multiple sclerosis. A delayed intervention randomized controlled trial was undertaken with multiple sclerosis patients deemed by staff to have palliative care needs. The intervention was a multiprofessional palliative care team assessment and follow-up. The intervention group was offered the team immediately (fast track, FI); the control group continued best standard care and then offered the team after 3 months (standard intervention, SI). The main outcome measures were: patient reported issues using the Palliative Care Outcome Scale and Multiple Sclerosis Impact Scale at 12 weeks and caregiver burden using the Zarit Burden Inventory. Sixty-nine people were referred to the service; 52 consented or were eligible to be randomized (26 to the FI and 26 to the SI groups). At 12 weeks people in the FI group had an improvement (mean change -1.0) in the total score of 5 key symptoms whereas there was deterioration in the SI group (mean change 1.1 , $F=4.75$, $p=0.035$). There was no difference in the change in general Palliative Care Outcome Scale or Multiple Sclerosis Impact Scale scores. There was an improvement in caregiver burden in the FI group and a deterioration in the SI group ($F=7.60$, $p=0.013$). Involvement with the palliative care service appeared to positively affect some key symptoms and reduced informal caregiver burden.

52 diadi

12 settimane

Paziente: POS, POS-S-MS

Caregiver: ZBI

2015

MS, MSA, PD, ALS

50 diadi

16 settimane

Paziente: SEIQoL-DW, VAS sintomi

Caregiver: CBI

► Additional material is published online only. To view please visit the journal online (<http://dx.doi.org/10.1136/bmjspcare-2014-000788>).

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doi:10.1136/bmjspcare-2014-000788

Research

FONDAZIONE
FARO

Specialist palliative care improves the quality of life in advanced neurodegenerative disorders: NE-PAL, a pilot randomised controlled study

Simone Veronese,¹ G Gallo,¹ A Valle,¹ C Cugno,¹ A Chio,² A Calvo,² P Cavalla,² M Zibetti,² C Rivoiro,³ D J Oliver⁴

ABSTRACT

Background This study analysed the impact on palliative care outcomes of a new specialist palliative care service for patients severely affected by amyotrophic lateral sclerosis (ALS/MND), multiple sclerosis, Parkinson's disease and related disorders (multiple system atrophy progressive supranuclear palsy, MSA-PSP).

Methods The design followed the Medical Research Council Framework for the evaluation of complex interventions. A phase II randomised controlled trial (RCT) was undertaken comparing an immediate referral to the service (FT, fast track) to a 16-week wait (standard track (ST), standard best practice) using a parallel arm design. The main outcome measures were Quality of Life (measured with Schedule for the Evaluation of Individual Quality of Life Direct Weight, SEIQoL-DW) and burden of the carers (Caregivers Burden Inventory, CBI), with secondary outcomes of symptoms, psychosocial and spiritual issues.

Results 50 patients severely affected by neurodegenerative conditions and their informal family carers were randomised: 25 FT, 25 ST. At baseline (T0), there were no differences between groups. 4 patients died during the follow-up (2 FT, 2 ST) and 2 FT patients dropped out before the end of the study. After 16 weeks (T1), FT participants scored significant improvement in the SEIQoL-DW index, pain dyspnoea sleep disturbance and bowel symptoms.

Conclusions This exploratory RCT provides evidence that no harm was experienced by SPCS for patients severely affected by neurodegenerative disorders. There was an improvement in quality of life and physical symptoms for neurological patients in palliative care. Caregiver burden was not affected by the service.

INTRODUCTION

Palliative care aims at improving quality of life (QoL) of patients and their families facing problems associated with incurable, progressive and life-limiting disease by means of the impeccable assessment and treatment of symptoms and other psychological, social and spiritual issues.¹ Patients affected by progressive neurodegenerative conditions suffer a high burden of symptoms²⁻³ and issues that are often managed by specialist palliative care teams.⁴ However, there is a challenge in providing specialist palliative care service (SPCS) for individuals with advanced neurological conditions as there is a great variability in disease trajectories and symptom profiles. This has been considered in the discussion of the provision of palliative and end-of-life care for this patient group,⁴ and there is evidence that the suggested triggers for consideration of care may be of help—these being patient request, family request, dysphagia, cognitive decline, dyspnoea, repeated infections (in particular, aspiration pneumonia), weight loss and marked decline in condition.^{4,5}

Although SPCS has been advocated in the care of patients with neurological diseases,⁶ there is very little available evidence about the impact of SPCS on the typical palliative care outcomes. Moreover, there is little definitive evidence for the effectiveness of palliative care generally. One review has shown that the evidence for benefit from specialised palliative care is sparse and limited by methodological shortcomings.⁷ Carefully planned trials, using a standardised

2018

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FARO

Original Research Paper

Randomized controlled trial of a home-based palliative approach for people with severe multiple sclerosis

Alessandra Solari, Andrea Giordano, Francesco Patti, Maria Grazia Grasso, Paolo Confalonieri, Lucia Palmisano, Michela Ponzio, Claudia Borreani, Rosalba Rosato, Simone Veronese, Paola Zaratina and Mario Alberto Battaglia; on behalf of the PeNSAMI Project*

Abstract

Background: Evidence on the efficacy of palliative care in persons with severe multiple sclerosis (MS) is scarce.

Objective: To assess the efficacy of a home-based palliative approach (HPA) for adults with severe MS and their carers.

Methods: Adults with severe MS-carer dyads were assigned (2:1 ratio) to either HPA or usual care (UC). At each center, a multi-professional team delivered the 6-month intervention. A blind examiner assessed dyads at baseline, 3 months, and 6 months. Primary outcome measures were Palliative care Outcome Scale-Symptoms-MS (POS-S-MS) and Schedule for the Evaluation of Individual Quality of Life-Direct Weighting (SEIQoL-DW, not assessed in severely cognitively compromised patients).

Results: Of 78 dyads randomized, 76 (50HPA, 26UC) were analyzed. Symptom burden (POS-S-MS) significantly reduced in HPA group compared to UC ($p=0.047$). Effect size was 0.20 at 3 months and 0.32 at 6 months, and statistical significance was borderline in per-protocol analysis ($p=0.062$). Changes in SEIQoL-DW index did not differ in the two groups, as changes in secondary patient and carer outcomes.

Conclusion: HPA slightly reduced symptoms burden. We found no evidence of HPA efficacy on patient quality of life and on secondary outcomes.

Multiple Sclerosis Journal

2018, Vol. 24(5) 663–674

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76 diadi
24 settimane
Paziente: POS-S-
MS, SEIQoL-DW,
HADS, EQ-5D
Caregiver: ZBI, SF-
36, HADS, EQ-5D

2019?



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OPTCARE NEURO

ABOUT US

STUDY

RESEARCH

- Global Health
- Research strategy
- Evaluating and improving care
- Outcome and assessment measures
- Symptom led research
- Living and Dying in society
- Key studies

DINAMO

OPTCARE Neuro →

- How to get involved
- C-CHANGE
- BuildCARE
- EuroImpact
- FunctionalTLS
- GUIDE_Care
- MORECare
- MORECare Capacity
- OACC
- OPTCare Elderly

OPTCARE Neuro

What is OPTCARE Neuro?

This is a study to evaluate a new service for people who are severely affected by long-term neurological conditions. These are: Multiple Sclerosis, Parkinsonism and Related Disorders (Idopathic Parkinson's Disease, Multiple System Atrophy and Progressive Supranuclear Palsy), and Motor Neurone Disease. We will be recruiting across 5 centres in the UK. People and their family members/carers are invited to participate if they have unresolved symptoms and problems and are not currently receiving specialist palliative care.

Specialist Palliative care will provide an extra layer of support to people living with these advanced illnesses and the people who are close to them. This service aims to enable people to live well with increasing illness by providing the support they need to pursue the things they and the people close to them feel are important, and to plan future care, particularly for when nearing the end of life. It will be delivered by specialist doctors, nurses and social workers from local palliative care services.

The palliative care provision for this study is short-term, with approximately 3 contacts with the specialist palliative care team. After being referred to the service (immediately or after 12 weeks so we can compare the 2 groups), the palliative care team will arrange an initial visit to assess what the patient needs help with. The team will offer approximately 2 follow-up visits, to review the care and support the patient and their family. The palliative care team will see the patient either at the hospital, or the patient's own home. The team works closely with the specialist neurology team and other services including their GP, who will continue to support the patient as usual.

NEWSLETTER ISSUE 4

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5 centri UK / MS, MSA, PD, ALS

356 diadi (target)

6-8 settimane

Paziente:

- IPOS-Neuro-5, POS, HADS, costi, ospedalizzazioni, EQ-5D**

Caregiver:

- ZBI-12, SF-12, FAMCARE 2**

PICOs

1. Terapie sintomatiche
2. Riabilitazione multi-disciplinare
3. Advance care planning
4. CP generali
5. CP specialistiche
6. Training/formazione dei caregiver
7. Supporto pratico/emotivo ai caregiver
8. Training/formazione in CP del personale sanitario dedicato alla SM
9. Training/formazione in SM dei palliativisti
10. Discutere con il personale sanitario il desiderio di anticipare la morte

ORIGINAL ARTICLE

Patient and caregiver involvement in the formulation of guideline questions: findings from the European Academy of Neurology guideline on palliative care of people with severe multiple sclerosis

S. Köpke^a, A. Giordano^b, S. Veronese^c, A. Christin Rahn^d, I. Kleiter^e, B. Basedow-Rajwicz^f, A. Fornari^g, M. A. Battaglia^h, J. Druilovicⁱ, L. Kooij^j, J. Koops^k, J. Mens^l, E. R. Meza Murrillo^m, I. Milanovⁿ, R. Mio^o, F. Patti^p, T. Pekmezovic^q, J. Sastre-Garriga^r, J. Vosburgh^s, R. Voltz^t, J. Bay^u, D. J. Oliver^v and A. Solari^w

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Keywords:

best practice, clinical practice guideline, mixed methods, multiple sclerosis, online survey, palliative care, patient and public involvement

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European Journal of
Neurology 2018, 0: 1-10

doi:10.1111/ene.13760

Background and purpose: Patient and public involvement in clinical practice guideline development is recommended to increase guideline trustworthiness and relevance. The aim was to engage multiple sclerosis (MS) patients and caregivers in the definition of the key questions to be answered in the European Academy of Neurology guideline on palliative care of people with severe MS.

Methods: A mixed methods approach was used: an international online survey launched by the national MS societies of eight countries, after pilot testing/debriefing on 20 MS patients and 18 caregivers, focus group meetings of Italian and German MS patients and caregivers.

Results: Of 1199 participants, 951 (79%) completed the whole online survey and 934 from seven countries were analysed: 751 (80%) were MS patients (74% women, mean age 46.1) and 183 (20%) were caregivers (36% spouses/partners, 72% women, mean age 47.4). Participants agreed/strongly agreed on inclusion of the nine pre-specified topics (from 89% for 'advance care planning' to 98% for 'multidisciplinary rehabilitation'), and <5% replied 'I prefer not to answer' to any topic. There were 569 free comments: 182 (32%) on the pre-specified topics, 227 (40%) on additional topics (16 guideline-pertinent) and 160 (28%) on outcomes. Five focus group meetings (three of MS patients, two of caregivers, and overall 35 participants) corroborated the survey findings. In addition, they allowed an explanation of the guideline production process and the exploration of patient-important outcomes and of taxing issues.

Conclusions: Multiple sclerosis patient and caregiver involvement was resource and time intensive, but rewarding. It was the key for the formulation of the 10 guideline questions and for the identification of patient-important outcomes.

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EANO palliative care task force

Review



www.thelancet.com/oncology Vol 18 June 2017

European Association for Neuro-Oncology (EANO) guidelines for palliative care in adults with glioma



Andrea Pace, Linda Dirven, Johan A F Koekkoek, Heidrun Golla, Jane Fleming, Roberta Rudà, Christine Marosi, Emilie Le Rhun, Robin Grant, Kathy Oliver, Ingela Oberg, Helen J Bulbeck, Alasdair G Rooney, Roger Henriksson, H Roeline W Pasman, Stefan Oberndorfer, Michael Weller, Martin J B Taphoorn, for the European Association of Neuro-Oncology palliative care task force

Patients with glioma present with complex palliative care needs throughout their disease trajectory. The life-limiting nature of gliomas and the presence of specific symptoms related to neurological deterioration necessitate an appropriate and early palliative care approach. The multidisciplinary palliative care task force of the European Association of Neuro-Oncology did a systematic review of the available scientific literature to formulate the best possible evidence-based recommendations for the palliative care of adult patients with glioma, with the aim to reduce symptom burden and improve the quality of life of patients and their caregivers, particularly in the end-of-life phase. When recommendations could not be made because of the scarcity of evidence, the task force either used evidence from studies of patients with systemic cancer or formulated expert opinion. Areas of palliative care that currently lack evidence and thus deserve attention for further research are fatigue, disorders of behaviour and mood, interventions for the needs of caregivers, and timing of advance care planning.

Lancet Oncol 2017; 18: e330-40

Neuro-Oncology Unit, Regina Elena Cancer Institute, Rome, Italy (A Pace MD); Department of Neurology, Leiden University Medical Center, Leiden, Netherlands (L Dirven PhD, J A F Koekkoek MD, Prof M J B Taphoorn MD); Department of Neurology, Haaglanden Medical Center, The Hague, Netherlands

Literature review

the care task for



Andrea Pace, Linda Dirven, Johan AF Koekkoek, Heidrun Golla, Jane Fleming, Roberta Rudà, Christine Marosi, Emilia Le Rhun, Robin Grant, Kathy Oliver, Ingela Oberg, Helen J Buebeck, Alriksson, Roeline W Pasma, Stefan Oberndorfer, Michael Weller, Martin JB Tap, Kerrigan, Simone Veronese, Tobias Walbert, Marike Broekman, EANO scientific board

Identification

Records identified through database searching
PubMed/Medline (n=11.719), Embase (n=9.040),
PsycINFO (n=4.059), Emcare (n=3.454), Cochrane
library (n=1.958), Web of Science (n=6.542)
(n=36.772)

Screening

Records screened after duplicates removed
(n=16.156)

Records excluded
(n=15.815)

Eligibility

Full-text articles assessed for eligibility
(n=341)

Full-text articles excluded, with reasons (n=215)

- Article without original data: n=133
- Not about mental capacity: n=42
- Other patient population: n=10
- <10 patients: n=4
- Not in English or published in a peer-reviewed journal: n=3
- No full-text available: n=12
- Other reason: n=9

Included

Total number of studies included in the review
(n=126)

Topics proposed



- **MC in brain tumor patients and other neurological diseases**
- **MC and patient- and treatment-related factors**
- **Tools to measure medical capacity**
- **MC and consent to research**
- **MC and EOL treatment decisions**
- **Surrogate decision making (proxy and HCP view)**
- **Interventions to improve medical capacity**

EURO-NEURO: the collaboration between neurology and palliative care across Europe

Introduction

This research project is being undertaken with the support of the European Academy of Neurology and the European Association for Palliative Care and is led by Professor David Oliver, who is Co-Chair of the EAN Palliative care Specialist Panel and Chair of the EAPC Reference Group on Palliative care and neurology. He is an Honorary Professor based within the Tizard Centre at the University of Kent, Canterbury.

We would like you to take part in this study. Before you decide please take time to read the below information. Feel free to discuss this project with others.

What is the purpose of the study?

The aim of this study is to understand more about the collaboration between neurology and palliative care in the care of patients with neurological disease across Europe.

Who is being asked to take part in this study?

We are asking all neurologists who are members of the EAN and palliative care specialists who are part of the EAPC network.

Neurology Services

Please estimate the number of patients your service sees (approximate numbers seen per year).

*

Parkinson's Disease

*

Parkinson's Plus – Progressive Supranuclear Palsy

*

Parkinson's Plus – Multiple System Atrophy

*

Multiple Sclerosis

*

Amyotrophic Lateral Sclerosis

*

Huntington's Disease

*

Alzheimer's Disease / Dementia

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Stroke

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EURO NEURO survey



- Due versioni online (professionisti di cure palliative e neurologi)
- Si accede tramite link (computer, tablet, smartphone)
- È anonima, gratuita e validata (KCL, CSI, KENT)
- 10-15 minuti per completare
- I neurologi stanno partecipando con entusiasmo.
- Chiedetemi il link: simone.veronese@fondazionefaro.it
- Perseguitatemi e diffondetela ai colleghi interessati!

Neurologi

<https://www.smartsurvey.co.uk/s/N1WAQ/>

Palliativisti

<https://www.smartsurvey.co.uk/s/DKDV6/>

Survey GdS



QUESTIONARIO GdS Bioetica CP SIN OTTOBRE 2018 - LEGGE 219/2017

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Per concludere

- I pazienti affetti da patologie neurologiche (ed i loro cari) hanno molti bisogni di cure palliative
- La collaborazione tra neurologia e cure palliative è la via maestra
- Le società scientifiche riconoscono la necessità di collaborare e della mutua formazione
- Abbiamo prove di efficacia delle cure palliative nei malati neurologici, ma la forza delle raccomandazioni non è ancora adeguata
- C'è fermento nella produzione di linee guida

Grazie per l'attenzione

