Cure palliative in neurologia

S. Veronese Fondazione FARO, Torino
GdS di Bioetica e Cure Palliative SIN
EAPC Reference group on Neurology
Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

http://www.who.int/cancer/palliative/definition/en/
WHO Definition of Palliative Care

- 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

http://www.who.int/cancer/palliative/definition/en/
Patients with Parkinson’s disease and ALS were cared for by St Christopher’s hospice in 1967 (Clark 2002, p. 322).

“You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.”

- Anger
- Finding meaning
- Regrets
- Loss of faith
- Fear of the unknown
- Isolation
- Loss of job – role
- Financial concerns
- Dependency
- Worries for family
- Fear of suffering
- Past experience of illness
- Anxiety – depression
- Feeling burden
- Anger
- Finding meaning
- Regrets
- Loss of faith
- Fear of the unknown

**TOTAL PAIN**

- Disease related symptoms
- Comorbidities
- Treatments

- Physical
- Psychological
- Social
- Spiritual
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:

c) «malato»: la persona affetta da una patologia ad andamento cronico ed evolutivo, per la quale non esistono terapie e, 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.

Education in palliative care

✓ 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

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,
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 neurologist 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
### Sommario

1. INTRODUZIONE: PERCHÉ LE CURE PALLIATIVE IN NEUROLOGIA ...... 7
2. PECULIARITÀ DELLE CURE PALLIATIVE NEI MALATI NEUROLOGICI ... 11
   La possibile lunga durata e la difficile definizione di terminalità........ 11
   Trattamenti specialistici complessi nelle fasi avanzate di malattie neurologiche......................................................... 12
   Non solo cronicità........................................................................... 12
   I problemi neurologici sono frequenti in altre condizioni soggette a CP. 13
   Sfide alle Cure Palliative dovute alla peculiarità dei caregiver dei malati con patologie neurologiche con grave disabilità ........................................... 13
3. MODELLI DI INTERVENTO DI CURE PALLIATIVE NELLE MALATTIE NEUROLOGICHE .................................. 18
4. INTERAzione tra équipe neurologiche, équipe di cure palliative e MMG .................. 26
5. PRINCIPALI MALATTIE NEUROLOGICHE CHE NECESSITANO DI CURE PALLIATIVE.............................. 29
   DEMENZE ................................................................................. 29
   Demenze degenerative ................................................................. 31
   Demenza vascolare .................................................................... 32
   Altre forme di demenza secondaria........................................... 33
6. LA COMUNICAZIONE COME STRUMENTO TERAPEUTICO ............. 44
   (a) Le capacità di adattamento dei malati.................................. 44
   (b) Le abilità comunicative dei sanitari...................................... 66
   (c) Gli strumenti che facilitano la comunicazione ....................... 68
   (d) Comunicare nella PAC.......................................................... 69
7. SUPPORTO EDUCAZIONALE ................................................. 73
8. LA GESTIONE DELLE FASI TERMINALI .................................. 77
9. ASPETTI ETICI DELLE CURE PALLIATIVE ......................... 84
   Il consenso informato................................................................... 84
   Pianificazione Anticipata/Condivisa delle Cure (PAC) ............... 86

Le Direttive/ disposizioni anticipate di trattamento (DAT) ...................... 88
L'amministratore di sostegno .......................................................... 90
La proporzionalità dei trattamenti.................................................. 91
La limitazione dei trattamenti........................................................ 92
Il processo decisionale eticamente fondato..................................... 94
10. LA SEDAZIONE PALLIATIVA ............................................ 98
    Definizioni.............................................................................. 98
    Giustificazioni etiche .................................................................. 99
    Giustificazioni giuridiche.......................................................... 100
APPENDICE. Casi clinici per il documento condiviso SIN-SICP sulle Cure Palliative in Neurologia .................................................. 103
   Il caso di Carlo, affetto da sclerosi multipla............................... 103
   Domande e riflessioni ................................................................ 105
   Il caso di Veronica affetta da SLA............................................. 106
   Domande e riflessioni ................................................................ 108
   Il caso di Maria, malattia di Parkinson ....................................... 109
   Domande e riflessioni ................................................................ 110
   Il caso di Paolo, affetto da demenza........................................... 111
   Domande e riflessioni ................................................................ 115
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

- Direttive anticipate
- Rifiuto o sospensione dei trattamenti
- Suicidio medicalmente assistito - eutanasia
- Consenso informato

- Bisogni psicologici
- Bisogni sociali

- Bisogni spirituali
- Aspetti culturali
- Formazione professionale
End of life care in long term neurological conditions
a framework for implementation
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 National service framework for long term conditions (2005)
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

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
LE sfide da affrontare per organizzare adeguate EoLC per persone con malattie neurodegenerative

- 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
<table>
<thead>
<tr>
<th>Disease</th>
<th>Prevalence</th>
<th>Estimated numbers+</th>
<th>Annual deaths*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parkinson’s disease</td>
<td>110-180/100,000</td>
<td>120,000</td>
<td>7700</td>
</tr>
<tr>
<td>Multiple sclerosis</td>
<td>110-140/100,000</td>
<td>100,000</td>
<td>1500</td>
</tr>
<tr>
<td>Motor neurone disease</td>
<td>6/100,000</td>
<td>5,000</td>
<td>1500</td>
</tr>
<tr>
<td>Huntingtons’ disease</td>
<td>6-10/100,000</td>
<td>5,000</td>
<td>240</td>
</tr>
<tr>
<td>Multiple Systems Atrophy</td>
<td>5/100,000</td>
<td>4,500</td>
<td>200</td>
</tr>
<tr>
<td>Progressive Supranuclear Palsy</td>
<td>6/100,000</td>
<td>5,000</td>
<td>310</td>
</tr>
</tbody>
</table>

+ 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
- Preffered 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

www.endoflifecareforadults.nhs.uk/tools
<table>
<thead>
<tr>
<th>Step 1</th>
<th>Step 2</th>
<th>Step 3</th>
<th>Step 4</th>
<th>Step 5</th>
<th>Step 6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discussions as end of life approaches</td>
<td>Assessment, care planning and review</td>
<td>Coordination of care</td>
<td>Delivery of high quality services</td>
<td>Care in the last days of life</td>
<td>Care after death</td>
</tr>
</tbody>
</table>

- Open, honest communication
- Identifying triggers for discussion
- Agreed care plan and regular review of needs and preferences
- Assessing needs of carers
- Strategic coordination
- Coordination of individual patient care
- Rapid response services
- High quality care provision in all settings
- Hospitals, community, care homes, hospices, community hospitals, prisons, secure hospitals and hostels
- Ambulance services
- Identification of the dying phase
- Review of needs and preferences for place of death
- Support for both patient and carer
- Recognition of wishes regarding resuscitation and organ donation
- Recognition that end of life care does not stop at the point of death.
- Timely verification and certification of death or referral to coroner
- Care and support of carer and family, including emotional and practical bereavement support

Support for carers and families

Information for patients and carers

Spiritual care services
“Triggers” for end of life care

Generali per le patologie neurologiche
- Richiesta dei pazienti
- Richiesta dei famigliari
- Disfagia
- Declino cognitivo
- Dispnea
- Infezioni ricorrenti e ricoveri non programmati
- Perdita di peso
- Marcato scadimento delle condizioni generali
Triggers in months prior to death

Hussain et al: Triggers in advanced neurological conditions: prediction and management of the terminal phase. BMJ Supp Pall Care 2014; 4: 30-37
Quando coinvolgere le cure palliative?

A. The traditional model of late involvement of palliative services
   - Neurology and medical
   - Diagnosis
   - Palliative care
   - Death

B. The model of early and increasing involvement of palliative services
   - Neurology and medical
   - Diagnosis
   - Palliative care
   - Death

C. The model of dynamic involvement of palliative services based on trigger points
   - Neurology and medical
   - Diagnosis
   - Palliative care
   - Death
   - Trigger points
Early integration of care

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

Assessment and care should be provided by multidisciplinary approach

- At least three professions
  - Physician
  - Nurse
  - Social Worker
  - Psychologist / counsellor
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
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
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
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
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
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.
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 offered the team immediately (fast track, FT); 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 FT and 26 to the SI groups). At 12 weeks people in the FT 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 FT 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.
Specialist palliative care improves the quality of life in advanced neurodegenerative disorders: NE-PAL, a pilot randomised controlled study

Simone Veronesi, 1 G Gallo, 1, A Valle, 1, C Cogno, 1, A Chio, 2, A Calvo, 2 P Cavalla, 2 M Zibetti, 2 C Riviero, 2 D J Oliver 1

ABSTRACT

Background: This study aimed to assess the impact of palliative care services in patients severely affected by amyotrophic lateral sclerosis (ALS/MSA), 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 phased randomised controlled trial (RCT) was undertaken comparing an immediate referral to the service (RT, fast track) to a 6-month wait (standard task [ST], standard best practice) using a parallel arm design. The main outcome measures were Quality of Life (QoL; measured with a Schedule for the Evaluation of Individual Qualities of Life Questionnaire, SQOL-Q) and scores of the Caregiver Burden Inventory (CBI), with secondary outcomes of symptoms, psychological, and spiritual issues.

Results: 50 patients severely affected by neurodegenerative conditions and their informal carers were randomised: 25 RT, 25 ST. At baseline (T1), there were no differences between groups. 4 patients died during the follow-up (2 RT, 2 ST) and 2 RT patients dropped out before the end of the study. After 56 weeks (T3), FT participants scored significant improvement in the SQOL-Q-DL index, pain, depression, sleep disturbance, and lower 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 mortality. Symptom control was not affected by the service.

INTRODUCTION

Palliative care aims at improving quality of life (QoL) of patients and their family through the management of symptoms and the psychological, social and spiritual distress. Patients affected by progressive neurodegenerative conditions suffer a high burden of symptoms and issues that are often managed by specialist palliative care teams. 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. The present article is based on the study of the provision of palliative and end-of-life care for this patient group, and there is evidence that the suggested triggers for consideration of care may be of help. Some patients report frequent, dysphoria, cognitive decline, dyspnoea, repeated infections (in particular, aspiration pneumonia), weight loss and marked decline in condition. Additionally, SPCS has been described in the context of patients with neurological disease, 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 specialist palliative care is sparse and limited by methodological shortcomings. Carefully planned trials, using a standardised...
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 Ponzo, Claudia Borreani, Rosalba Rosato, Simone Veronesi, Paola Zarrarin 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 caregivers.
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, 26 UC) 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, no changes in secondary, patient and caregiver outcomes.
Conclusion: HPA slightly reduced symptoms burden. We found no evidence of HPA efficacy on patient quality of life and on secondary outcomes.
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
PICO's

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
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.
Literature review: the care-task for palliative care

Andrea Pace, Linda Dirven, Johan AF Koekkoek, Heidrun Golla, Jane Fleming, Roberta Rudà, Christine Marosi, Emilie Le Rhudy, Robin Grant, Kathy Oliver, Ingela Oberg, Helen J Bulbeck, Alfrédo Pasman, Emilia Niksson, Roeline W Pasman, Stefan Oberndorfer, Michael Weller, Martin JB Tap, Kerrigan, Simone Veronese, Tobias Walbert, Marike Broekman, EANO scientific board.
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
- Stroke
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/
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