Perché il neurologo deve interessarsi alle Cure Palliative?

Eugenio Pucci

Gruppo di studio di Bioetica e Cure Palliative della SIN

UOC Neurologia ASUR Marche AV4 - Fermo

Definizione delle CP

Raccomandazioni *EAPC/EAN*

La comunità neurologica deve avere competenze palliative

Bisogni e accesso alle CP

La sfida al modello della terminalità

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.

ART. 2

(Definizioni).

1. Ai fini della presente legge si intende per:

a) « cure palliative »: l'insieme degli interventi terapeutici, diagnostici e assistenziali, rivolti sia alla persona malata sia al suo nucleo familiare, finalizzati alla cura attiva e totale dei pazienti la cui malattia di base, caratterizzata da un'inarrestabile evoluzione e da una prognosi infausta, non risponde piu' a trattamenti specifici;

Non solo morte…

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, nonche' la persona affetta da una patologia dolorosa cronica da moderata a severa;

Definizione

EAPC ONLUS
European Association for Palliative Care
Non Governmental Organisation (NGO) recognised by the Council of Europe

Le cure palliative sono la cura attiva e globale prestata al paziente quando la malattia non risponde più alle terapie aventi come scopo la guarigione.
Il controllo del dolore e degli altri sintomi, dei problemi psicologici, sociali e spirituali assume importanza primaria.
Le cure palliative hanno carattere interdisciplinare e coinvolgono il paziente, la sua famiglia e la comunità in generale. Provvedono una presa in carico del paziente che si preoccupi di garantire i bisogni più elementari ovunque si trovi il paziente, a casa, o in ospedale.
Le cure palliative rispettano la vita e considerano il morire un processo naturale. Il loro scopo non è quello di accelerare o differire la morte, ma quello di preservare la migliore qualità della vita possibile fino alla fine.

Non solo terapia del dolore e cure terminali!

Traiettoria di una malattia neurologica inguaribile con disabilità progressiva

Rielaborata da Field, M. J. & Cassel, C. K. (Ed.). (1997) Approaching Death: Improving care at the end of life. Division of Health Care Services. Institute of Medicine. Washington D.C.: National Academy Press.

Non solo cronicità… STROKE

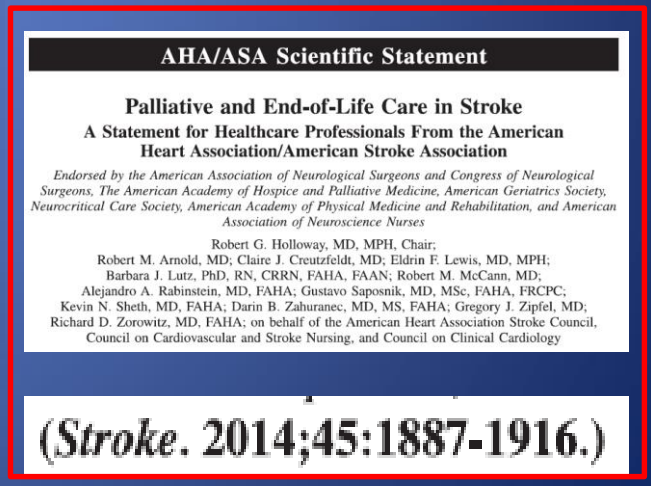
incidenza di circa 200.000 casi/anno

20-30% mortalità in fase acuta

seconda causa di morte secondo WHO

Lo *stroke* (Holloway 2014, Braun 2016), i traumi cranio-midollari gravi (Livingston 2011) e le encefalomieliti infettive ed a patogenesi immuno-mediata rappresentano una grande sfida perché la rapida progressione di alcune condizioni in un *setting* di acuzie può richiedere un intervento molto precoce delle CP.

SICP-SIN 2018



AHA/ASA Scientific Statement

Palliative and End-of-Life Care in Stroke

A Statement for Healthcare Professionals From the American Heart Association/American Stroke Association

Endorsed by the American Association of Neurological Surgeons and Congress of Neurological Surgeons, The American Academy of Hospice and Palliative Medicine, American Geriatrics Society, Neurocritical Care Society, American Academy of Physical Medicine and Rehabilitation, and American Association of Neuroscience Nurses

Robert G. Holloway, MD, MPH, Chair; Robert M. Arnold, MD; Claire J. Creutzfeldt, MD; Eldrin F. Lewis, MD, MPH; Barbara J. Lutz, PhD, RN, CRRN, FAHA, FAAN; Robert M. McCann, MD; Alejandro A. Rabinstein, MD, FAHA; Gustavo Saposnik, MD, MSc, FAHA, FRCPC; Kevin N. Sheth, MD, FAHA; Darin B. Zahuranec, MD, MS, FAHA; Gregory J. Zipfel, MD; Richard D. Zorowitz, MD, FAHA; on behalf of the American Heart Association Stroke Council, Council on Cardiovascular and Stroke Nursing, and Council on Clinical Cardiology

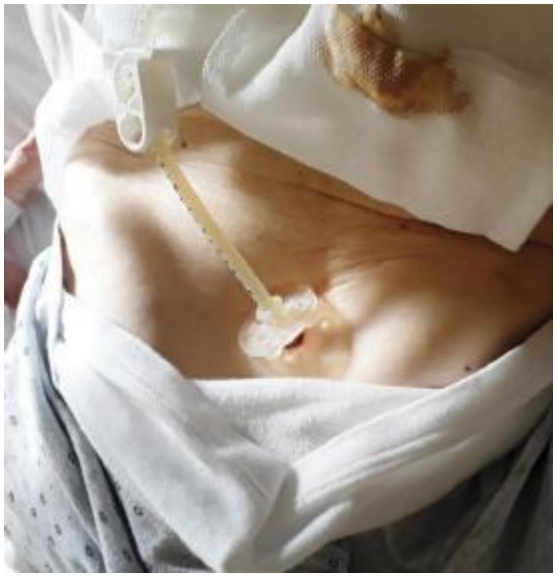
(*Stroke*. 2014;45:1887-1916.)

Non solo cronicità…
NEUROTRAUMATOLOGIA

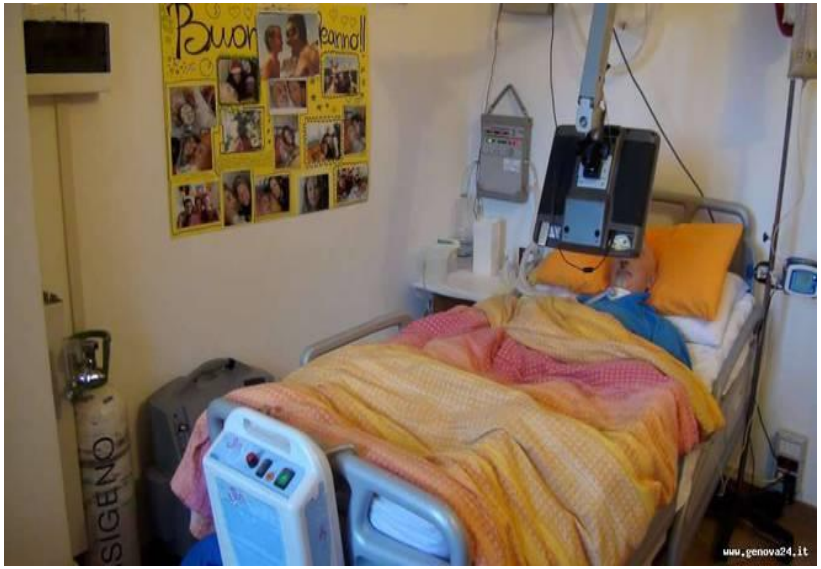
End-of-life decisions in patients with severe acute brain injury

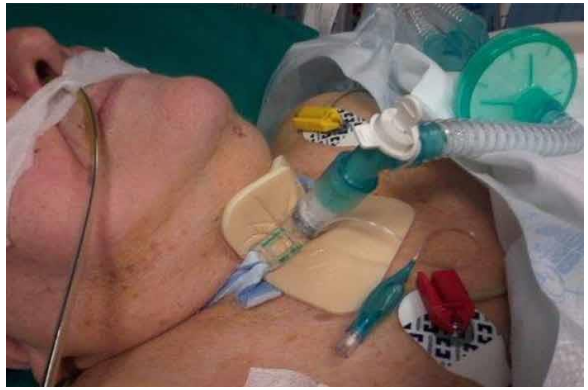
Marjolein Geurts, Malcolm R Macleod, Ghislaine J M W van Thiel, Jan van Gijn, L Jaap Kappelle, H Bart van der Worp

***Lancet Neurol* 2014;13:515-24**



Le scelte
e le loro conseguenze





Peculiarità delle CP in Neurologia

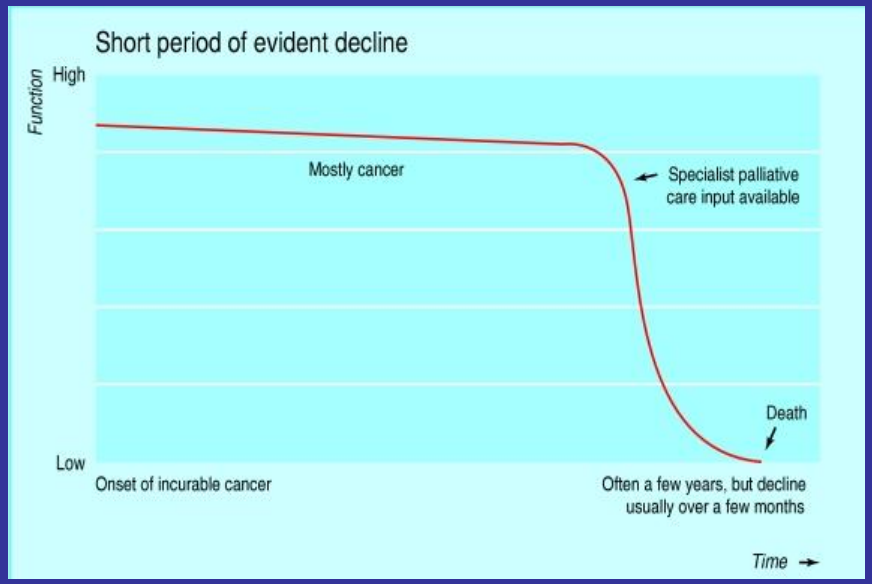
- **Lunga permanenza in condizioni di grave disabilità oppure condizioni di acuzie**
- **Difficoltà di prognosi: evoluzione, durata e «*end stage*»**
- **Variabilità e peculiarità dei sintomi (trattamenti sintomatici complessi)**
- **I criteri generali usati per identificare l' «*end stage*» (*trigger*) in oncologia non sono facilmente applicabili in ambito neurologico (*PEG*, ventilazione assistita, Karnofsky, ecc)**

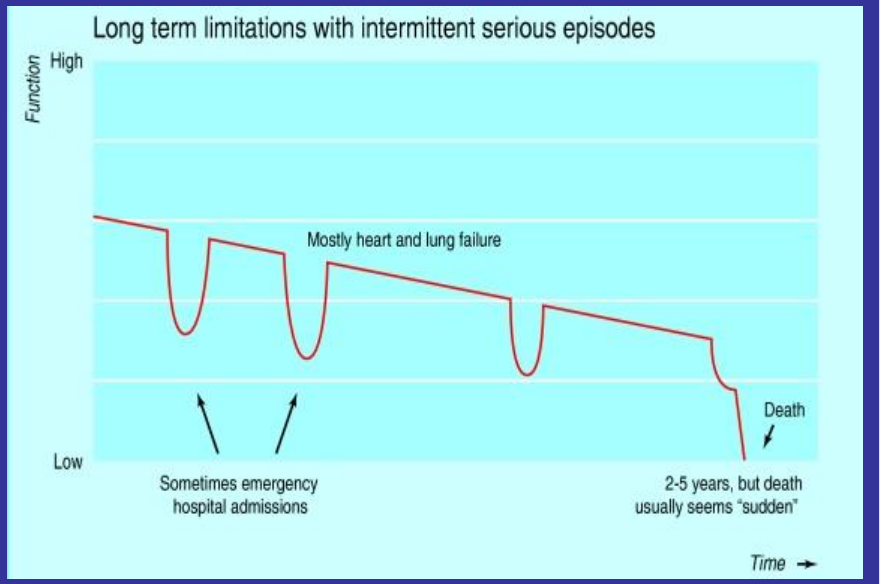
MODELLI DI INTERVENTO DI CURE PALLIATIVE NELLE MALATTIE NEUROLOGICHE

"Cure palliative precoci e simultanee"

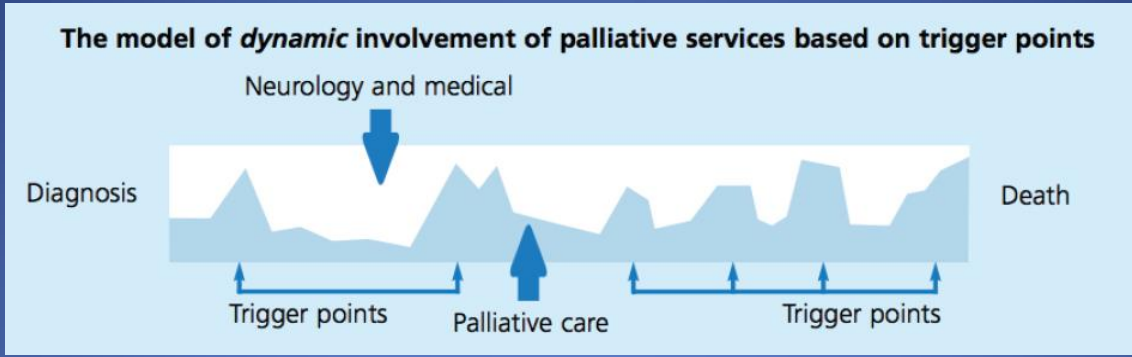
Dall' "approccio palliativo" ai "Servizi di cure palliative"

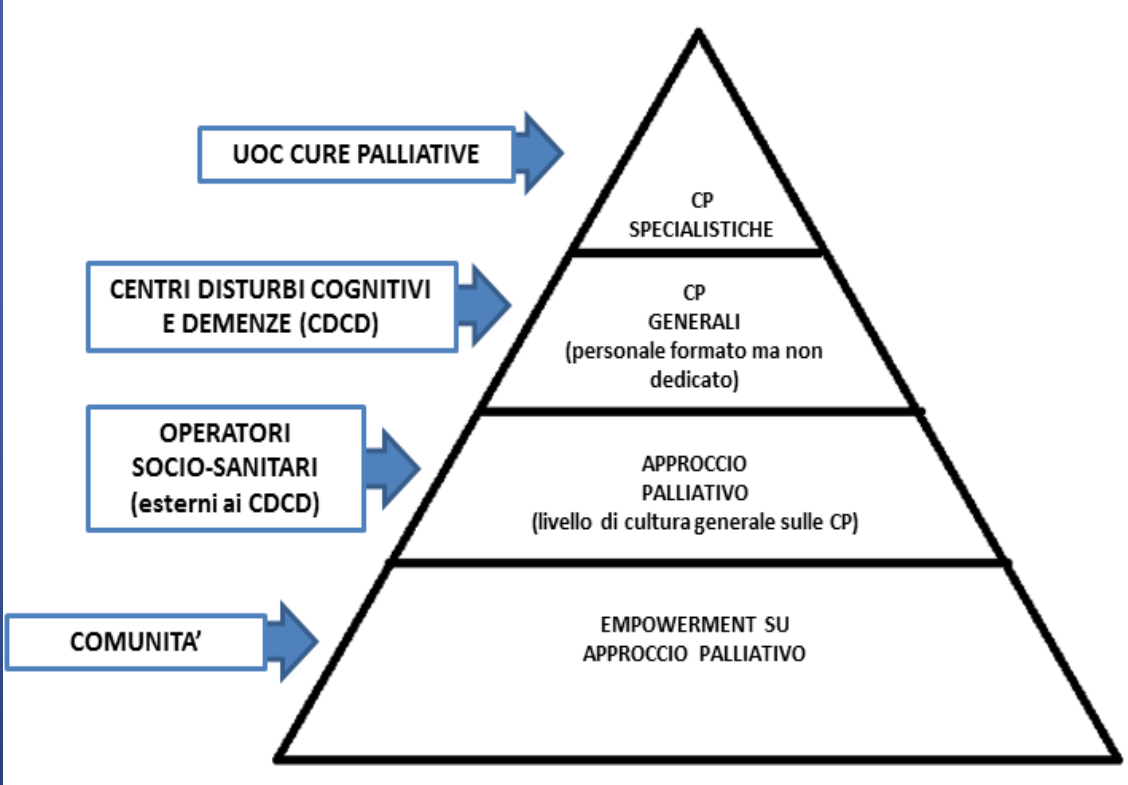
- **PRECOCI: la malattia inguaribile è ancora lontana dal «fine vita» (PIANIFICAZIONE CONDIVISA DELLE CURE)**
- **SIMULTANEE: possono essere contestualmente praticate terapie finalizzate al controllo della malattia**
- **L'assistenza orientata in senso palliativo non deve essere basata su un criterio temporale (es. morte attesa in 12 mesi), ma sui BISOGNI biologici, psicologici, spirituali, ecc della persona e della suoi affetti, rispettando le preferenze del malato**





L’esempio della demenza





Come neurologi possiamo scegliere come correre: cure palliative di base? specialistiche?

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

European Journal of Neurology 2016, 23: 30–38

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…continued and repeated discussion (changes in function – physical and cognitive – and preferences)

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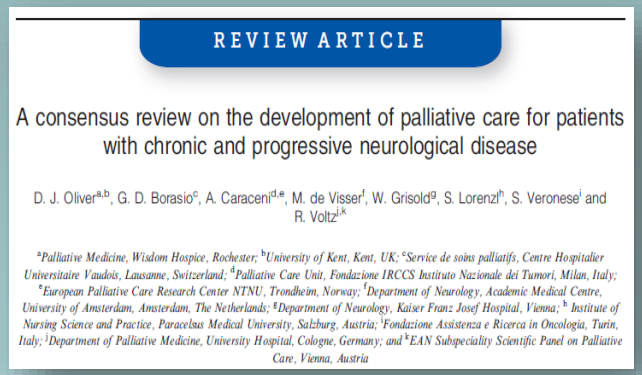

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PC training and continuing education of neurologists & specialist palliative care professionals

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L'accesso dei malati neurologici alle CP resta difficile …

" Dove dobbiamo andare per avere il cancro?"

06 novembre 2018

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

E' online la *survey* "*EURO-NEURO – the collaboration between neurology and palliative care across Europe*", promossa da EAN e EAPC.

La *survey* è descritta nel *flier* "EAN-EURO-NEURO" che potete scaricare al seguente *link*.

Impiegherete non più di 15 minuti per un obiettivo importante.

Vi ringraziamo per la collaborazione.