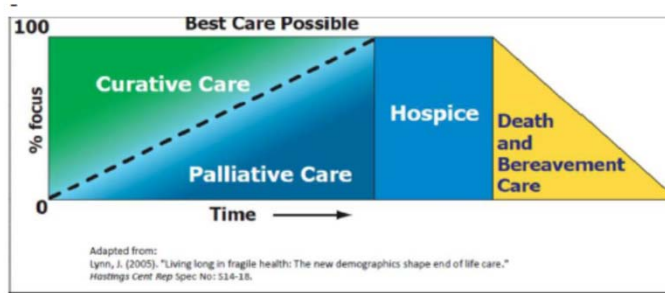


Becoming Confident in Promoting ACP Discussion
by Health and Social Care Professionals: the local
experience of palliative care model for patients
with Motor Neuron Disease and their caregivers

Dr. Benjamin Cheng
Specialist in Palliative Medicine
MBBS, MRCP (UK), FRCP(Glasg), FHKAM (Medicine)

- * Shared Role among
 - * Neurologist
 - * Rehabilitation Specialist
 - * Respiratory physician
 - * GI physician
 - * Allied Health: PT / OT / ST / Dietician
 - * Palliative Care team

Early PC integration



運動神經元疾病

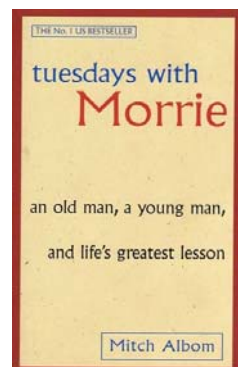
Motor Neuron Disease- MND

- * 運動神經元漸進性退化
- * 造成全身肌肉萎縮及無力的疾病
- * 肌萎縮性脊髓側索硬化症(ALS)是成人最常見的運動神經元疾病
- * 「漸凍人」
- * 因病患脊髓、腦幹或大腦運動皮質區之運動神經元漸進性的退化
- * 引起全身肌肉萎縮和無力，而導致疾病末期的全身癱瘓、呼吸衰竭和死亡。

漸凍人



What do they have in common?





HOSPITAL AUTHORITY New Territories West Cluster Department of Medicine & Geriatrics (Rehabilitation block) ALS Functional Rating Scale (Chinese version) 肌肉萎縮性側索硬化症功能評估量表修正版 (ALSFRS-R)		For Hospital Admitted Patient, please use "HN" Label. For AE/OP attendance, please use AE/OP Label Name: HKID: HN/OP No.: Sex/D.O.B.: Dept: Hospital: * CPH / POH / SLH / TMH * Pls circle as appropriate			
項目	取較低分數計分	日期			
一、語言	(4) 正常語言功能 (3) 可察覺到語言功能障礙 (2) 重複說話可讓人聽懂 (1) 講話需伴隨非語言性的溝通 (0) 完全喪失功能性語言				
二、唾液	(4) 正常 (3) 口中確實有稍多的唾液，晚間可能會流口水(註:白天不會流口水) (2) 中度過多的唾液，可能小量流口水 (1) 顯著過多的唾液，會有些流口水 (0) 顯著的流口水，需不斷的使用紙巾或手帕				
三、吞嚥	(4) 可正常的吞嚥日常食物 (3) 初期飲食異常一偶而會噎到 (2) 需改變食物的黏稠度 (1) 需要從膳食管補充食物 (0) 不自由進食 (全部由靜脈內注射或經腸道灌食)				
四、寫字	(4) 正常 (3) 緩慢或潦草，但所有的字皆可辨識 (2) 並非所有的字可辨識 (1) 可握筆，但無法寫字 (0) 無法握筆				

五、切割食物及使用餐具						
對沒有胃造口的患者 (Oral)	(4) 正常 (3) 有點緩慢或笨拙，但不需別人幫忙 (2) 雖笨拙與緩慢，尚可切割大部份的食物，但需要他人極微的協助 (1) 需要他人切割食物，但仍可使用餐具，自己慢慢進食 (0) 需人餵食					
對胃造口的患者 (NG or PEG)	(4) 正常 (3) 笨拙但可自行獨立完成所有操作 (2) 需協助綁紮或打結 (1) 能稍微協助照顧者 (0) 無法執行任何任務					
六、穿著衣褲與個人衛生	(4) 正常功能 (3) 能獨立完成自我照顧，但費力或效率低 (2) 需間歇性地幫助或採用替代方式 (1) 需看護協助自我照顧 (0) 完全依賴他人					
七、床上翻身與調整床單	(4) 正常功能 (3) 有點緩慢與笨拙，但不需別人幫忙 (2) 可自己翻身或調整床單，但動作相當困難 (1) 有初步動作，但無法獨自完成翻身或調整床單 (0) 無法執行					
八、步行	(4) 正常 (3) 初期出現步行困難 (2) 使用輔具走路 (1) 無法走路，只有功能性動作 (0) 沒有出現有意義的腳動					

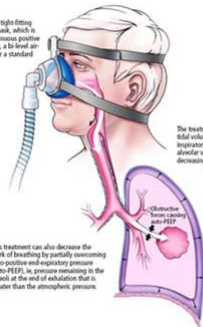
八、步行	(4) 正常 (3) 初期出現步行困難 (2) 使用輔具走路 (1) 無法走路，只有功能性動作 (0) 沒有出現有意義的腳動					
九、上樓梯	(4) 正常 (3) 緩慢 (2) 稍微不穩或疲乏 (1) 需要協助 (0) 無法執行					
十、呼吸困難 (新)	(4) 無 (3) 步行時發生 (2) 執行下列一或多項時發生-吃飯、洗澡、穿衣 (日常生活) (1) 休息時發生，靜坐或躺著時呼吸困難 (0) 明顯呼吸困難，考慮使用機械式呼吸支持系統					
十一、端坐呼吸(新)	(4) 無 (3) 有時夜間因呼吸短促而睡眠困難，但通常不需使用兩個枕頭 (2) 需使用兩個以上枕頭睡眠 (1) 只能端坐睡眠 (0) 無法入睡					
十二、呼吸換氣不足(新)	(4) 無 (3) 間斷使用雙相氣道正壓呼吸(BiPAP) (2) 夜間持續使用雙相氣道正壓呼吸 (1) 白天與夜間持續使用雙相氣道正壓呼吸 (0) 需插管或氣切以便使用侵入性呼吸器					
總分						
Assessed by (Signature / nurse chop)						

Cedarbaum JM. BDNF ALS Study Group (Phase III). J Neurol Sci 1999; 169: 13-21

(I) Respiratory failure

In selected patients with hypercapnic respiratory failure due to an acute exacerbation of chronic obstructive pulmonary disease (COPD), noninvasive positive pressure ventilation, added to usual medical therapy, reduces the need for endotracheal intubation, the length of hospital stay, and the risk of death.

The patient wears a tight-fitting nasal or full facial mask, which is connected to a continuous positive airway pressure unit, a bi-level airway pressure unit, or a standard ventilator.



The treatment provides a larger tidal volume with the same inspiratory effort, thus improving alveolar ventilation and decreasing the work of breathing.

This treatment can also decrease the work of breathing by partially overcoming airway-positive end-expiratory pressure (auto-PEEP), is pressure remaining in the alveoli at the end of exhalation that is greater than the atmospheric pressure.

CCP
Medical Illustration: Joseph Fungrazo

ive ventilation)

(2) Loss of motor function



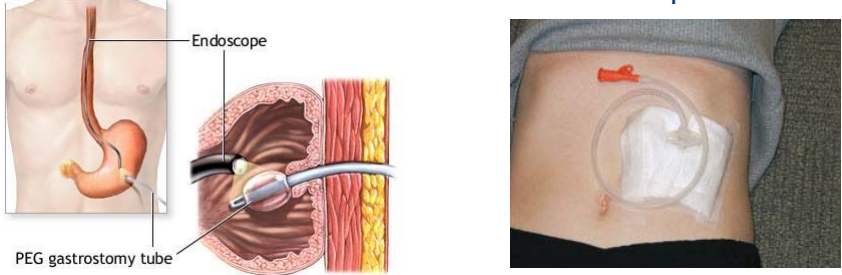
復康治療。利用物理治療和職業治療，及多種輔助儀器來改善病人的活動能力。

家居探訪。護士透過家訪，為病人舒緩徵狀和疼痛，並提供心理支持，指導及協助家人照顧病人。



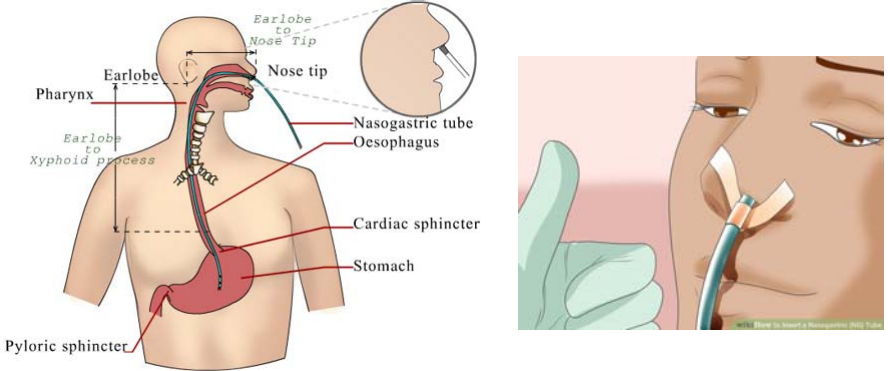
(3) Malnutrition & swallowing problem

* 經皮內視鏡胃造口術 (percutaneous endoscopic)



The image contains three visual elements: 1) A diagram of a human torso showing the stomach and the placement of a PEG gastrostomy tube. 2) A cross-sectional diagram of the stomach wall showing the endoscope and the PEG gastrostomy tube inserted through the abdominal wall. 3) A photograph of a person's abdomen with a PEG gastrostomy tube secured by a white adhesive dressing.

(3) MALNUTRITION & SWALLOWING PROBLEM



The image contains two visual elements: 1) An anatomical diagram of the human head and neck in profile, showing the path of a nasogastric tube from the nose, through the pharynx and esophagus, into the stomach. Labels include: Earlobe to Nose Tip, Earlobe to Xiphoid process, Pharynx, Nasogastric tube, Oesophagus, Cardiac sphincter, Stomach, and Pyloric sphincter. 2) A photograph of a person's nose with a nasogastric tube inserted and secured with adhesive tape.

Respiratory Failure



RESEARCH PAPER

Assessment of pulmonary function in amyotrophic lateral sclerosis: when can polygraphy help evaluate the need for non-invasive ventilation?

Tino Prell, Thomas M Ringer, Kara Wullenkord, Philipp Garrison, Anne Gunkel, Beatrice Stubendorff, Otto W Witte, Julian Grosskreutz

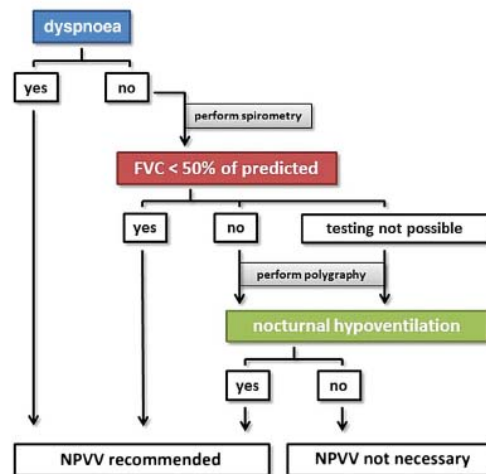


Figure 1 Proposed algorithm for the evaluation of the respiratory state and the need for NPPV (FVC, forced vital capacity; NPPV, non-invasive positive-pressure ventilation).

Invasive ventilation via tracheostomy

- * 0% in UK
- * 1-14% in USA
- * 3% in Germany
- * 2-5% in France
- * 11% in Northern Italy
- * 27-45% in Japan
- * *(End of life management in patients with ALS, Lancet Neurology Apr 2015)*

Nutritional problem in MND

Nutritional problem in MND

- * Malnutrition is a significant problem in MND.
- * A significant & independent prognostic factor for survival time in ALS/MND.
- * BMI < 20 is an independent predictor of life expectancy, relative risk of death is 7.7-fold over non-malnourished counterparts.

Timing of PEG

- * There is no study on the timing of PEG
- * If PEG placement is delayed until pt can absolutely not take orally, patient may be nutritionally depleted.
- * Better survival in pt who received a PEG at a higher BMI.
- * Delaying PEG may result in additional risk due to further decline in pulmonary status.
- * A diminished FVC is a key prognostic indicator of worsening ALS/MND.

Method of enteral tube feeding

- * There is little evidence to support any specific approach
- * A case series (Gregory et al 2002) of 33 pt with FVC<50%, PEG placement using NIPPV with nasal mask for ventilatory support.
- * RIG is a possible alternative, fluoroscopy guided without use of sedation. A retrospective study comparing pt with FVC<50% showed more favorable outcome with RIG than PEG(Chio et al 2004). Problem: RIG has smaller caliber, greater chance of obstruction.

- * NGT
- * PEG
- * RIG (radiologically inserted gastrostomy)

Examples of Enteral Access

Feeding Routes Through The Nose
(or alternatively may be oral)

- 1) Nasogastric
- 2) Nasoduodenal
- 3) Nasojejunal

Gastrostomy Options*

- Percutaneous Endoscopic Gastrostomy (PEG)
- Percutaneous Radiologic Gastrostomy (PRG)
- Percutaneous Endoscopic Jejunostomy (PEJ)
- Percutaneous Radiologic Jejunostomy (PRJ)
- Percutaneous Endoscopic Gastrojejunostomy (PEG/J)
- Button
- Surgically placed Gastrostomy

Jejunostomy


*Gastrostomy and jejunostomy tubes may be placed endoscopically, radiologically, or surgically.


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PEG vs RIG

- * PEG
- * Procedure time ~30 min
- * Endoscopy guided
- * Increased risk with pulmonary decline FVC <50%
- * RIG
- * Procedure time ~ 60mn
- * Fluoroscopy guided
- * More favorable for declined pulmonary status

- * PEG is associated with improved nutrition and should be inserted early. The operation is hazardous in patients with VC <50%: RIG may be a better alternative.
- * Non-invasive positive pressure ventilation improves survival and quality of life.
- * Maintaining the patient's ability to communicate is essential.

- 
- * During the course of the disease, every effort should be made to maintain patient autonomy.
 - * Advance directives for palliative end of life care are important and should be discussed early with the patient and relatives.

- 
- * PEG placement is not for everyone
 - * The decision not to have PEG should be respected
 - * Patient may be too late in the disease course for PEG when the resp function declined
 - * While patient waiting for the procedure or during the procedure, a more upright posture is better – patient is not comfortable lying flat due to excessive secretions in the oropharynx.

Advance Care Planning

* **Advanced Care Planning**

- * Feeding (Oral / Ryle's Tube / PEG)
- * Ventilator use in Respiratory failure (O₂ supplement / NIPPV / intubation+/- tracheostomy)
- * DNACPR
- * Management of Other reversible factors (e.g. anticoagulation in DVT, antibiotics use in infections)

預設照顧計劃 (Advance Care Planning-ACP)

- * 若生命即將走到盡頭，盡力搶救是否是病者心中的選擇呢？除了搶救，是否已經再無選擇呢？
- * 在最後一段人生旅程，好的生活質素遠比靠高科技維持生命更為重要。
- * 有些末期病者表達他們希望一切順其自然，讓生命自然及有尊嚴地結束。

「預設醫療指示」

- + 必須有兩名見證人見證，簽署
- + 其中一名見證人必須是醫生
- + 兩名見證人均不是遺產受益人
- + 「預設醫療指示」是在病人喪失自決能力時才生效
- + 在啟動任何「預設醫療指示」前最少有兩名醫生確認和核證
- + 醫生會根據及尊重有效的「預設醫療指示」來提供治療




ADVANCE DIRECTIVE

1. Full AD form (revised)
2. Short AD form (new)

Hospital Authority

New AD Short Form

 醫院管理局 HOSPITAL AUTHORITY	<h3 style="margin: 0;">預設醫療指示</h3> <p style="margin: 0;">(當病情到了末期時拒絕心肺復甦術)</p>	以正楷書寫或貼上病人標籤 入院/門診號碼：..... 姓名(英文)：.....(中文)..... 身份證號碼：..... 性別：..... 年齡：..... 部門：..... 組別：..... 病房/床號：...../.....
---	--	--

第I部： 此預設醫療指示作出者的詳細個人資料

姓名：..... 身份證號碼：.....
 性別：..... 出生日期：..... 電話號碼：.....
 住宅住址：.....

第II部： 背景

- 本人.....(請清楚填上姓名)年滿 18 歲，現填銷本人以前曾就自己的醫護及治療作出的所有預設醫療指示(如有的話)，並自願作出下述預設醫療指示。
- 如經本人的主診醫生及最少另一名醫生診斷，證實本人是病情到了末期^a，以致無法參與作出關於自己的醫護及治療的決定，則本人對自己的醫護及治療的指示如下：
本人不接受心肺復甦術。
- 本人是在此預設醫療指示第 III 部所述的兩名見證人面前作此指示，而該兩名見證人並非本人的遺囑、或本人所持有的任何保險單、或本人所訂立或代本人訂立的任何其他文書享有權益的受益人。
- 本人明白可隨時撤銷此預設醫療指示

_____ 日期
 此預設醫療指示作出者的簽署

^a 病情到了末期指患有嚴重、持續惡化及不可逆轉的疾病，而且對對症治療毫無反應，預期壽命短暫，僅得數日、數星期或數月的生命；至於進行維持生命治療的作用，只在於延遲死亡一類的家庭。

預設醫療指示(當病情到了末期時拒絕心肺復甦術) HA9013M/R

Change in HA Advance Directive (AD)

(A) 第 1 類情況——病情到了末期

(註：在此指示中——“病情到了末期”指患有嚴重、持續惡化及不可逆轉的疾病，而且對對症治療毫無反應，預期壽命短暫，僅得數日、數星期或數月的生命；至於進行維持生命治療的作用，只在於延遲死亡一類的家庭；及“維持生命治療”指任何有可能延遲病人死亡的治療，例子包括使用心肺復甦術、人工輔助呼吸、血液製品及血管擴張劑、為特定疾病而設的專門治療(例如化學治療或透析治療)、在感染可能致命的疾病時給予抗人工營養及流體營養。(人工營養及流體營養指透過導管灌輸食物和水份。))

本人不接受以下維持生命治療：

- 心肺復甦術
- 其他：.....

除了基本護理和舒緩治療外，本人不接受任何維持生命治療^a。就本表格而言，非人工的營養及流體營養屬基本護理的一部分。

但如臨床判斷認為有需要的話，我想繼續接受人工的營養及流體營養，直至死亡臨近和不可避免為止。

(B) 第 2 類情況——持續植物人狀況或不可逆轉的昏迷狀況

(註：在此指示中——“維持生命治療”指任何有可能延遲病人死亡的治療，例子包括使用心肺復甦術、人工輔助呼吸、血液製品及血管擴張劑、為特定疾病而設的專門治療(例如化學治療或透析治療)、在感染可能致命的疾病時給予抗人工營養及流體營養。(人工營養及流體營養指透過導管灌輸食物和水份。))

本人不接受以下維持生命治療：

- 心肺復甦術
- 其他：.....

除了基本護理和舒緩治療外，本人不接受任何維持生命治療^a。就本表格而言，非人工的營養及流體營養屬基本護理的一部分。

但如臨床判斷認為有需要的話，我想繼續接受人工的營養及流體營養，直至死亡臨近和不可避免為止。

Terminally ill

PVS or irreversible coma

Change in HA Advance Directive (AD)

New

(c) 第 3 類情況—其他晚期不可逆轉的生存受限疾病，即：

End-stage irreversible
life limiting condition

(註：在此指示中 -

“其他晚期不可逆轉的生存受限疾病”指不列入第 1 或第 2 類的嚴重、持續惡化及不可逆轉疾病，而病情已到了晚期，及生存受限，例子包括：

(1) 晚期腎衰竭病人、晚期運動神經元疾病或晚期慢性阻塞性肺病病人，因為他們可能用透析治療或輔助呼吸治療維持生命，而不列入第 1 類；以及

(2) 不列入第 2 類的不可逆轉主要腦功能喪失及機能狀況極差的病人。

“維持生命治療”指任何有可能延遲病人死亡的治療，例子包括使用心肺復蘇法、人工輔助呼吸、血液製品、心臟起搏器及血管擴張劑、為特定疾病而設的專門治療（例如化學治療或透析治療）、在感染可能致命的疾病時給予抗生素，以及人工營養及流體營養。（人工營養及流體營養指透過腸胃管餵食食物和水份。）

本人不接受以下維持生命治療：

心肺復蘇法

其他：_____

除了基本護理和舒緩治療外，本人不接受任何維持生命治療⁵。就本表格而言，非人工的營養及流體營養屬基本護理的一部分。

但如臨床判斷認為有需要的話，我想繼續接受人工的營養及流體營養，直至死亡臨近和不可避免為止。

Journal Sharing

Original Article

Advance care planning in motor neuron disease: A qualitative study of caregiver perspectives

Leigh Murray¹, Phyllis N Butow^{2,3}, Kate White⁴,
Matthew C Kiernan^{5,6}, Natalie D'Abrew⁴ and Helen Herz⁷



Palliative Medicine
1-8
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SAGE

Abstract

Background: Motor neuron disease is a fatal disease, characterised by progressive loss of motor function, often associated with cognitive deterioration and, in some, the development of frontotemporal dementia. Life-sustaining technologies are available (e.g. non-invasive ventilation and enteral nutrition) but may compromise quality of life for some patients. Timely commencement of 'Advance Care Planning' enables patients to participate in future care choices; however, this approach has rarely been explored in motor neuron disease.

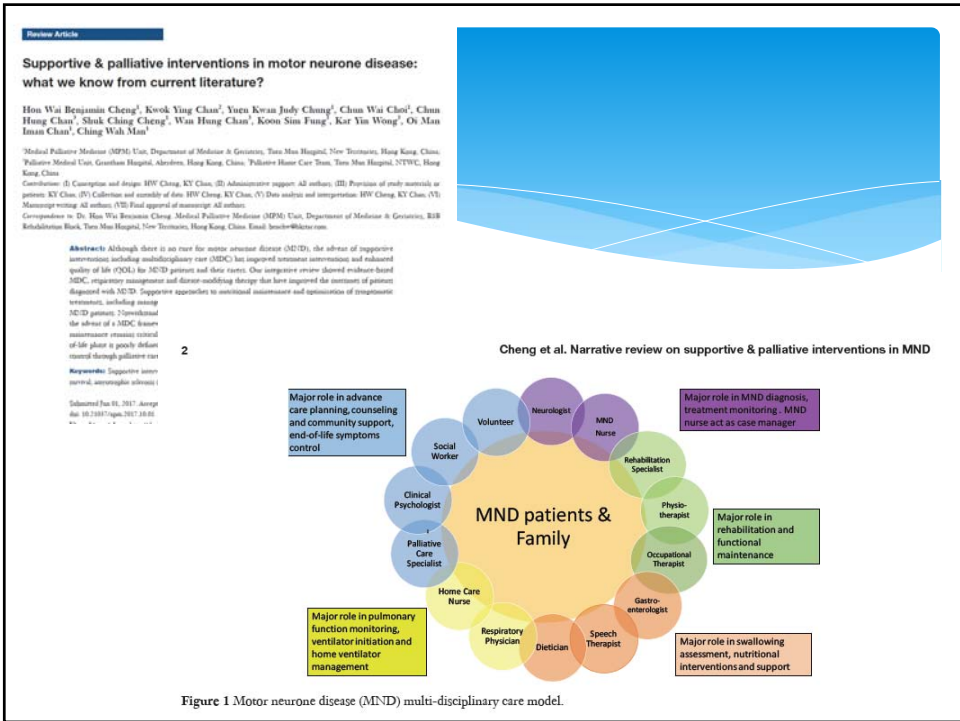
Aim: We aimed to investigate caregiver perspectives on the acceptability and impact of advance care planning, documented in a letter format, for patients with motor neuron disease and caregivers.

Design: This is a qualitative cross-sectional study. Data were analysed by a narrative synthesis approach.

Participants and setting: Structured interviews were held with 18 former caregivers of deceased patients with motor neuron disease. A total of 10 patients had created a disease-specific advanced directive, 'Letter of Future Care', and 8 had not.

Results: A total of four global themes emerged: *Readiness for death, Empowerment, Connections and Clarifying decisions and choices*. Many felt the letter of future care was or would be beneficial, engendering autonomy and respect for patients, easing difficult decision-making and enhancing communication within families. However, individuals' 'readiness' to accept encroaching death would influence uptake. Appropriate timing to commence advance care planning may depend on case-based clinical and personal characteristics.

Conclusion: Advance care planning can assist patients to achieve a sense of control and 'peace of mind' and facilitates important family discussion. However, the timing and style of its introduction needs to be approached sensitively. Tools and strategies for increasing the efficacy of advance care planning for motor neuron disease should be evaluated and implemented.



Annals of Palliative Medicine, 2017

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Table 2 Symptom management for MND patients approaching end-of-life (82,83)

Symptoms approaching end-of-life	Pharmacological treatment option	Dosage and route at treatment initiation	Additions & non-pharmacological treatment option
Dyspnea	Strong opioids	Morphine 5–10 mg PO/NG tube/PEG/SC	Electric fans
	Benzodiazepines	Fentanyl 25–50 microgram SC	Non-invasive ventilation
Respiratory secretions	Hyoscine butylbromide	Hyoscine butylbromide 20–40 mg SC	Cough augmentation
	Glycopyrronium		Chest physiotherapy
			Sputum suction
Pain	Non-opioids in mild pain	Morphine 5–10 mg PO/NG tube/PEG/SC	Proper positioning
	Opioids in refractory pain		Transdermal opioid patch as alternative
Terminal agitation	Benzodiazepines	Lorazepam 0.5 mg PO/NG tube/PEG Midazolam 2.5 mg SC	Arrangement of single quiet room Encourage family accompany
			Continuous SC benzodiazepine infusion in refractory cases
Anxiety upon ventilation withdrawal	Opioids	Morphine 5–10 mg SC	May require continuous SC opioid/ benzodiazepine infusion
	Benzodiazepines	Midazolam 5–10 mg SC	

MND, motor neurone disease; PO, per-oral; NG, nasogastric; SC, subcutaneous; PEG, percutaneous endoscopic gastrostomy.

End-of-life Characteristics and Palliative Care Provision for Patients With Motor Neuron Disease

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Abstract

Motor neuron disease (MND) is a neurodegenerative disease and manifested as progressive decline in physical, respiratory, swallowing and communication function, and ultimately death. Traditional model of care was fragmented and did not match with multifacet needs of patients and carers. Furthermore, there could be lack of integrated care at end of life for patients with MND in most lower- and middle-income countries or in places with inadequate palliative care (PC) coverage. In view of this, a special workgroup for patients with MND, which includes neurologist, respiratory physician, rehabilitation specialist, and PC physician was formed in Hong Kong since year 2011. In various disease phase, each specialty team plays a leading role in coordinated care of patients with MND. From July 2011 to June 2017, a total of 52 patients with MND were referred for PC; 41 deceased patients with MND were included into data analysis. Major cause of death remains pneumonia (54.8%) and respiratory failure (40.5%). Most of the patients with MND (66.7%) died in acute ward and neurology units, with only 11.9% dying in PC units and hospices. The PC team plays a major role in advance care planning (ACP), and most patients had their ACP documented at second or third PC clinic visit (93.8%). Patients with MND often have limitations in mobility, swallowing difficulty, respiratory insufficiency requiring ventilator support, and various psychosocial needs. This highlighted the importance of early PC referral.

Table 1. Demographic and Health Variables of Study Participants.^a

	n	%	Mean	SD
Age (years)	42		59	11.5
Sex				
Female	14	33.3		
Male	28	66.7		
Feeding option received				
Comfort feeding	20	47.6		
Nasogastric tube	16	38.1		
Gastrostomy (PEG/RIG)	6	14.3		
Ventilator support				
No ventilator support	17	40.5		
NIPPV	15	35.7		
Invasive ventilation	9	21.4		
Place of death				
Acute ward setting	28	66.7		
Convalescent and rehabilitation ward	6	14.3		
PC ward and hospice	5	11.9		
Home	3	7.1		
Immediate cause of death				
Pneumonia	23	54.8		
Respiratory failure	17	40.5		
Cardiac arrest	1	2.4		
Peritonitis secondary to PEG leakage	1	2.4		
Do-not-attempt cardiopulmonary resuscitation in place before death	40	95.2%		
Documented ACP in place	32	76.2		
Signed AD in place	16	38.1		

Abbreviations: ACP, advance care planning; AD, advance directive; NIPPV, noninvasive positive pressure ventilation; PC, palliative care; PEG, percutaneous endoscopic gastrostomy; RIG, radiologically inserted gastrostomy; SD, standard deviation.^aN = 42.

	Riluzole (1995)	Edaravone (2017)	Relyvrio (2022)
Route and Dosage	Oral; 50mg BD	IV or oral 60mg/day for 10 days (14 days for 1 st cycle) + 14 days drug free period	Oral; 1 sachet (3g sodium phenylbutyrate + 1g taurursodiol) daily for 3 weeks then twice daily
Cost	HKD68.2/tab (-HKD4092/month)	1 st cycle (28-day): USD712.24 Subsequent cycles: USD508.74	USD158000/year
Evidence	<p>Cochrane review (2013)</p> <ul style="list-style-type: none"> Based on 4 RCTs (1994-2002) 974 Riluzole treated patients + 503 placebo treated patients Reduced risks of mortality or tracheostomy at 12 months (HR=0.83, p=0.046) Increase in median survival by 3 months (11.8 months vs 14.8 months) Increased probability of 1-year survival by 9% (49% vs 58%) Slower rate of decline on both bulbar and limb functions 	<p>Edaravone (MCI-186) ALS 19 Study Group [Lancet 2017]</p> <ul style="list-style-type: none"> 12-week observation period → if decrease in ALSFRS-R = 1-4 → randomization → 24-week double-blind period Edaravone group (n=68) vs placebo group (n= 66) Excluded if ALSFRS-R dyspnea, orthopnea or respiratory insufficiency score ≤3 before randomization Slower decline in ALSFRS-R with a mean score difference of 2.49 (-5.01 vs -7.5, p=0.0013) 	<p>CENTAUR (89 Tx group vs 48 placebo) [NEJM 2020]: slower decline in ALSFRS-R over 24-week (p=0.03)</p> <p>CENTAUR open-label extension phase (Tx up to 30 months; longest post-randomization FU = 35 months)</p> <ul style="list-style-type: none"> Reduced death risks (HR=0.56, p=0.023) with 6.5 months longer median survival (18.5 months vs 25 months) [Muscle and Nerve 2021] Longer tracheostomy / ventilation-free survival (HR=0.53, p=0.003) and delayed first hospitalization (HR=0.56, p=0.03) [BMJ 2022]
S/E	Nausea, asthenia, elevated ALT	Abdominal discomfort, eczema	GI upset

Role of PC team

* In-patient care



Mobilize Community Support

主要服務：

- 在家學養及舒緩照顧
- 病人及家屬互助小組
- 預備支援及哀傷輔導
- 義工培訓及服務
- 公眾教育及講座



服務特色：

- 跨專業團隊：
由社會服務機構、醫院和香港大學三方面合作推展，為晚期病患者及其家屬提供社區及住院內的生活照顧、情緒支援及治喪陪伴。
- 兩層支援：
服務由註冊社工及受訓義工共同推行，為晚期病患者及家屬提供社交及情緒支援。
- 社會回饋：
透過香港大學的研究，促進本港社區臨終支援服務的發展。

有關「賽馬會安寧頌」：

隨著香港人口老化，晚期病患者人數不斷增加，公眾對社區晚期病人護理服務的需求亦日漸增加。為此，賽馬會慈善信託基金會於2014年撥款一億三千一百萬港元推行為期三年的「賽馬會安寧頌」計劃，藉以改善社區晚期護理服務質素，以及為相關服務的專業人員提供培訓，並舉辦公眾教育活動。「賽馬會安寧頌」結合各界力量，透過不同服務模式聯繫社區及醫療系統，強化現有護理服務，計劃將在社區試行五項創新服務模式，為晚期病患者提供全面的支援，讓他們可以在充份知情下作出合適的臨終護理選擇，提升他們的生活質素。詳情請瀏覽 <http://www.jceccc.hk/>

合作機構：



賽馬會安寧頌
安寧在家
居家照顧支援服務



香港賽馬會慈善信託基金會
The Hong Kong Jockey Club Charities Trust
111-113 號 德輔道中 1001 號

香港護理安老協會
The Hong Kong Association of Home Care Workers
香港安老服務發展中心
The Home Care Support Centre
香港安老服務發展中心

What are they? Where are they?



Let's work together for MND patients, thank you!

