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

Molly Chan M. N. Service Director

Hong Kong Sheng Kung Hui Welfare Council Limited

Content

1. Journey of MND patient
2. Case conceptualization
3. Case sharing

Different types of MND

ALS Amyotrophic lateral sclerosis	- 2/3 of diagnosed cases, mainly male adult - affects upper motor neurons (brain) and lower motor neurons (spinal cord) - progressive muscle weakness, atrophy, and eventually paralysis	2-5
PBP Progressive bulbar palsy	- 1/4 of diagnosed cases, mainly women and elderly - motor neurons in the bulbar region (function of speech, chewing, swallowing, and facial movements), slurred speech, difficulty swallowing, and weak facial muscles	0.5-3
PMA Progressive muscular atrophy	- 5-7% of diagnosed cases, mainly male adult affects lower motor neurons, leading to muscle weakness, wasting, and fasciculations (twitching), not usually involve the upper motor neurons	5-10
PLS Primary lateral sclerosis	- mainly male adult upper motor neurons, causing muscle stiffness, weakness, and spasticity, not typically involving the lower motor neurons	?

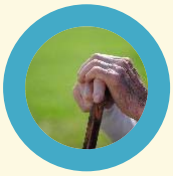
Reference:運動神經細胞疾病_疾病患者及照顧者手冊

- Incidence rate: around 1/50000
- Age of incidence: 35-70
- The number of male patients: twice that of female patients
- Approximately 10% of MMD patients can survive for 10 years
- Average survival rate: 2-5 years

Understanding of MND patients

4P model	Biological	Psychological	Social
predisposing factor	- susceptible or vulnerable to developing a particular issue or condition - long-standing and may have a significant influence on a person's life - e.g. **Genetic factors**, temperament and **personality traits**, early life experience		
precipitating factor	- recent events or triggers - e.g. **Life events**, **traumatic experiences**, environmental stressors, substance use or medication changes, biological factors		
perpetuating factors	- maintain or worsen - e.g. Maladaptive coping strategies, negative thinking patterns, emotional dysregulation, social reinforcement, **lack of social support**, environmental triggers		
Protective factor	- internal and external resources, traits, or experiences, enhance an individual's resilience - e.g. **Positive social support and interpersonal relationships**, effective problem-solving skills, healthy lifestyle, psychological resilience, **learning and developmental opportunities**		

Commonality of MND patient



Sound mind with deteriorating health condition

Poor expression
Low mood
Frustration
Lost of control

The developmental stage of patient

"Too early" to face death

Family and social role

Young children
From care giver to care receiver
Work role

Restriction of social connection

Limitation of expression and mobility
Low self esteem
Difficult to explain

Discuss ACP with MND patients

Patients' values, beliefs and wishes

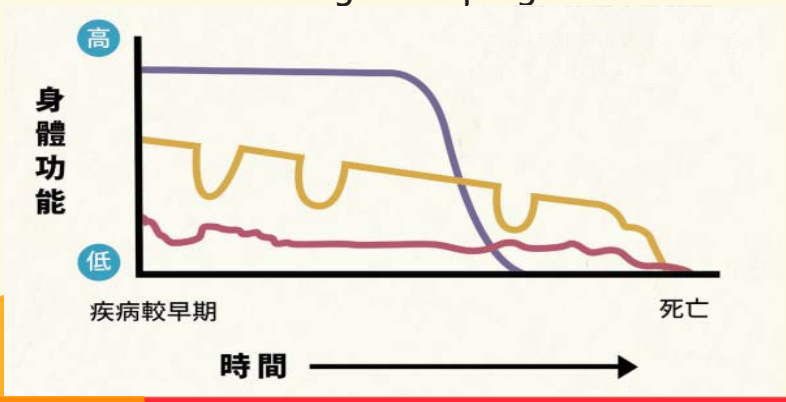
Preferences for future medical or personal care

Documentation: Advance directive, Will, EPA

Assign a key person for future consultation and decision

Tips for discussing ACP with MND patients

1. Increase motivation to discuss ACP
   - More understanding to the prognosis of illness



Tips for discussing ACP with MND patients

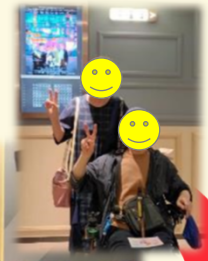
2. Release the stress from practical care
   - Introducing community resources
   - share information between family




Tips for discussing ACP with MND patients

3. Encourage connection between patients in similar situation
   - Mutual *support group/program* of MND patients



關於
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- 由2004年開始服務
- 致力為全港不同地區、年齡、種族，和宗教背景的臨終病者、病者家屬，及喪親人士提供服務，以協助病者安然面對死亡、紓緩家屬面對失去親人時的哀傷，以及提供生活方面的援助

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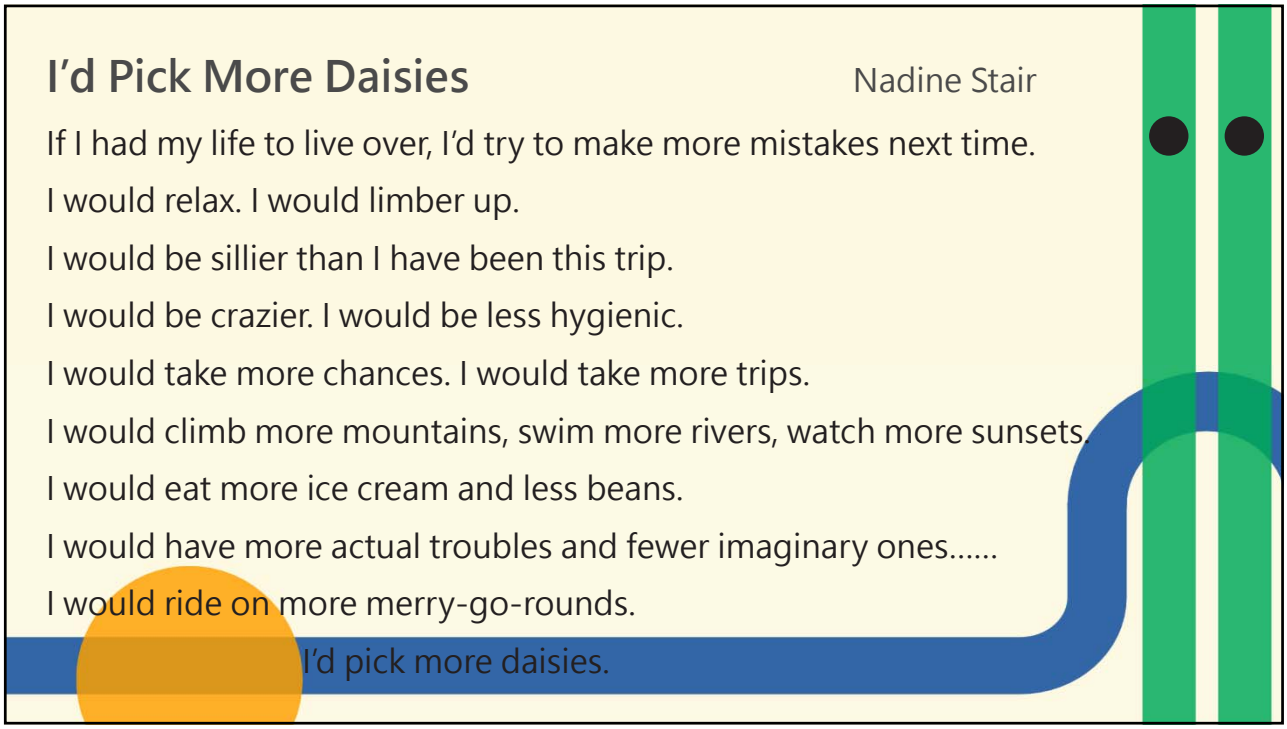
I'd Pick More Daisies
Nadine Stair
If I had my life to live over, I'd try to make more mistakes next time.
I would relax. I would limber up.
I would be sillier than I have been this trip.
I would be crazier. I would be less hygienic.
I would take more chances. I would take more trips.
I would climb more mountains, swim more rivers, watch more sunsets.
I would eat more ice cream and less beans.
I would have more actual troubles and fewer imaginary ones……
I would ride on more merry-go-rounds.
I'd pick more daisies.