Palliative Care for Patients with Motor Neurone Disease through Multi-specialties Collaboration

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HA Convention 2015
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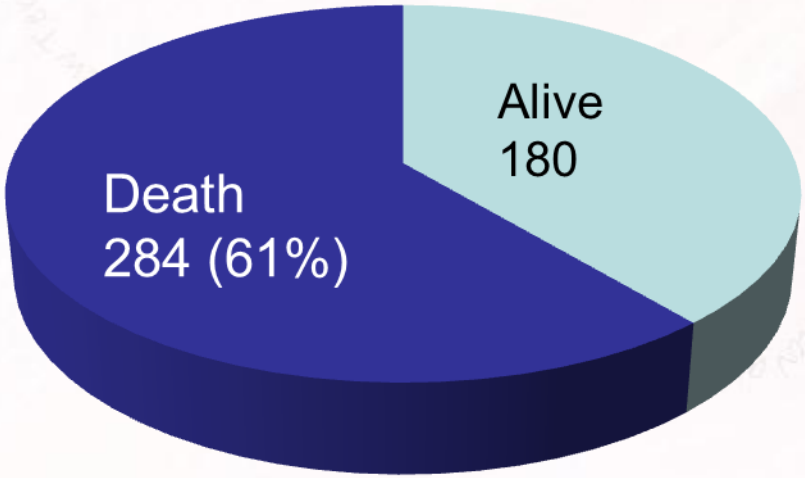
HA Statistics

- Diagnosis: ICD9 with 335.20 (Motor Neurone Disease or Amyotrophic Lateral Sclerosis)
- CDARS of Hospital Authority
- Period: 1/4/2011 to 31/3/2015 (in-patient & out-patient)



- Total 464
- Mean age (yr): 62.2 (20-92)
- M:F = 1.75 : 1.0
- 284 deaths (61%), average 71 deaths/ year
- 180 alive

Clinical Data Analysis and Reporting System (CDARS). http://cdars.home/production/JAVA/info/login.jsp

- Fatigue
- Progressive muscle weakness & wasting
- Loss of weight
- Fasciculation, cramp and spasticity

- Dysarthria-slurred speech
- Saliva and mucus problems
- Dysphagia (paralysis of bulbar muscles)

- Respiratory muscle weakness

Course of Disease

- Every person develops the disease in a different way with variable onset & progression
- Symptoms experienced depends on the area of nervous system affected
- Always progressive with no remissions
- Respiratory failure is main cause of death

Prognosis

- Average survival 2-5 years from onset
- Poor prognosis associated with
  - older age at presentation
  - bulbar onset
  - early involvement of respiratory muscles
  - malnutrition
  - development of hypermetabolic state

Experience of MND Patient

“我覺得我患這個病比患癌症更慘，癌症都有治療，做唔到手術都可以試下電療、化療、和標靶藥... 但係我這個病係無得醫、無得控制的!”

I think this disease is worse than cancer. There are various treatment options for cancer, like operation, radiotherapy, chemotherapy, and targeted therapy.

However, MND has no cure, no control!

Psychosocial Impact

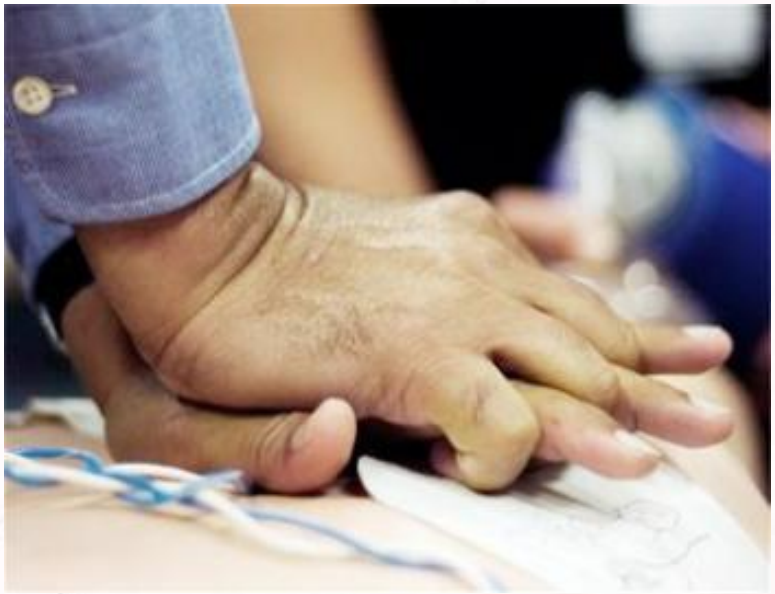
- Depression (up to 30-50%)

Compared with cancer, MND has

- More demoralization
- More hopelessness
- More suicidal ideation

Clarke DM, McLeod JE, Smith GC, Trauer T, Kissane DW. A comparison of psychosocial & physical functioning in patients with motor neurone disease and metastatic cancer. J Palliative Care. 2005; 21(3): 173-179

Undesirable consequences…



CONCISE GUIDANCE TO GOOD PRACTICE

A series of evidence-based guidelines for clinical management

NUMBER 10

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

NATIONAL GUIDELINES

March 2008

CLINICAL STANDARDS
Royal College of Physicians
Setting higher medical standards

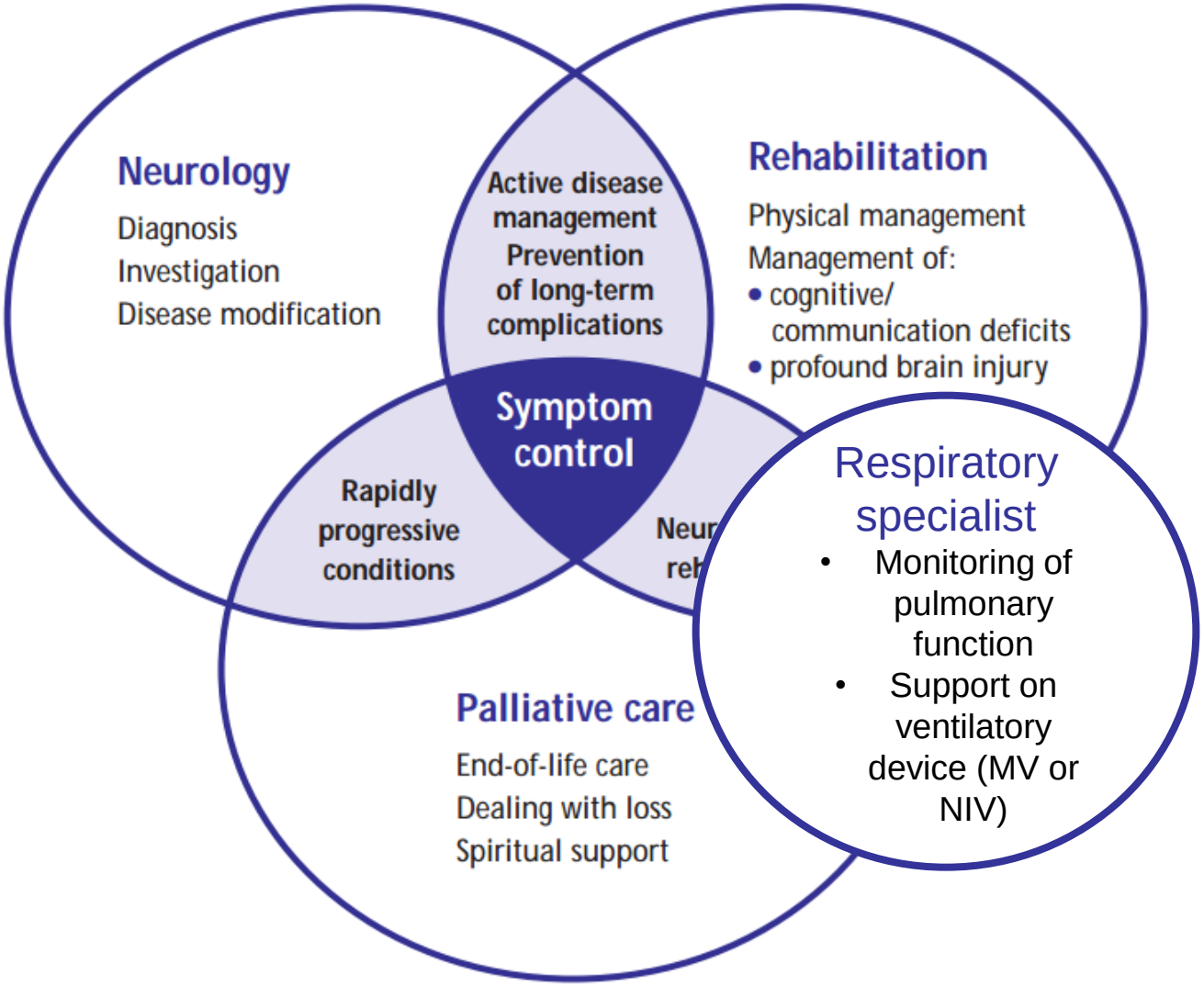
THE NATIONAL COUNCIL FOR PALLIATIVE CARE

BSRM
British Society of Rehabilitation Medicine

Interface between neurology, rehabilitation & palliative care is recommended to address the diagnostic, restorative & palliative phases of LTNCs.

Long-term neurological conditions: management at the interface between neurology, rehabilitation & palliative care. National Guidelines. Concise Guidance to Good Practice. Royal College of Physicians. 2008.

The Interface & the Role



Long-term neurological conditions: management at the interface between neurology, rehabilitation & palliative care. National Guidelines. Concise Guidance to Good Practice. Royal College of Physicians. 2008.

TMH Multi-specialties Collaboration

- MND taskforce formed in mid 2013
- 41 patients dx MND (4/2013 – 3/2015)

- 41 cases
- 2 died in as in-patient on presentation
- 3 followed up by other clusters
- 5 working on diagnosis

Neurology

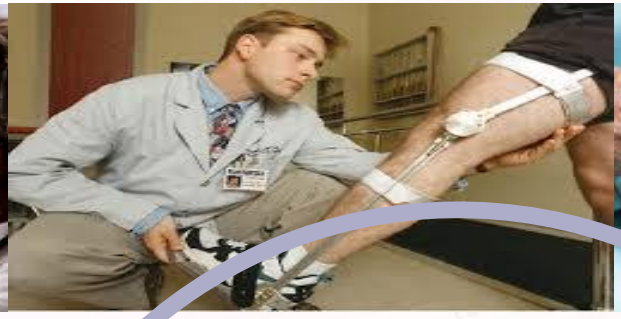
Rehabilitation

- 35 cases
- 4 are functionally good

Respirology

- 31 cases

Palliative care


Neurology

- Diagnosis
- Counselling for disease trajectory & prognosis
- Treatment: Riluzole

Rehabilitation

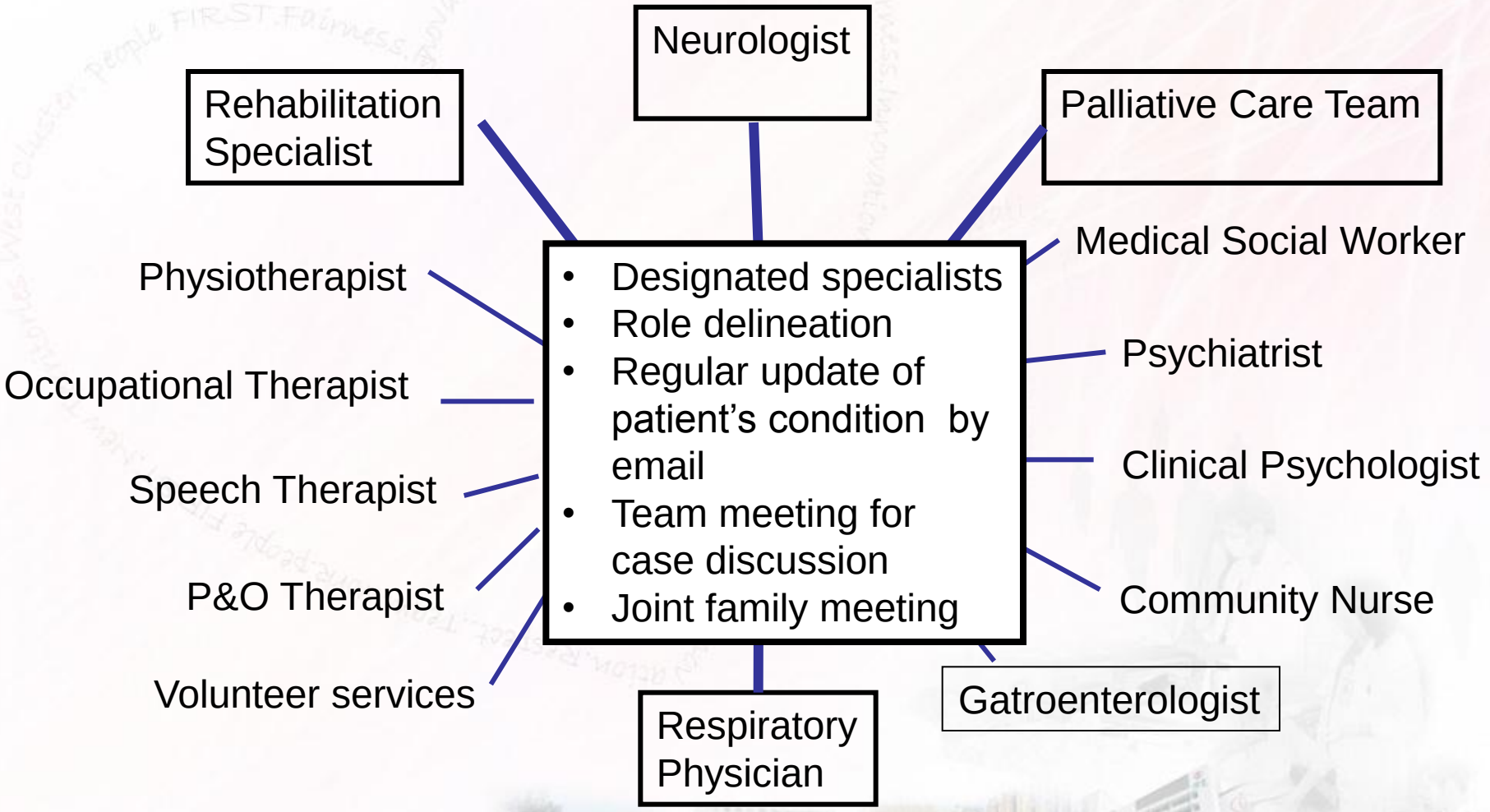
- Functional evaluation (ALSFRS-R)
- Determine goals of rehab & optimize function
- Baseline lung function & interval monitoring
- Coordinate for PEG

Respirology +/- GI

Palliative care

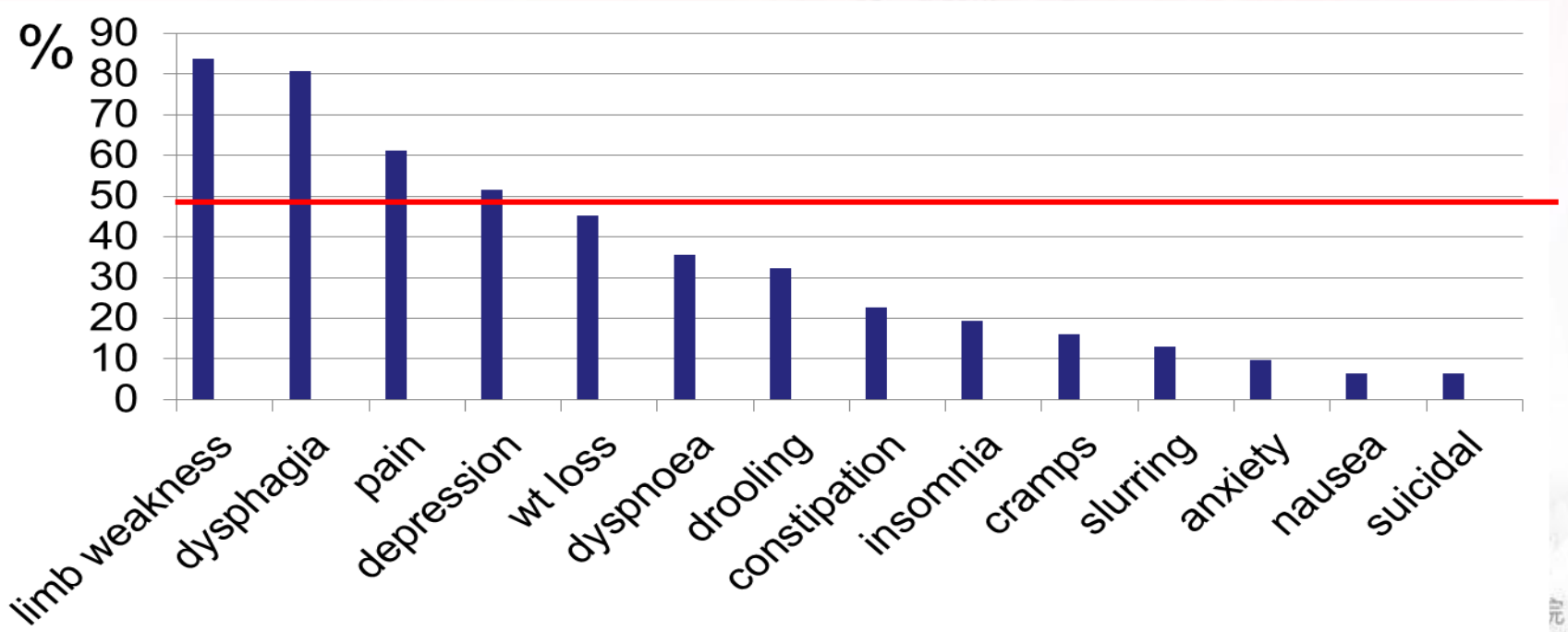
- Evaluate & facilitate disease acceptance
- Management of distressing symptoms
- Support for EOL decisions & Advance Care Planning
- Bereavement counselling

TMH Multi-specialties Collaboration

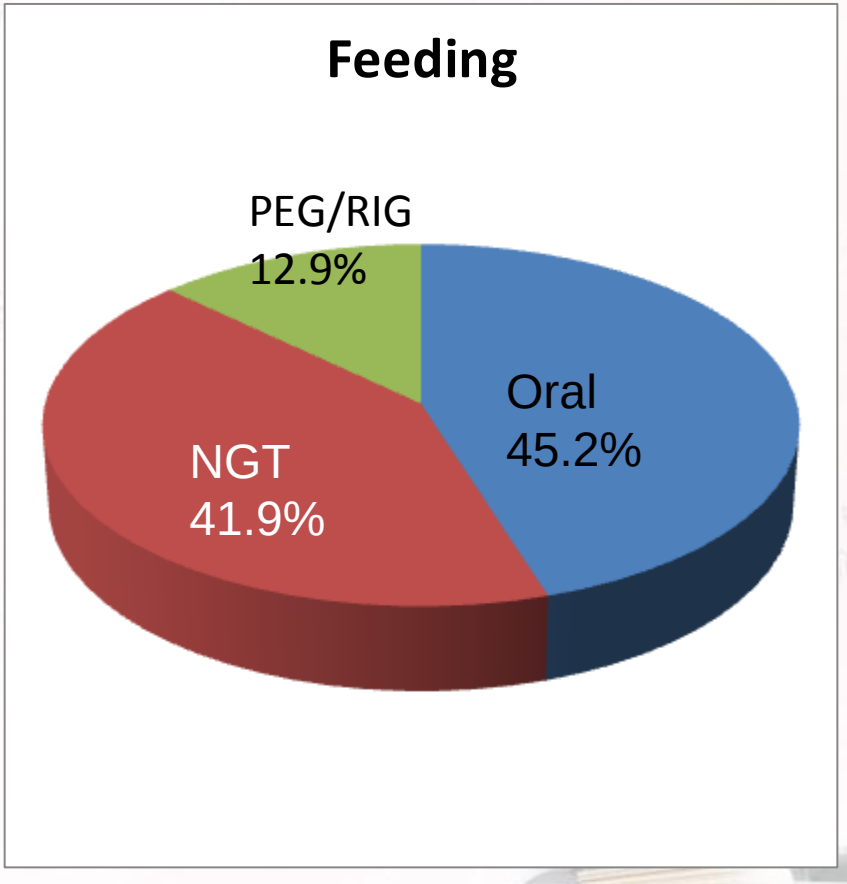


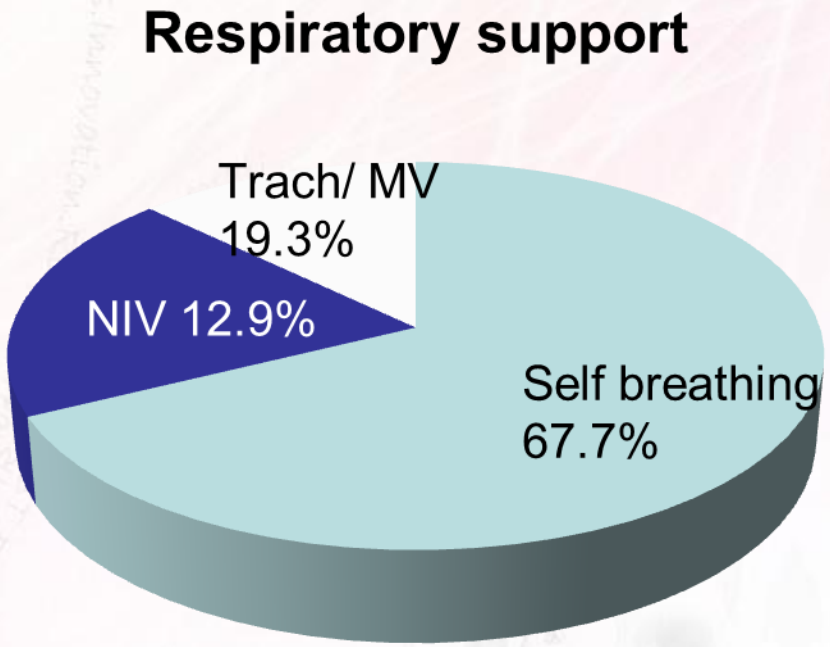
Patient characteristics & symptom prevalence

Mean age (year)	58.5 (33-98)
M:F	1.6 : 1
Bulbar onset	4 (12.9%)
Symptom onset to diagnosis (months)	4
Diagnosis to PC service (months)	6.5
Average number of symptom	4.8



Specific Interventions

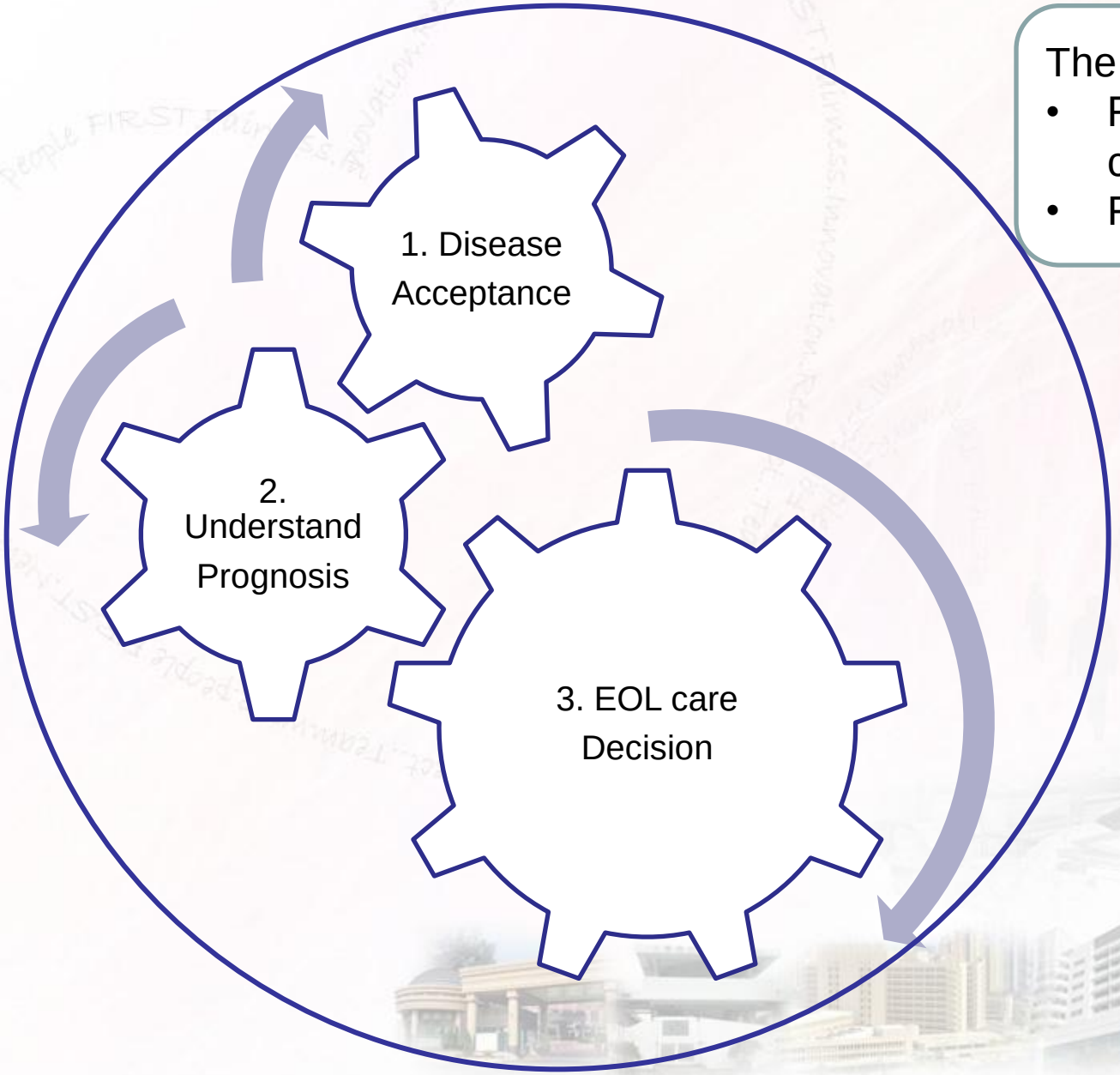




Mode	Total	Died
MV	4	3
NIV	6	5
Self breathing	21	8

* Fifty percent died with NIV/MV

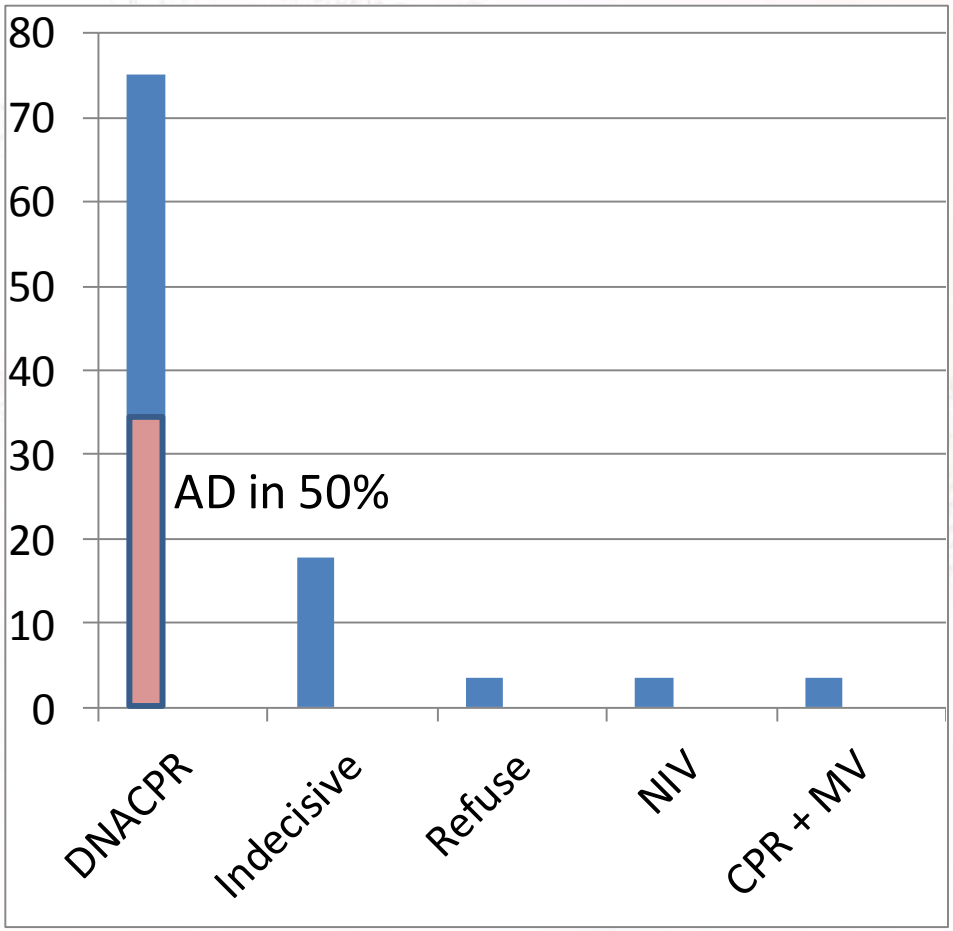
ACP Process



The prerequisites:

- Patient's symptoms controlled
- Family engaged

Advance Care Planning



- Mentally competent = 28
  - DNACPR = 21 (75%)
    - 50% signed AD, the other opted for CMS documentation
    - 1 opt for NIV & no CPR
  - Indecisive = 5 (17.6%)
  - Refuse = 1 (3.6%)
  - CPR + MV = 1 (3.6%)
- MIP = 3

Survival

Number of death = 16 (51.6%)	Duration (days)
Diagnosis to death (overall)	277 (9.2 months) *
Bulbar onset (PBP n=3) vs ALS	82 vs 322
Average duration under PC	118

* Duration is under-estimated as some patients enrolled still survive.

	Multi-specialties Collaboration (n=16)	Pre-collaboration (2011-2013 n=38)
CPR	0	6 (15.8%)
Family dissatisfaction (Coroner/ complaint)	0	2 (5.3%)

All patients died with a plan honouring their wish.

Case Sharing

新界西・醫院聯網
New Territories West Cluster

Mr. Chan M/61

- Presented to surgical for abdominal pain and weight loss. Negative workup.
- Confirm diagnosis of MND by Neurologist.
- Deteriorated & defaulted all the appointments
- Palliative Home Care phone contact:
  - Depressed with suicidal thoughts
  - Wife crying over the phone
- Palliative home visit with doctor

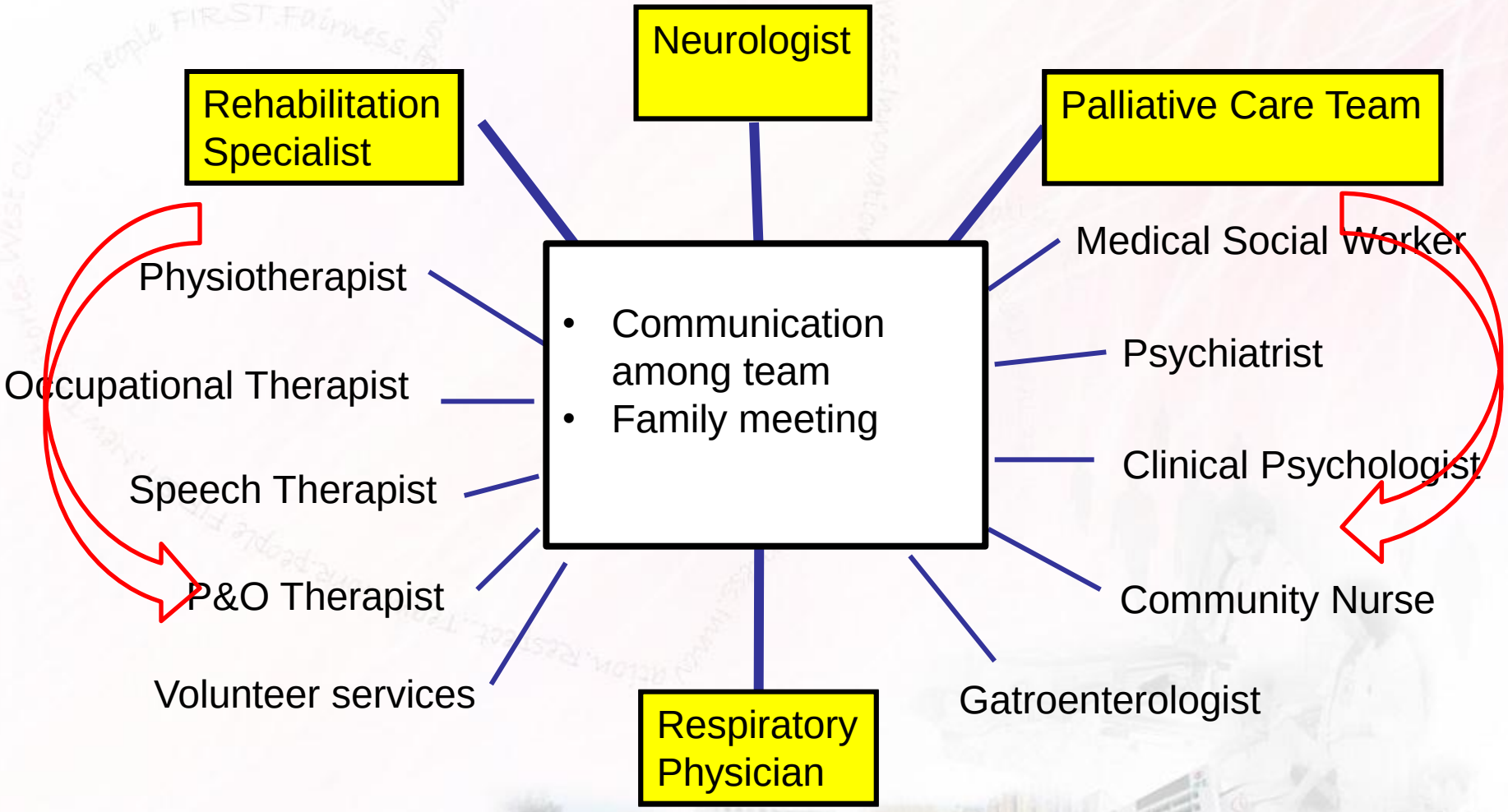
Mr. Chan

Living environment:

- Rented flat with 1 bedroom
- Patient slept on sofa in living room, could not enter bedroom due to deteriorated mobility

- Problems:
  - Cachexic: BW 62→ 43.5kg
  - Pain: over limbs & bony prominence. NRS 7/10.
  - Swallowing problem: occasional choking
  - Depression: insomnia, sense of hopelessness & worthlessness, suicidal idea

Multi-disciplinary Approach



Mr. Chan

- Management:
  - PC nurse: active listening, life reivew
  - MSW: sort out financial issues, refer volunteer group.
  - Start anti-depressant, analgesic
  - Refer OT for home visit
  - Rebook all defaulted appointments with NEATS arrangement
  - Refer psy for patient and wife

- Subsequent PC clinic FU. ACP discussed. Refused NIV/intubation and CPR. Patient passed away in 12/2014 due to respiratory failure with DNACPR in place.


THANK YOU

http://raymmar.com/photographing-guy-als-changed-life/

Acknowledgement

- Dr. CK Mok (COS, M&G, TMH)
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- TMH OT Department (Ms Joyce Cheung)