賽馬會安寧頌
JCECC
Jockey Club End-of-Life Community Care Project

Listen to our voice: Advance Care Planning in Dementia Care

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PhD of Social Welfare in Dementia (CUHK)
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Master of Science in Clinical Gerontology (CUHK)
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IPA Young Researchers Network (International)
Winner of Social Impact Award (British Council)

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Jockey Club Centre for Positive Ageing

Global concern of persons with dementia

2 out of 3

people globally believe there is little or no understanding of **dementia** in their countries

131.5 million people will be living with **dementia** by 2050

68% in low and middle income **countries**

Every **3 seconds** someone in the world develops **dementia**

(WHO, 2017)

Source: https://www.pexels.com/search/time

Dementia Innovation Readiness Index 2020:

30 Global Cities

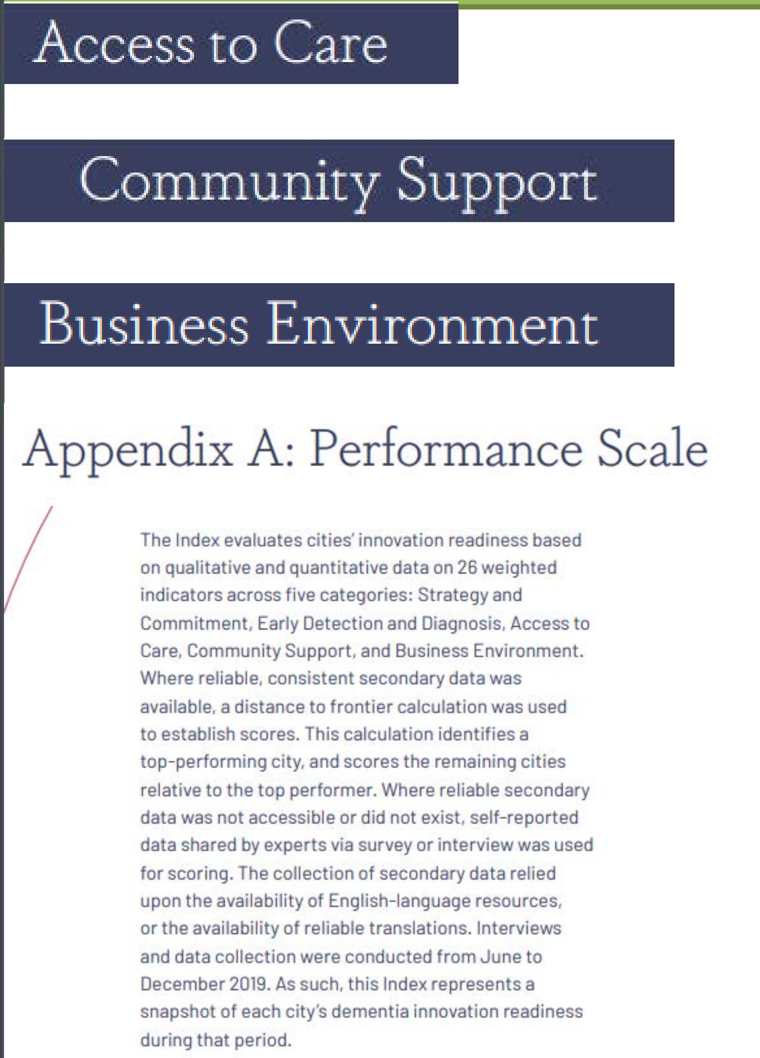
Global Coalition on Aging

Alzheimer's Disease International

LIEN foundation

Strategy and Commitment

Early Detection and Diagnosis



Access to Care

Community Support

Business Environment

Appendix A: Performance Scale

The Index evaluates cities' innovation readiness based on qualitative and quantitative data on 26 weighted indicators across five categories: Strategy and Commitment, Early Detection and Diagnosis, Access to Care, Community Support, and Business Environment. Where reliable, consistent secondary data was available, a distance to frontier calculation was used to establish scores. This calculation identifies a top-performing city, and scores the remaining cities relative to the top performer. Where reliable secondary data was not accessible or did not exist, self-reported data shared by experts via survey or interview was used for scoring. The collection of secondary data relied upon the availability of English-language resources, or the availability of reliable translations. Interviews and data collection were conducted from June to December 2019. As such, this Index represents a snapshot of each city's dementia innovation readiness during that period.

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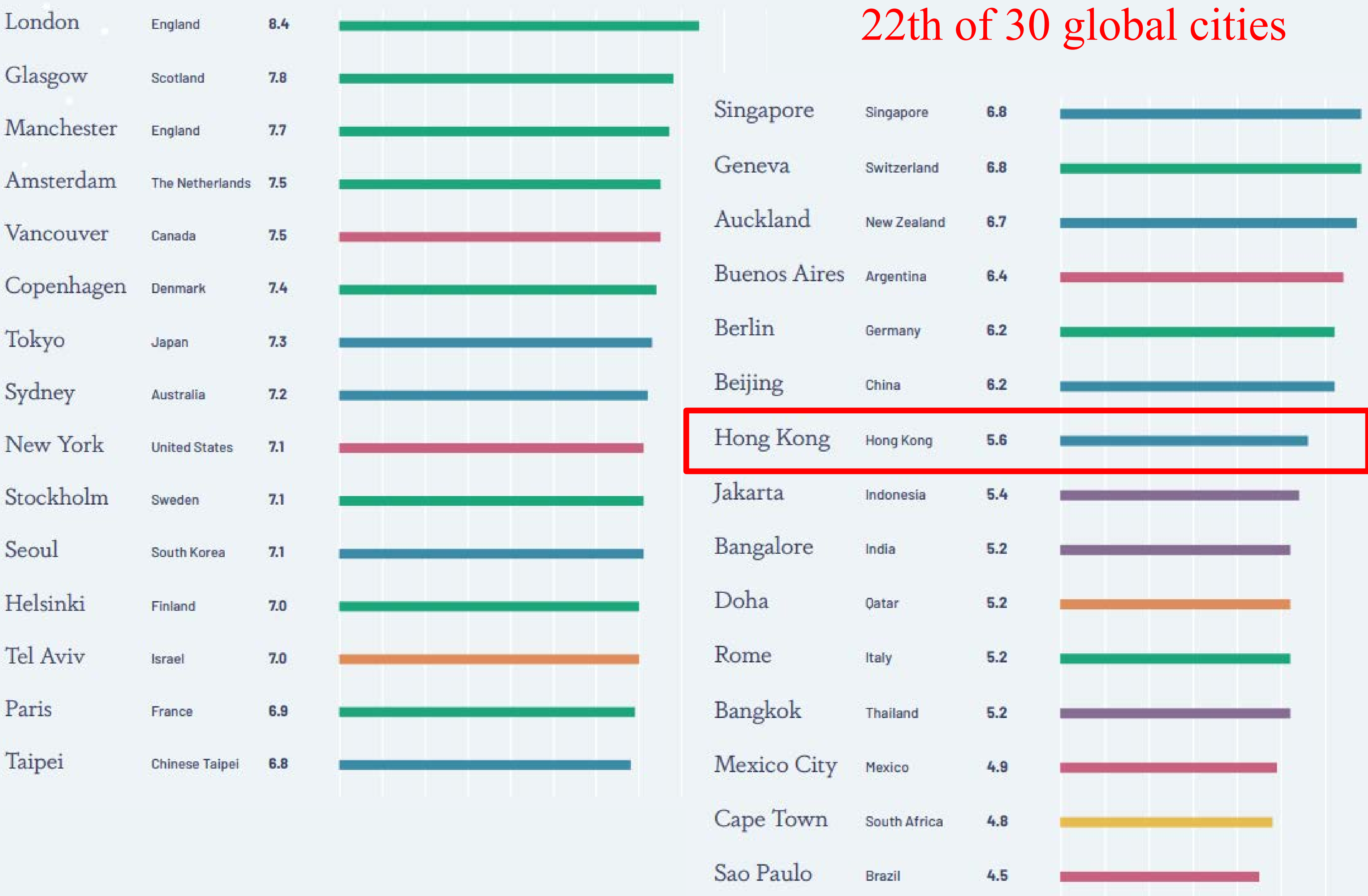
Scoring can be referenced to p.51

Dementia Innovation Readiness in Cities

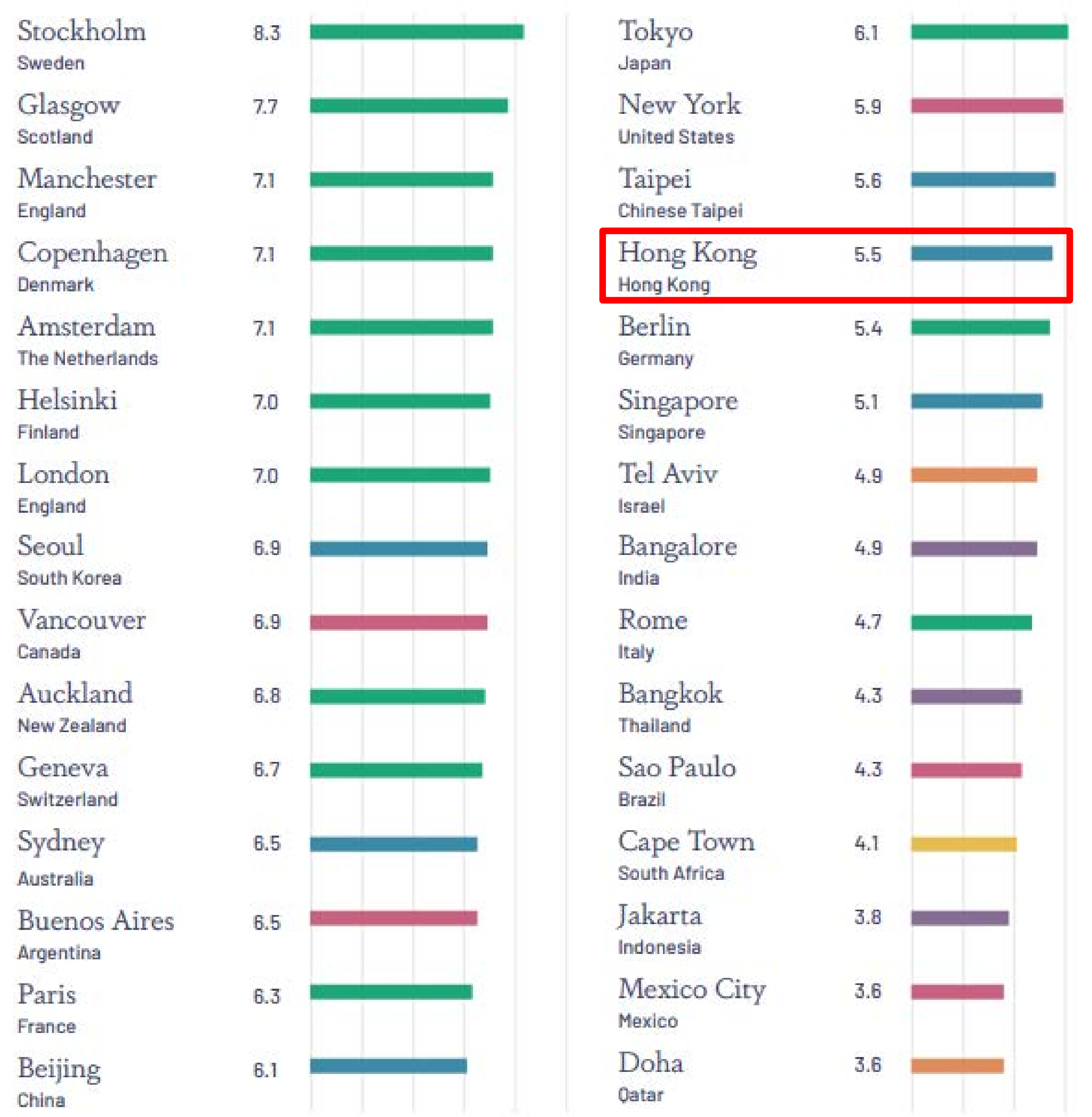
Overall Scores



Hong Kong is ranked at the 22th of 30 global cities

HK is ranked at the 19th

Early Detection and Diagnosis Scores



City	Country	Score
Stockholm	Sweden	8.3
Glasgow	Scotland	7.7
Manchester	England	7.1
Copenhagen	Denmark	7.1
Amsterdam	The Netherlands	7.1
Helsinki	Finland	7.0
London	England	7.0
Seoul	South Korea	6.9
Vancouver	Canada	6.9
Auckland	New Zealand	6.8
Geneva	Switzerland	6.7
Sydney	Australia	6.5
Buenos Aires	Argentina	6.5
Paris	France	6.3
Beijing	China	6.1
Tokyo	Japan	6.1
New York	United States	5.9
Taipei	Chinese Taipei	5.6
Hong Kong	Hong Kong	5.5
Berlin	Germany	5.4
Singapore	Singapore	5.1
Tel Aviv	Israel	4.9
Bangalore	India	4.9
Rome	Italy	4.7
Bangkok	Thailand	4.3
Sao Paulo	Brazil	4.3
Cape Town	South Africa	4.1
Jakarta	Indonesia	3.8
Mexico City	Mexico	3.6
Doha	Qatar	3.6

Access to Care Scores

HK is ranked at the 25th

City	Country	Score
Copenhagen	Denmark	9.5
Amsterdam	The Netherlands	9.2
Geneva	Switzerland	8.2
Sydney	Australia	8.2
Stockholm	Sweden	8.0
Manchester	England	7.7
Helsinki	Finland	7.6
Berlin	Germany	7.5
Tokyo	Japan	7.5
London	England	7.5
Paris	France	7.4
New York	United States	7.3
Vancouver	Canada	7.2
Auckland	New Zealand	7.2
Tel Aviv	Israel	7.1
Seoul	South Korea	7.0
Glasgow	Scotland	7.0
Singapore	Singapore	6.9
Buenos Aires	Argentina	6.7
Rome	Italy	6.3
Beijing	China	6.1
Taipei	Chinese Taipei	6.0
Sao Paulo	Brazil	5.6
Mexico City	Mexico	5.5
Hong Kong	Hong Kong	5.3
Bangalore	India	5.3
Cape Town	South Africa	5.2
Jakarta	Indonesia	5.2
Bangkok	Thailand	5.0
Doha	Qatar	4.9

Access to Care

Cities should prioritize developing and co-ordinating post-diagnostic support programs as a way to tailor care services to the unique needs of people living with dementia. Experts identified post-diagnostic support as one of the areas in which cities should most urgently be funded, incentivized, and empowered to provide locally tailored care services.

Post-diagnostic support services can be especially useful in helping people with dementia and their families navigate complex funding and care systems to access benefits and reduce out-of-pocket costs. However, experts report that post-diagnostic support is not consistently available or prioritized as an area of need.

(1) Equip people newly diagnosed with dementia with knowledge and skills on healthy ageing in the hope to delay further deterioration; Advanced Care Planning is one of the key elements.
(2) Promote the concepts of early diagnosis and empowerment to the person with MCI/dementia and caregivers in a family approach to local GPs and social welfare sector; and
(3) Establish a family-approach intervention model targeting people newly diagnosed with dementia who are not currently targeted by public healthcare services;
(4) Strengthen self-efficacy and resilience of family caregivers for further dementia care tasks;
(5) Raise public awareness in dementia and the importance of early interventions.

The Economist Intelligence Unit

The 2015 Quality of Death Index

Ranking palliative care across the world

A report by The Economist Intelligence Unit

Commissioned by

LIEN foundation

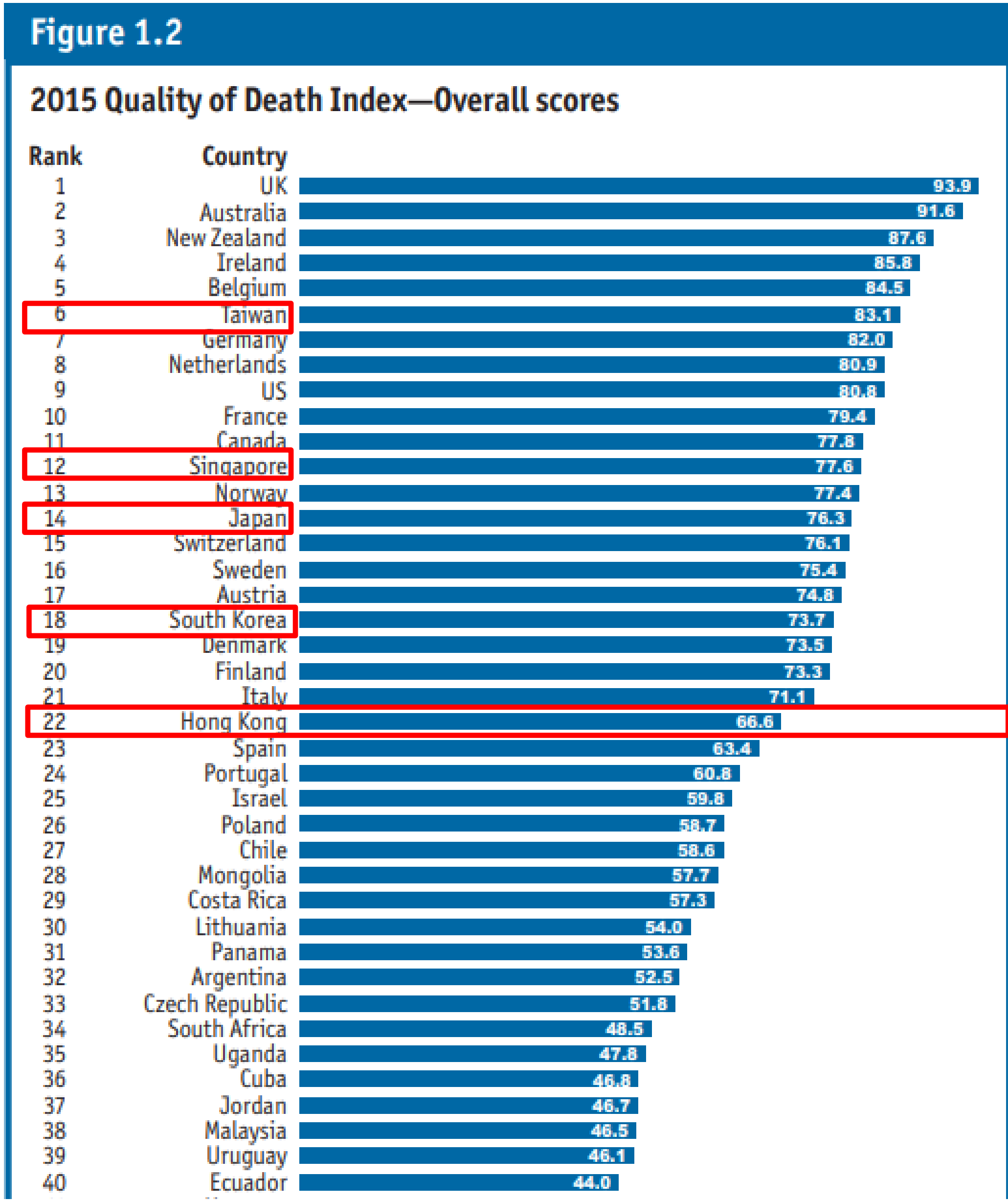


Figure 1.2

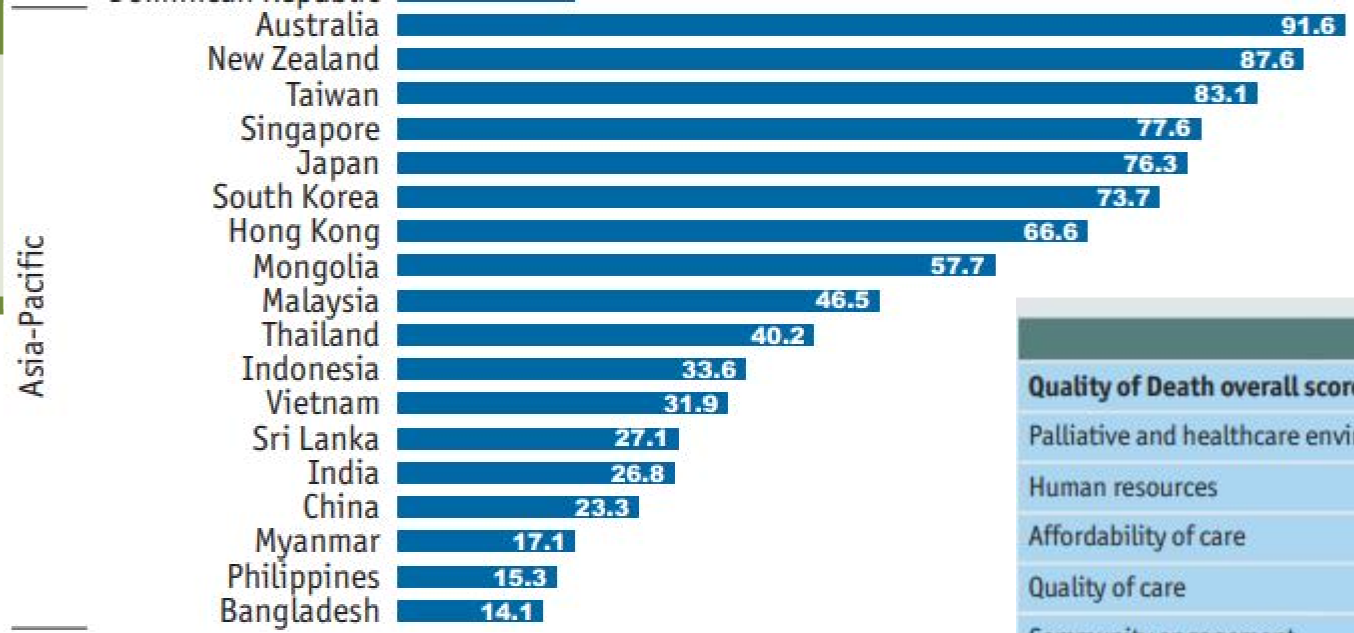
2015 Quality of Death Index—Overall scores

Rank	Country	Score
1	UK	93.9
2	Australia	91.6
3	New Zealand	87.6
4	Ireland	85.8
5	Belgium	84.5
6	Taiwan	83.1
7	Germany	82.0
8	Netherlands	80.9
9	US	80.8
10	France	79.4
11	Canada	77.8
12	Singapore	77.6
13	Norway	77.4
14	Japan	76.3
15	Switzerland	76.1
16	Sweden	75.4
17	Austria	74.8
18	South Korea	73.7
19	Denmark	73.5
20	Finland	73.3
21	Italy	71.1
22	Hong Kong	66.6
23	Spain	63.4
24	Portugal	60.8
25	Israel	59.8
26	Poland	58.7
27	Chile	58.6
28	Mongolia	57.7
29	Costa Rica	57.3
30	Lithuania	54.0
31	Panama	53.6
32	Argentina	52.5
33	Czech Republic	51.8
34	South Africa	48.5
35	Uganda	47.8
36	Cuba	46.8
37	Jordan	46.7
38	Malaysia	46.5
39	Uruguay	46.1
40	Ecuador	44.0

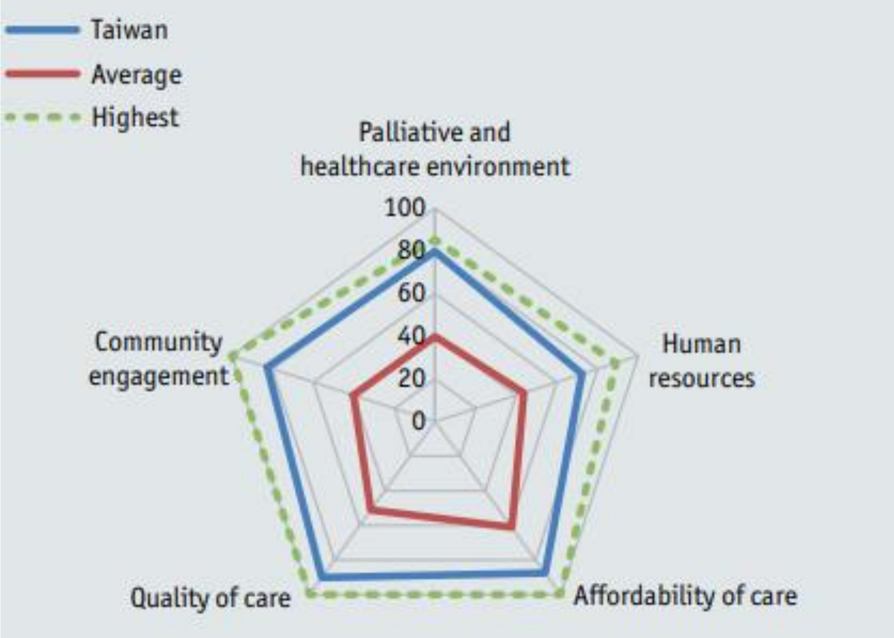
Hong Kong is ranked at

22th among 80 countries/cities

Case study of Taiwan



	Rank/80	Score/100
Quality of Death overall score (supply)	**6**	**83.1**
Palliative and healthcare environment	5	79.6
Human resources	9	72.2
Affordability of care	=6	87.5
Quality of care	=8	90.0
Community engagement	=5	82.5



① Palliative and healthcare environment category (20% weighting) → 28th in rank

② Human resources category (20% weighting) → 20th in rank

③ Affordability of care category (20% weighting) → 18th in rank

④ Quality of care category (30% weighting) → 20th in rank

⑤ Community engagement (10% weighting) → 38th in rank

Figure 7.1

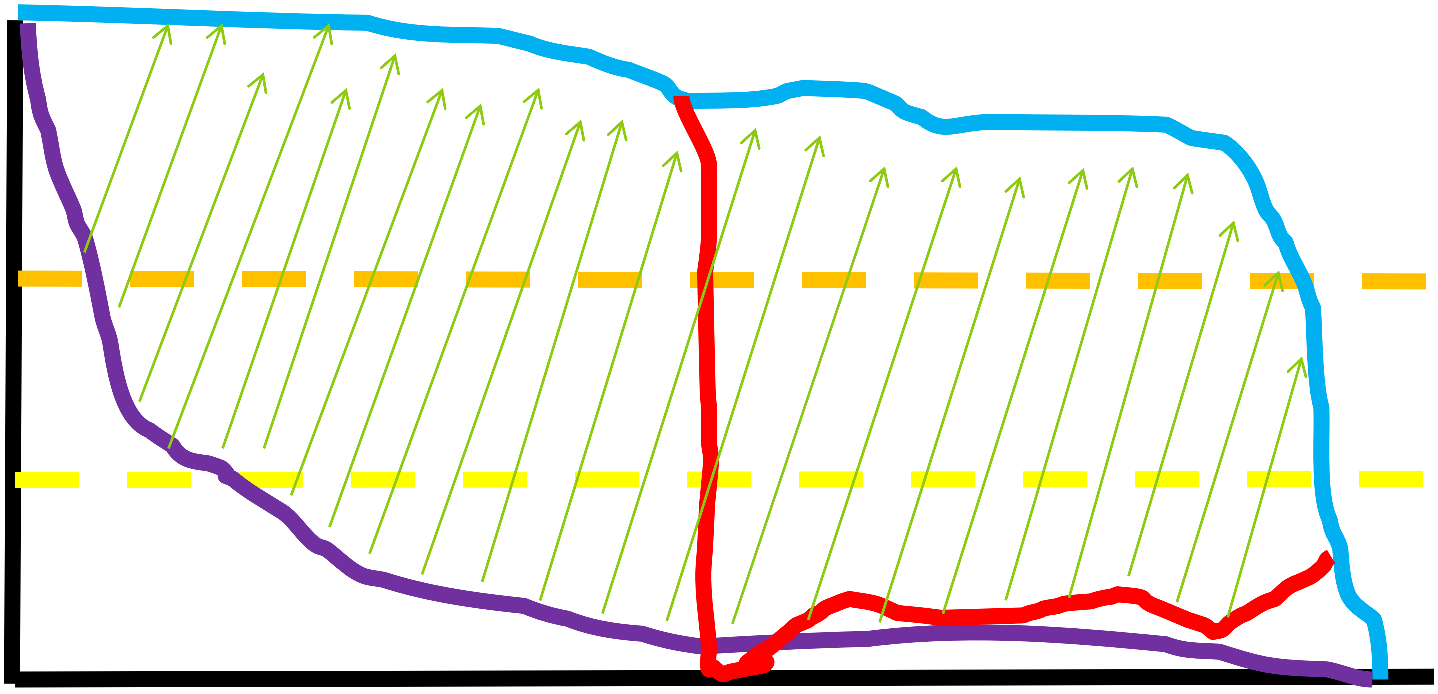
Palliative care demand vs supply

What is your “CHOICE” ?

Make Health Last. What will your last 10 years look like?

- https://www.youtube.com/watch?v=Qo6QNU8kHxI

The Leaf Model



Emergency (Acute Hospital)

Why the red line happen?

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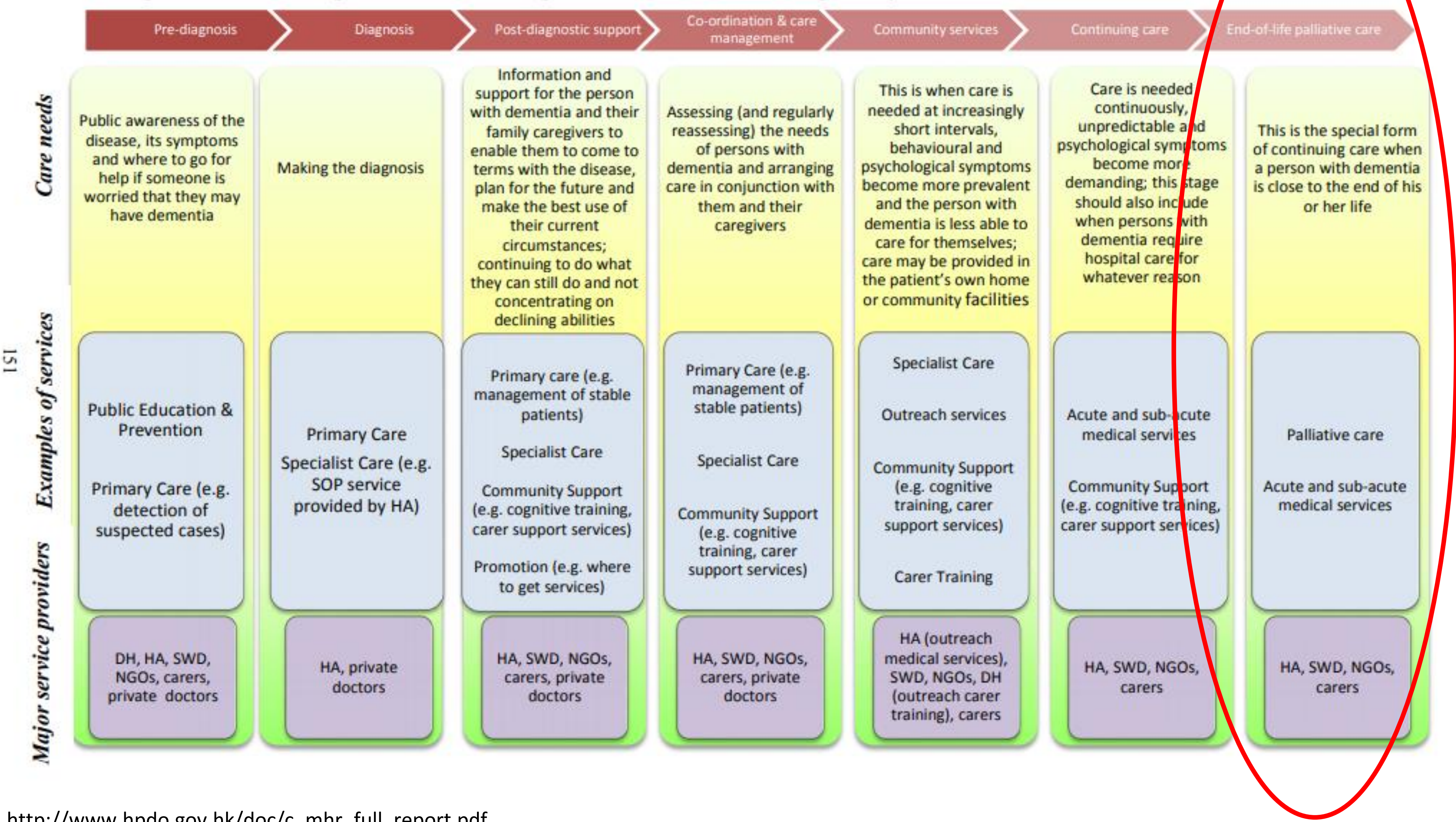
Jockey Club Centre for Positive Ageing

(DSDC, 2017)

When we need to start on thinking of ACP?

Figure 4.11 Seven-Stage Model for Planning Dementia Services Promulgated by WHO and the Alzheimer's Disease International



	Pre-diagnosis	Diagnosis	Post-diagnostic support	Co-ordination & care management	Community services	Continuing care	End-of-life palliative care
Care needs	Public awareness of the disease, its symptoms and where to go for help if someone is worried that they may have dementia	Making the diagnosis	Information and support for the person with dementia and their family caregivers to enable them to come to terms with the disease, plan for the future and make the best use of their current circumstances; continuing to do what they can still do and not concentrating on declining abilities	Assessing (and regularly reassessing) the needs of persons with dementia and arranging care in conjunction with them and their caregivers	This is when care is needed at increasingly short intervals, behavioural and psychological symptoms become more prevalent and the person with dementia is less able to care for themselves; care may be provided in the patient's own home or community facilities	Care is needed continuously, unpredictable and psychological symptoms become more demanding; this stage should also include when persons with dementia require hospital care for whatever reason	This is the special form of continuing care when a person with dementia is close to the end of his or her life
Examples of services	Public Education & Prevention Primary Care (e.g. detection of suspected cases)	Primary Care Specialist Care (e.g. SOP service provided by HA)	Primary care (e.g. management of stable patients) Specialist Care Community Support (e.g. cognitive training, carer support services) Promotion (e.g. where to get services)	Primary Care (e.g. management of stable patients) Specialist Care Community Support (e.g. cognitive training, carer support services)	Specialist Care Outreach services Community Support (e.g. cognitive training, carer support services) Carer Training	Acute and sub-acute medical services Community Support (e.g. cognitive training, carer support services)	Palliative care Acute and sub-acute medical services
Major service providers	DH, HA, SWD, NGOs, carers, private doctors	HA, private doctors	HA, SWD, NGOs, carers, private doctors	HA, SWD, NGOs, carers, private doctors	HA (outreach medical services), SWD, NGOs, DH (outreach carer training), carers	HA, SWD, NGOs, carers	HA, SWD, NGOs, carers

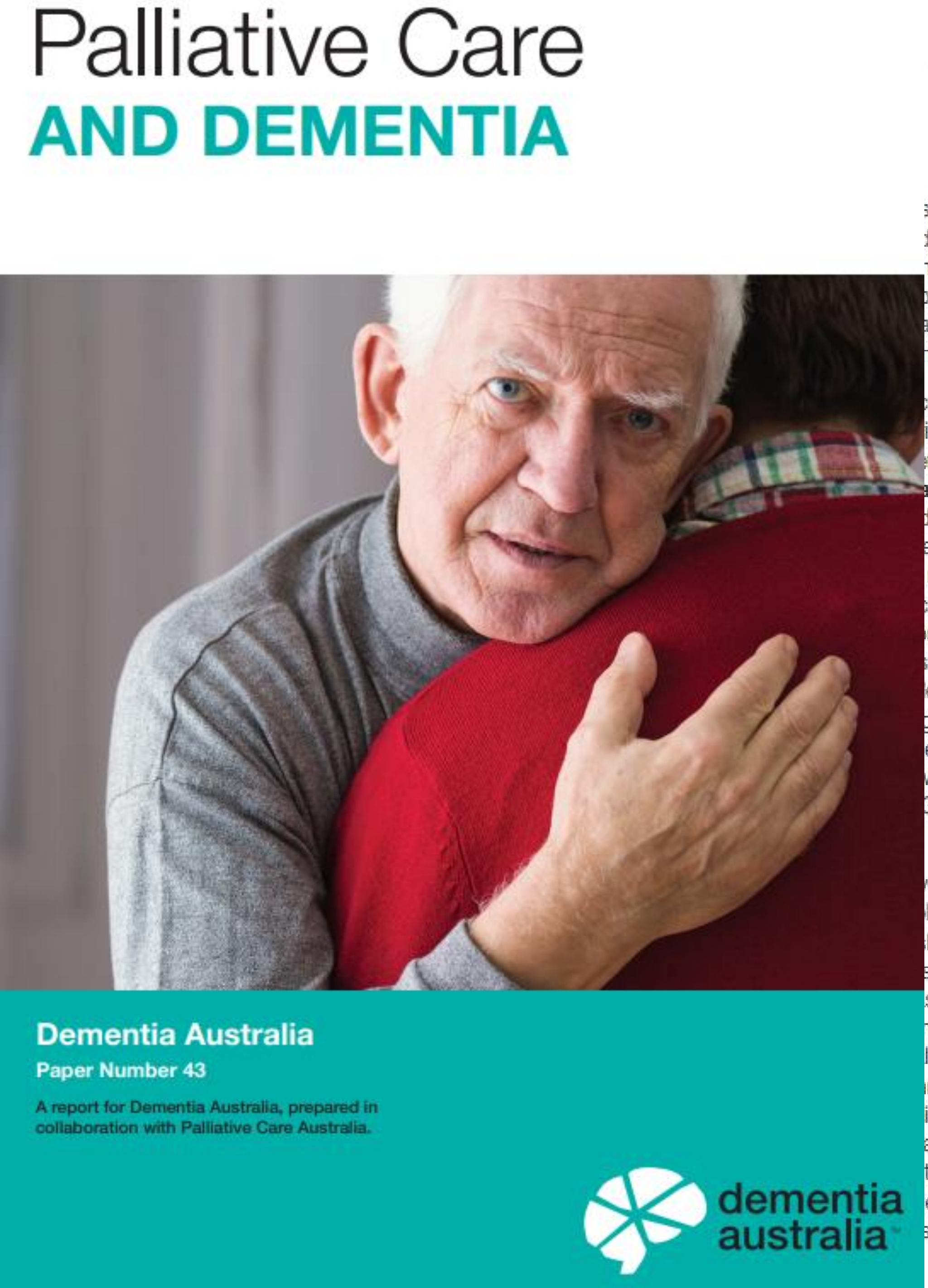
http://www.hpdo.gov.hk/doc/c_mhr_full_report.pdf

(Food and Health Bureau, 2017)

Remember – definition of ACP

- ACP enables individuals to reflect upon the meanings & consequences of serious illness scenarios, to define goals and preferences for future medical treatment & care, to discuss these goals & preferences with family & healthcare providers, & to record and review these preferences if appropriate.

(Lancet Oncology, 2017)

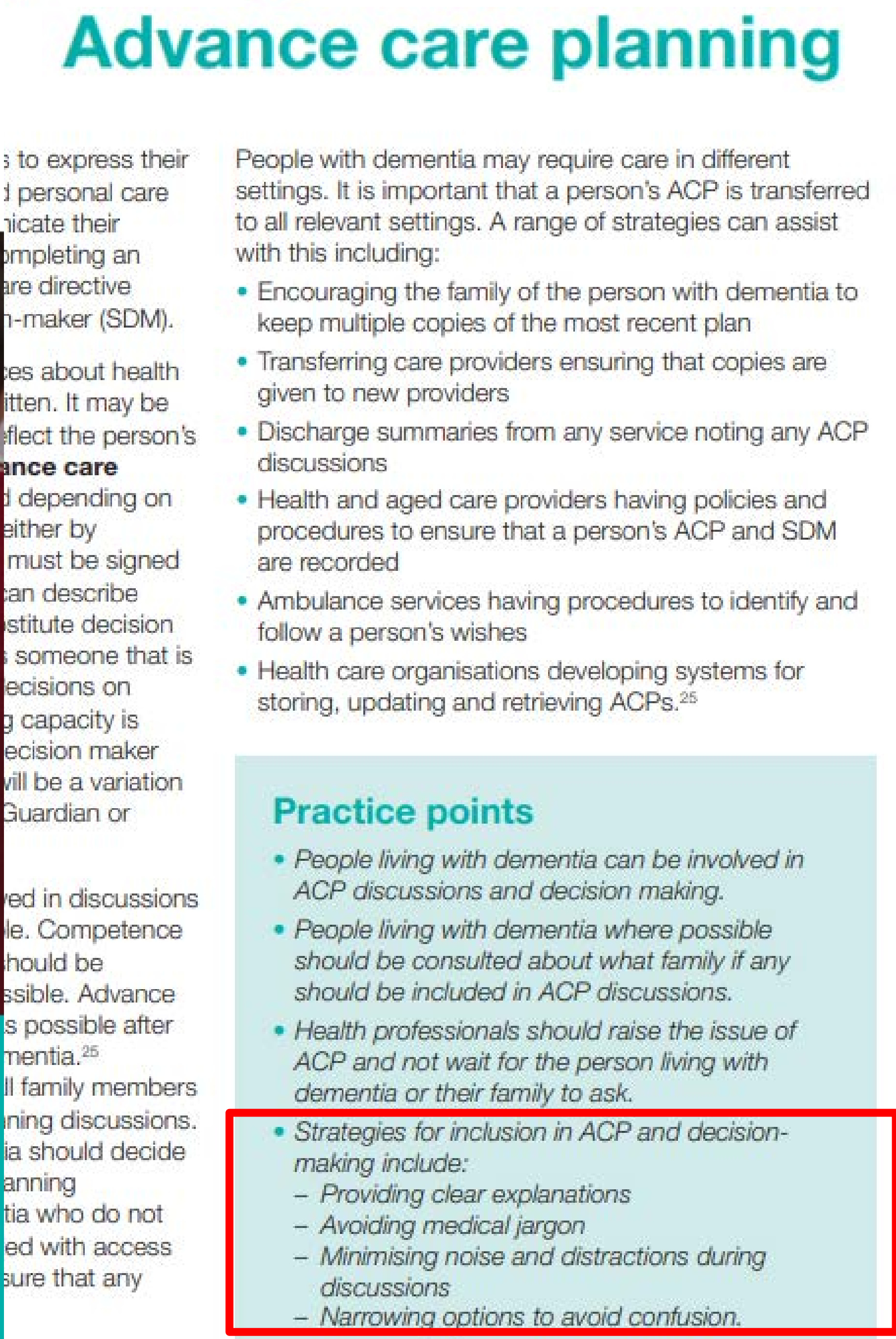


Palliative Care
AND DEMENTIA

Dementia Australia

Paper Number 43

A report for Dementia Australia, prepared in collaboration with Palliative Care Australia.



Advance care planning

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People with dementia may require care in different settings. It is important that a person's ACP is transferred to all relevant settings. A range of strategies can assist with this including:

- Encouraging the family of the person with dementia to keep multiple copies of the most recent plan
- Transferring care providers ensuring that copies are given to new providers
- Discharge summaries from any service noting any ACP discussions
- Health and aged care providers having policies and procedures to ensure that a person's ACP and SDM are recorded
- Ambulance services having procedures to identify and follow a person's wishes
- Health care organisations developing systems for storing, updating and retrieving ACPs.[25]

Practice points

- *People living with dementia can be involved in ACP discussions and decision making.*
- *People living with dementia where possible should be consulted about what family if any should be included in ACP discussions.*
- *Health professionals should raise the issue of ACP and not wait for the person living with dementia or their family to ask.*
- *Strategies for inclusion in ACP and decision-making include:*
  - *Providing clear explanations*
  - *Avoiding medical jargon*
  - *Minimising noise and distractions during discussions*
  - *Narrowing options to avoid confusion.*

Listen to me – Step 1

- Relationship building and not task-oriented
- Support me to initiate the topic and at the right time in my schedule (Start as soon as possible)
- Understand my emotional status and my readiness of my family members (empathy to my context)
- I am ready to have a family meeting
- I want to have a professional consultation
- Make me into ethical considerations and get my consent with mutual agreement
- Stop going on while I am not in good condition

(Bram et al., 2018; Chui, 2018; Piers et al., 2018)

Listen to me - Step 2



- With my suitable levels of information and rhythm as well as relevant materials to facilitate our discussion
- Enough time for me to discuss and think over
- I preferred to make it at home/ familiar places
- Please trust my mental capacity in a changing mode rather than a static mode (repeated the questions)
- Let me participate more with some friendly options, such as MC questions or yes/no questions or pictures
- Involve my family but not only ask my family
- I love talking ACP with a relax atmosphere

(Bram et al., 2018; Chui, 2018; Piers et al., 2018)

Listen to me - Step 3

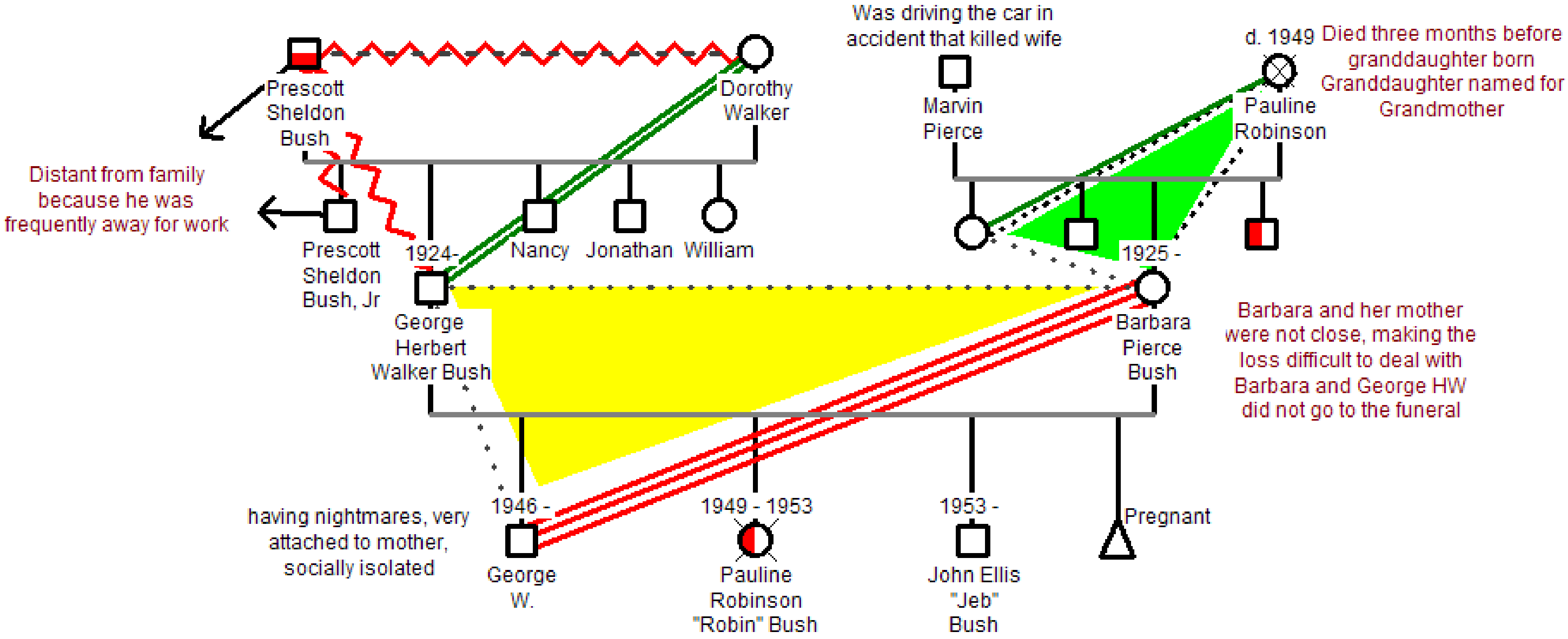
- Help me documented and ask me back later on whenever is necessary. Show me the materials…
- Structured implementation and follow my decision
- Clarification with me about my awareness of understanding my progress of dementia
- My perception of ACP should be paid attention (Impact)
- Ongoing detect me any fears or concerns in ACP
- Make wishes list and end-of-life decisions (AD)
- Consider my personality and my background again, like getting through my life story (This is ME~~)

(Bram et al., 2018; Chui, 2018; Piers et al., 2018)

Listen to them (family members)

- What is ACP and how can I access this application
- Mentioned about ACP at the intake stage but not now to do…
- Provide me the “selected” information rather than bulky one
- Please facilitate me to discuss with the person with dementia
- Start the conversation in-between and go through all at the discharge plan of post-diagnostic support (within a year)
- Be flexibility and it will be good to have a family meeting including all of the stakeholders
- Understanding the family genogram and analyze their dynamics before the discussion

Genogram and family functioning with dynamics



Was driving the car in accident that killed wife

Died three months before granddaughter born Granddaughter named for Grandmother

Distant from family because he was frequently away for work

Barbara and her mother were not close, making the loss difficult to deal with Barbara and George HW did not go to the funeral

having nightmares, very attached to mother, socially isolated

Jeb eventually became the "golden child" and was said to be mother's favorite

Warm reminders for three collaborated parties

Family

- In traditional Chinese culture, family factors and views of family members are important considerations.
- Depending on circumstances, family members may assume the following roles:
    - Understand the wish of the patient, who is mentally competent and take up the expected role in the future care plan;
    - If the patient is mentally incompetent, give input on the patient's prior wish or preference to the medical team, who would work out a care plan with the family by consensus building based on the best interests of the patient; and
    - Parents of a minor can communicate with the medical team and arrive at a consensus, taking into consideration all the aspects stated above.
- Family support is important to the patient. We understand that the family may be under stress. Should they need assistance, healthcare workers are ready to help.

Clinicians

- In the communication process, clinicians often assume a facilitating and guiding role, and:
  - Provide information on disease prognosis, treatment options available, benefits and risks, as well as related medical evidence, including end-of-life scenarios;
  - Facilitate the patient to express his/her values and preferences for treatment with good communication skills using a patient-centered approach and empower patient autonomy;
  - Encourage the family to listen to the patient's concerns and elicit views from family members; and
  - Resolve disagreement and deal with emotional responses as necessary and work towards a consensus for an agreed care plan.

Patient

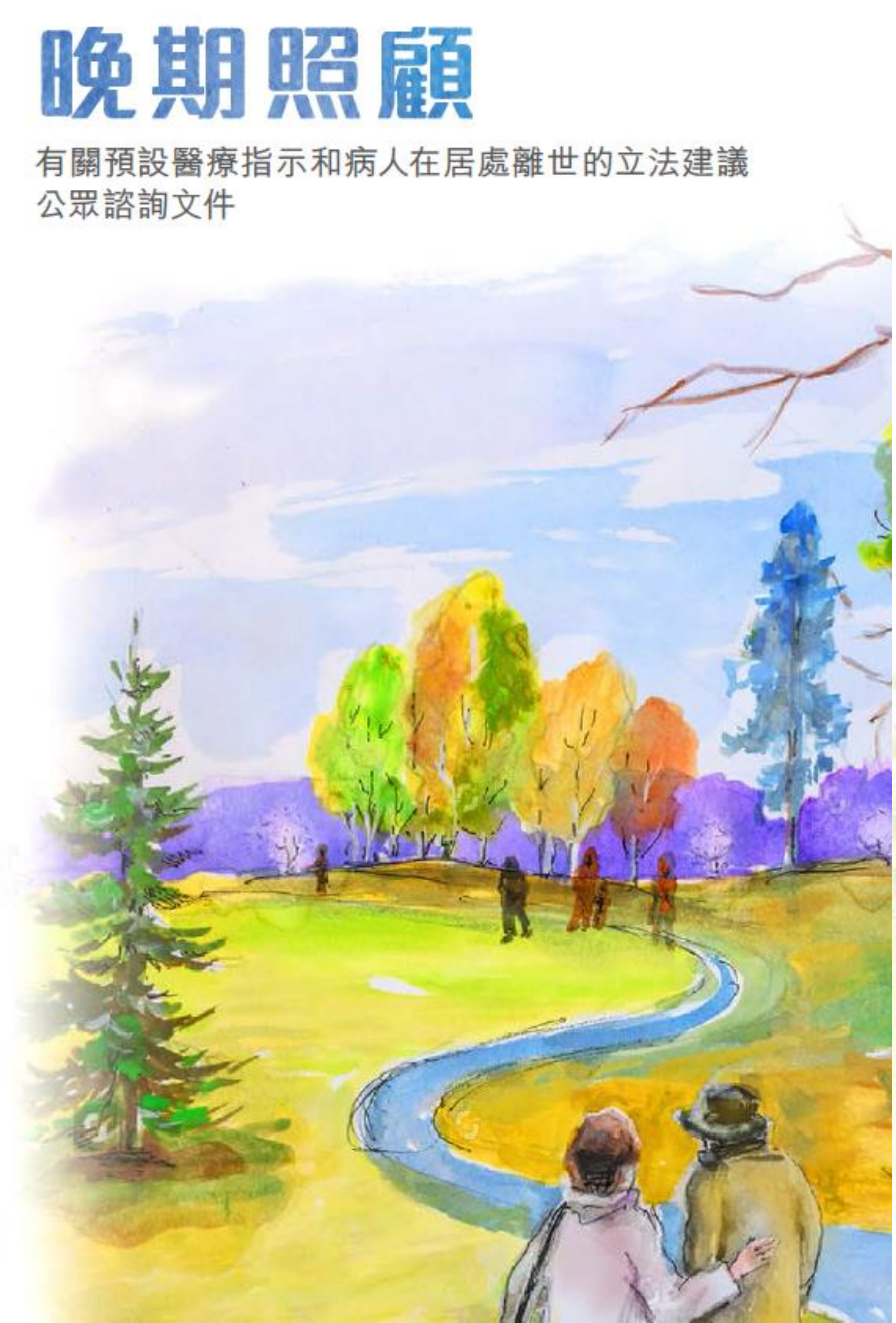
- The patient takes a central role in the discussion. He/she can express his/her views, values and needs to the medical team and the family. Healthcare workers will assist if difficulties arise.
- Scope of views expressed can include expectation for medical and personal care, expected roles of healthcare workers and the family. The patient can also refuse specified LST in the end stage, including cardiopulmonary resuscitation.
- As for paediatric patients, they are encouraged to participate in the discussion. However, the extent of participation depends on their mental capacity. There is currently no international standard on the age requirement, but a minor cannot sign an AD.

Barriers to promote ACP

Tilburgs, B., Vernooij-Dassen, M., Koopmans, R., van Gennip, H., Engels, Y., & Perry, M. (2018). Barriers and facilitators for GPs in dementia advance care planning: a systematic integrative review. *PLoS One*, *13*(6), e0198535.

- Lack of knowledge over the ACP and legal status
- Unable to deal with the persons with dementia
- Persons with dementia do not want to upset others
- Religions' consideration and its conviction
- Family rejected to think over and avoid the topic
- Variation of information from different professionals
- Changes of health condition during the caring time
- Limited accessibility and programme to conduct ACP
- Afraid to diminish hope and Traditional Chinese culture

Brooke, J., & Kirk, M. (2014). Advance care planning for people living with dementia. *British journal of community nursing*, *19*(10), 490-495.



晚期照顧

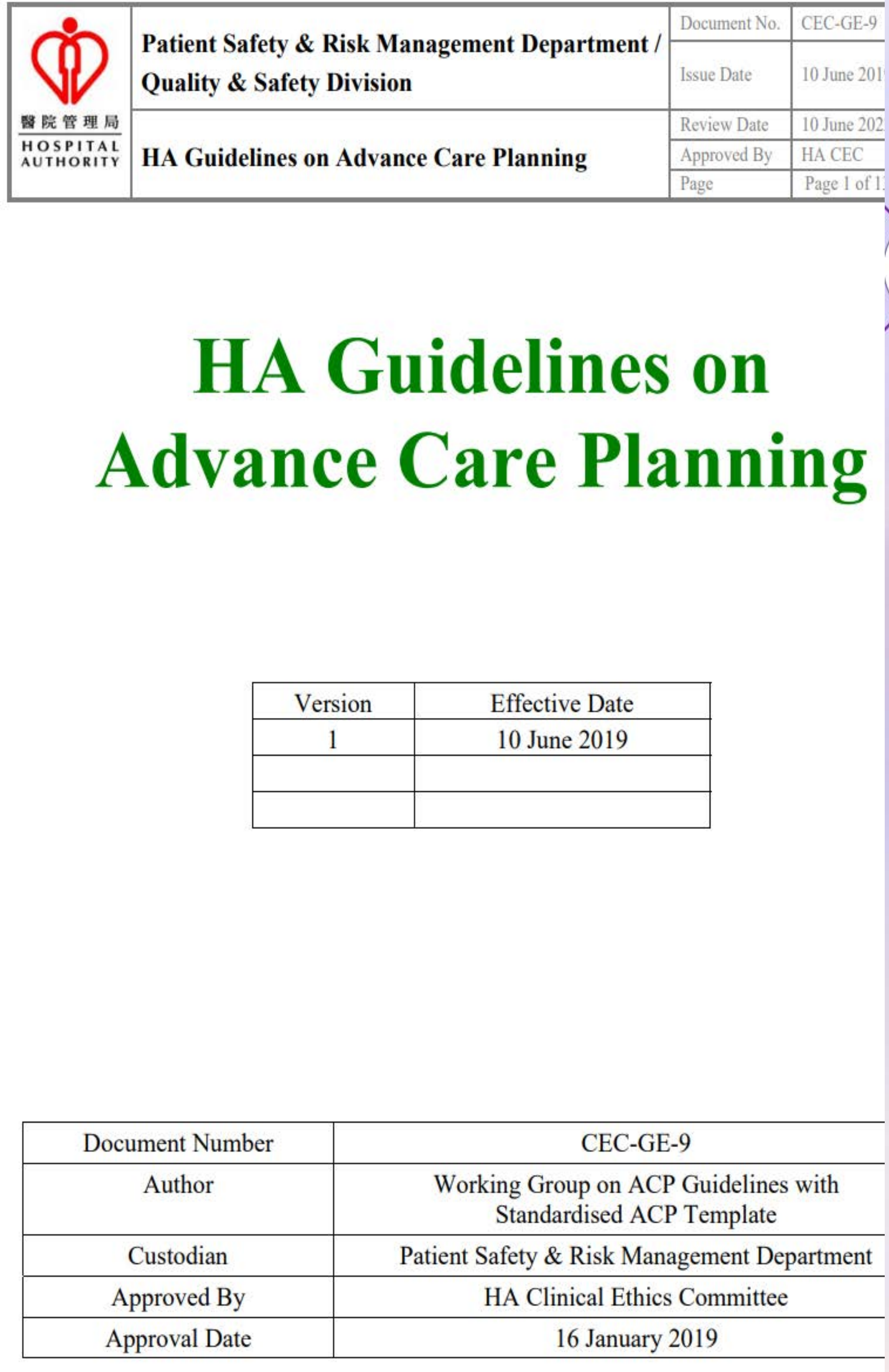
有關預設醫療指示和病人在居處離世的立法建議
公眾諮詢文件

晚期照顧：邁步向前

有關預設醫療指示和病人在居處離世的立法建議
公眾諮詢報告

食物及衞生局
Food and Health Bureau

(FHB, 2020)

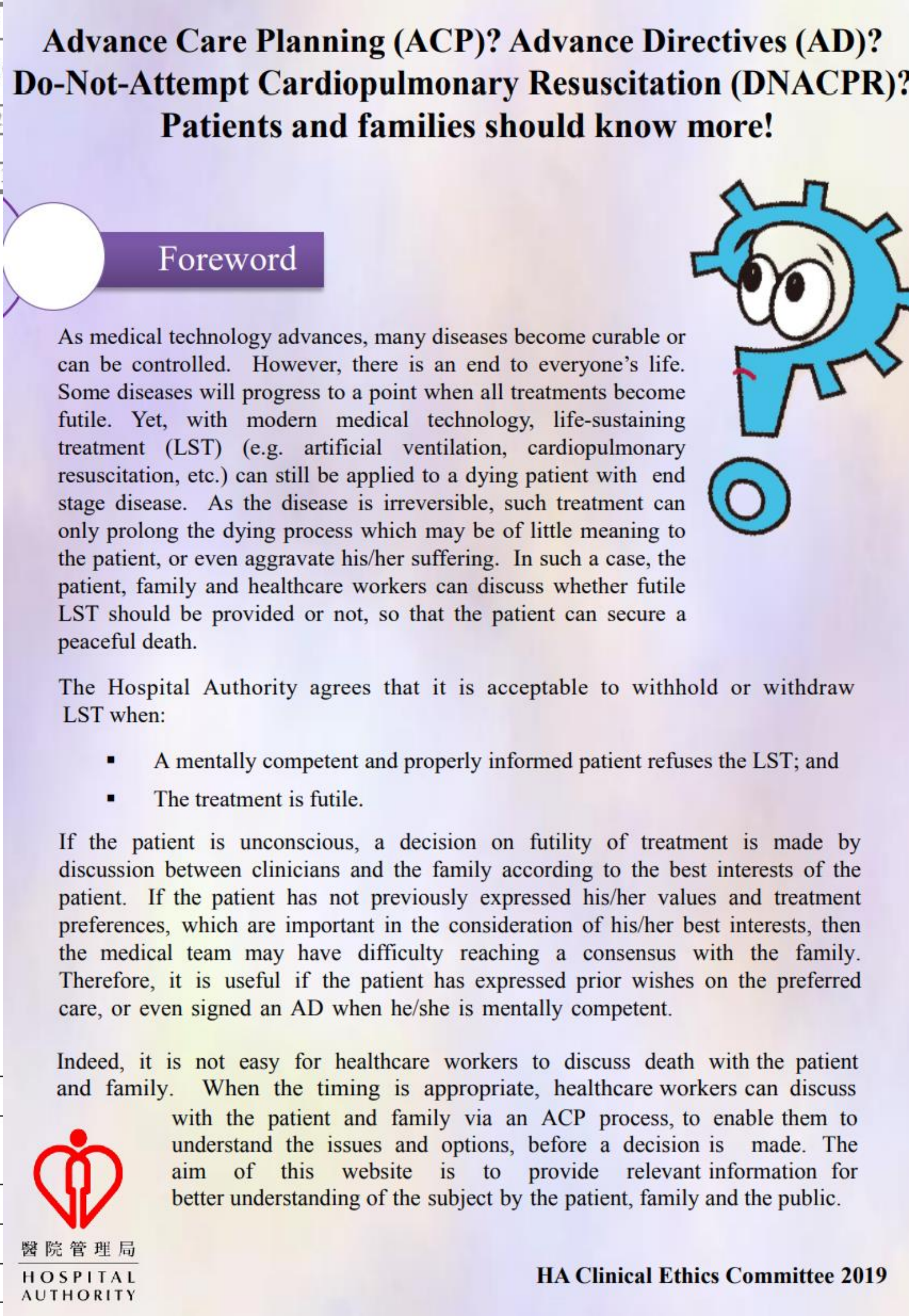


醫院管理局 HOSPITAL AUTHORITY			
	Patient Safety & Risk Management Department / Quality & Safety Division	Document No.	CEC-GE-9
		Issue Date	10 June 201
	HA Guidelines on Advance Care Planning	Review Date	10 June 202
		Approved By	HA CEC
		Page	Page 1 of 1

HA Guidelines on Advance Care Planning

Version	Effective Date
1	10 June 2019

Document Number	CEC-GE-9
Author	Working Group on ACP Guidelines with Standardised ACP Template
Custodian	Patient Safety & Risk Management Department
Approved By	HA Clinical Ethics Committee
Approval Date	16 January 2019



Advance Care Planning (ACP)? Advance Directives (AD)? Do-Not-Attempt Cardiopulmonary Resuscitation (DNACPR)? Patients and families should know more!

Foreword

As medical technology advances, many diseases become curable or can be controlled. However, there is an end to everyone's life. Some diseases will progress to a point when all treatments become futile. Yet, with modern medical technology, life-sustaining treatment (LST) (e.g. artificial ventilation, cardiopulmonary resuscitation, etc.) can still be applied to a dying patient with end stage disease. As the disease is irreversible, such treatment can only prolong the dying process which may be of little meaning to the patient, or even aggravate his/her suffering. In such a case, the patient, family and healthcare workers can discuss whether futile LST should be provided or not, so that the patient can secure a peaceful death.

The Hospital Authority agrees that it is acceptable to withhold or withdraw LST when:

- A mentally competent and properly informed patient refuses the LST; and
- The treatment is futile.

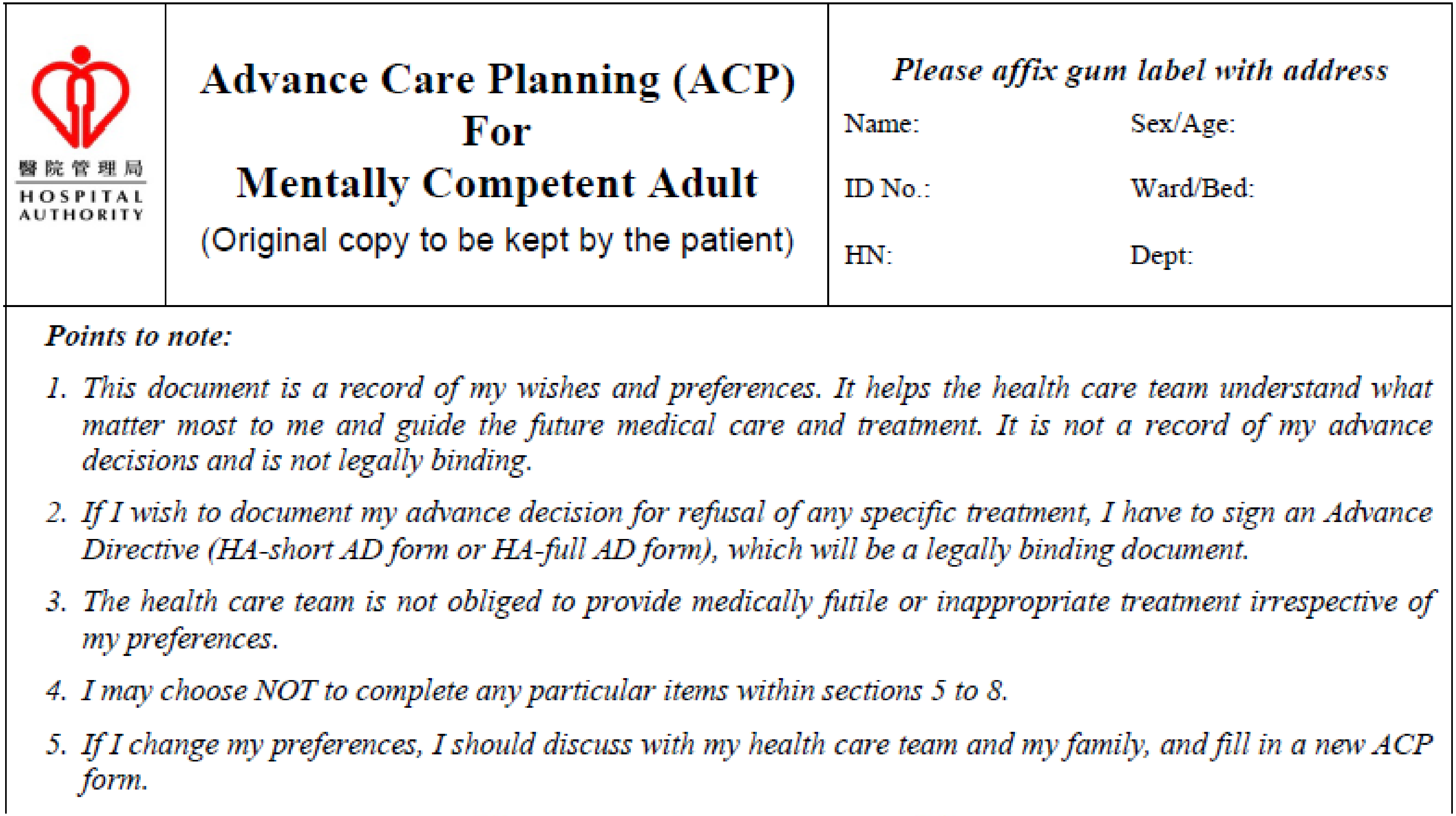
If the patient is unconscious, a decision on futility of treatment is made by discussion between clinicians and the family according to the best interests of the patient. If the patient has not previously expressed his/her values and treatment preferences, which are important in the consideration of his/her best interests, then the medical team may have difficulty reaching a consensus with the family. Therefore, it is useful if the patient has expressed prior wishes on the preferred care, or even signed an AD when he/she is mentally competent.

Indeed, it is not easy for healthcare workers to discuss death with the patient and family. When the timing is appropriate, healthcare workers can discuss with the patient and family via an ACP process, to enable them to understand the issues and options, before a decision is made. The aim of this website is to provide relevant information for better understanding of the subject by the patient, family and the public.

醫院管理局
HOSPITAL AUTHORITY

HA Clinical Ethics Committee 2019

Rehearsal on the ACP forms (User)



醫院管理局
HOSPITAL AUTHORITY

Advance Care Planning (ACP)
For
Mentally Competent Adult
(Original copy to be kept by the patient)

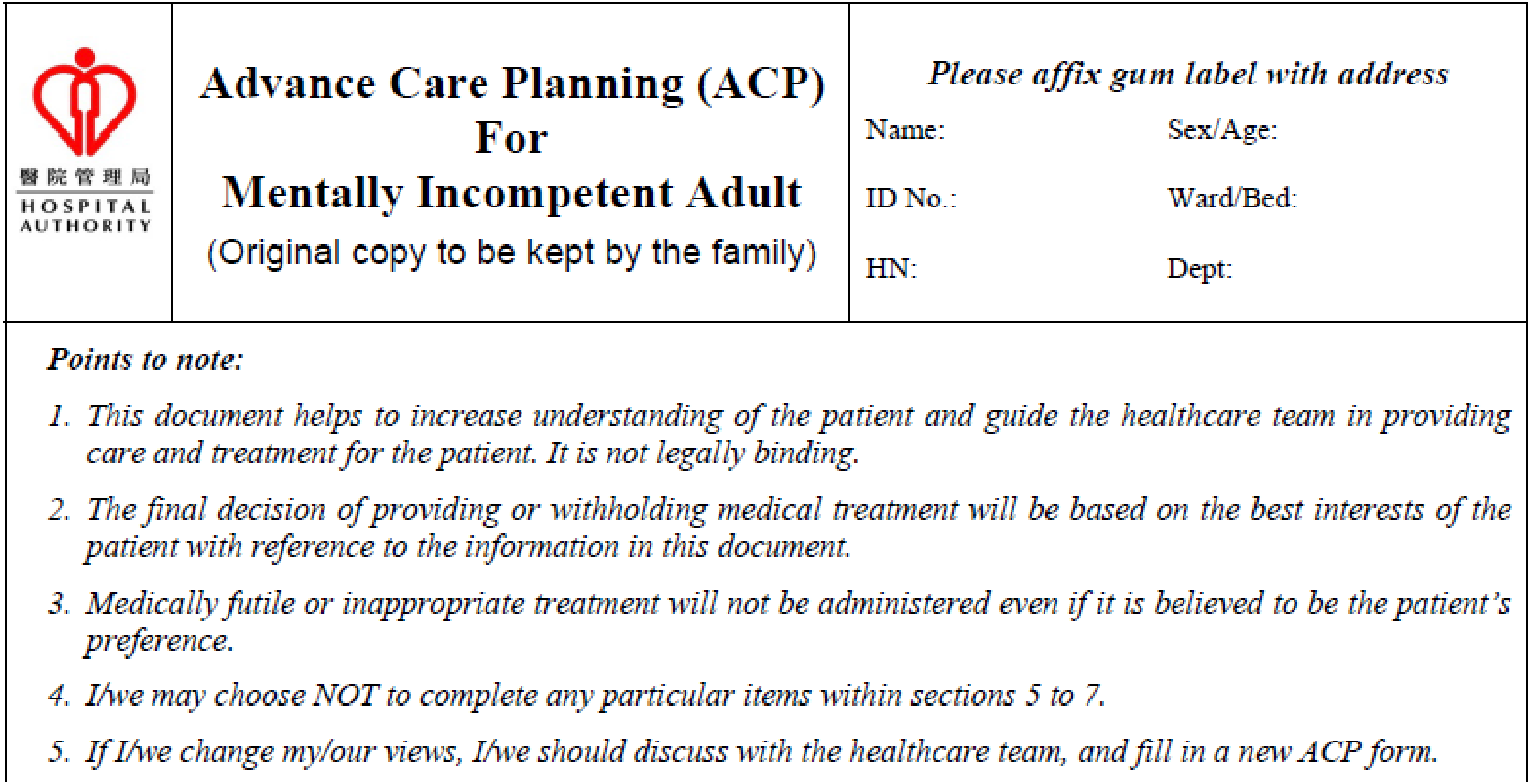
Please affix gum label with address

Name:	Sex/Age:
ID No.:	Ward/Bed:
HN:	Dept:

Points to note:

1. *This document is a record of my wishes and preferences. It helps the health care team understand what matter most to me and guide the future medical care and treatment. It is not a record of my advance decisions and is not legally binding.*
2. *If I wish to document my advance decision for refusal of any specific treatment, I have to sign an Advance Directive (HA-short AD form or HA-full AD form), which will be a legally binding document.*
3. *The health care team is not obliged to provide medically futile or inappropriate treatment irrespective of my preferences.*
4. *I may choose NOT to complete any particular items within sections 5 to 8.*
5. *If I change my preferences, I should discuss with my health care team and my family, and fill in a new ACP form.*

Rehearsal on the ACP forms (Family)



醫院管理局
HOSPITAL AUTHORITY

Advance Care Planning (ACP)
For
Mentally Incompetent Adult

(Original copy to be kept by the family)

Please affix gum label with address

Name: Sex/Age:

ID No.: Ward/Bed:

HN: Dept:

Points to note:

1. *This document helps to increase understanding of the patient and guide the healthcare team in providing care and treatment for the patient. It is not legally binding.*
2. *The final decision of providing or withholding medical treatment will be based on the best interests of the patient with reference to the information in this document.*
3. *Medically futile or inappropriate treatment will not be administered even if it is believed to be the patient's preference.*
4. *I/we may choose NOT to complete any particular items within sections 5 to 7.*
5. *If I/we change my/our views, I/we should discuss with the healthcare team, and fill in a new ACP form.*

Rehearsal on the AD forms

醫院管理局
HOSPITAL AUTHORITY

預設醫療指示 [1]

請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：………………………………………………（請以正楷書寫）
身份證號碼：…………………………………………
性別：男性／女性
出生日期：____／____／___
(日) (月) (年)

住址：……………………………………………………………………

賽馬會耆智園
Jockey Club Centre for Positive Ageing

TESTIMONIALS

"I find the ACP session very beneficial as the explanations helps us to understand our father's wishes better." – Caregiver 1

"ACP is good as it allows the patient and family to be aware of possible future scenarios a dementia patient may face Knowing the patient's choices helps to relieve the carer's stress." – Caregiver 2

"I am glad I did ACP as it allows me to document down my preferences and this helps lessen the stress on my children to make decisions for me, in the event I am not able to decide for myself. " – Patient

WHO WE ARE

We are a team of healthcare professionals who are passionate in empowering patients to have a say about their current and future care plans.

Centre for Geriatric Medicine
A Partner of The Institute of Geriatrics & Active Ageing
Tan Tock Seng Hospital, Annex 2, Level B1
7 Jalan Tan Tock Seng, Singapore 308440

CONTACT:
appointment line: Tel: 6359 6100
Fax: 6359 6101

PECC-GRM-ED-2018-441-v1

CENTRE FOR GERIATRIC MEDICINE

ADVANCE CARE PLANNING IN DEMENTIA

The registered medical practitioner or the solicitor witnessing the EPA cannot be:

- ✗ the attorney(s);
- ✗ the spouses of the attorney(s);
- ✗ any person related by blood or marriage to the donor; or
- ✗ any person related by blood or marriage to the attorney(s).

**If the donor is physically incapable of signing, he/she may instruct other person to sign the EPA on his/her behalf. That person must sign the EPA under the direction and in the presence of the donor, also in the presence of a registered medical practitioner and a solicitor.

The person signing on the donor's behalf cannot be:

- ✗ the attorney(s);
- ✗ the spouses of the attorney(s);
- ✗ the registered medical practitioner or the solicitor witnessing the EPA; or
- ✗ the spouse of the registered medical practitioner or the solicitor.

If you want to obtain more information, or understand the law in relation to an Enduring Power of Attorney, please visit the Bilingual Laws Information System of the Department of Justice at **www.legislation.gov.hk/eng/index.htm**, or the Community Legal Information Centre (CLIC) of The University of Hong Kong website at **www.clic.org.hk/en**, which contains materials on EPA prepared by CLIC under the sponsorship of the Department of Justice.

Note: Please consult a practising solicitor prior to executing an EPA.

Designed by the Information Services Department

Enduring Powers of Attorney

General Information

Department of
JUSTICE


賽馬會耆智園
Jockey Club Centre for Positive Ageing
蚪尾
the tail Before

主辦機構

賽馬會耆智園 Jockey Club Centre for Positive Ageing

合辦機構

榮華慈善基金 Wing Wah Charity Foundation

協辦機構

The Hong Kong Geriatrics Society 香港老人科醫學會

腦退化症微電影《蚪尾》社區放映計劃
暨「輕訴・意願」晚期照顧分享會

嘉賓及講者：崔志文先生（賽馬會耆智園高級訓練顧問）
家屬照顧者
對象：腦退化症家屬照顧者、業界同工及有興趣之人士

劉玉翠　張崇德
主演

黃飛鵬
作品

報名請按此

What is our experience in JCCPA?

Discuss in Post-diagnostic Package

Copyright © Alzheimer Scotland 2015

FIVE Pillars Model in Scotland

- Supporting Community Connections - Support to maintain and develop social networks.
- Peer Support - From other people with dementia, their families and carers to help come to terms with ill and maintain wellbeing and resilience.
- Planning for Future Care - Support, when they are ready, to plan the shape of their future care from their own perspective together with those around them, developing a personal plan with their choices, hopes and aspirations which can guide professionals.
- Understanding the Illness and Managing the Symptoms - Support to come to terms with dementia and learn about self-management of the condition.
- Planning for Future Decision Making - Support to set up powers of attorney and other legal issues.

(Alzheimer's Scotland, 2015)

Discuss in Post-diagnostic Package

Planning for future decision-making

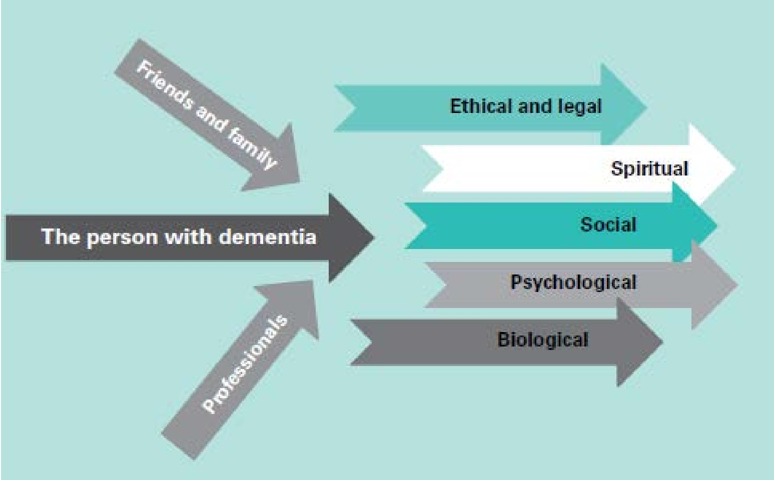
Supporting community connections

Understanding the illness and managing symptoms

Peer support

Planning for future care

MODELS OF DEMENTIA CARE: PERSON-CENTRED, PALLIATIVE AND SUPPORTIVE



A DISCUSSION PAPER FOR ALZHEIMER'S AUSTRALIA ON DEATH AND DEMENTIA
PAPER 35 JUNE, 2013
BY PROFESSOR JULIAN HUGHES

Three-dimensional discussion among
"Person with dementia, Family members & Professionals"

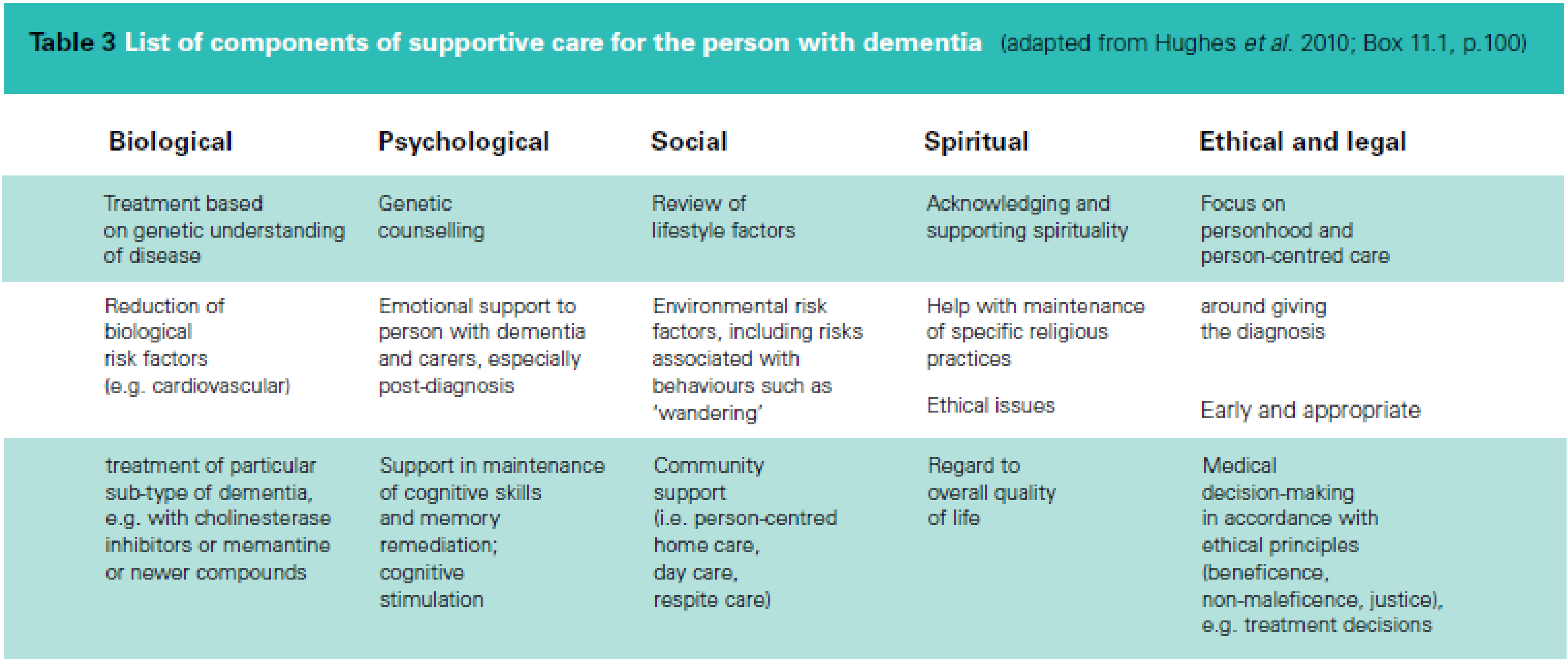


Table 3 List of components of supportive care for the person with dementia (adapted from Hughes *et al.* 2010; Box 11.1, p.100)

Biological	Psychological	Social	Spiritual	Ethical and legal
Treatment based on genetic understanding of disease	Genetic counselling	Review of lifestyle factors	Acknowledging and supporting spirituality	Focus on personhood and person-centred care
Reduction of biological risk factors (e.g. cardiovascular)	Emotional support to person with dementia and carers, especially post-diagnosis	Environmental risk factors, including risks associated with behaviours such as 'wandering'	Help with maintenance of specific religious practices Ethical issues	around giving the diagnosis Early and appropriate
treatment of particular sub-type of dementia, e.g. with cholinesterase inhibitors or memantine or newer compounds	Support in maintenance of cognitive skills and memory remediation; cognitive stimulation	Community support (i.e. person-centred home care, day care, respite care)	Regard to overall quality of life	Medical decision-making in accordance with ethical principles (beneficence, non-maleficence, justice), e.g. treatment decisions

Three-dimensional discussion

為參加者的生活作出規劃
This helps the client plan an engaged and fulfilled life following diagnosis

In partnership with

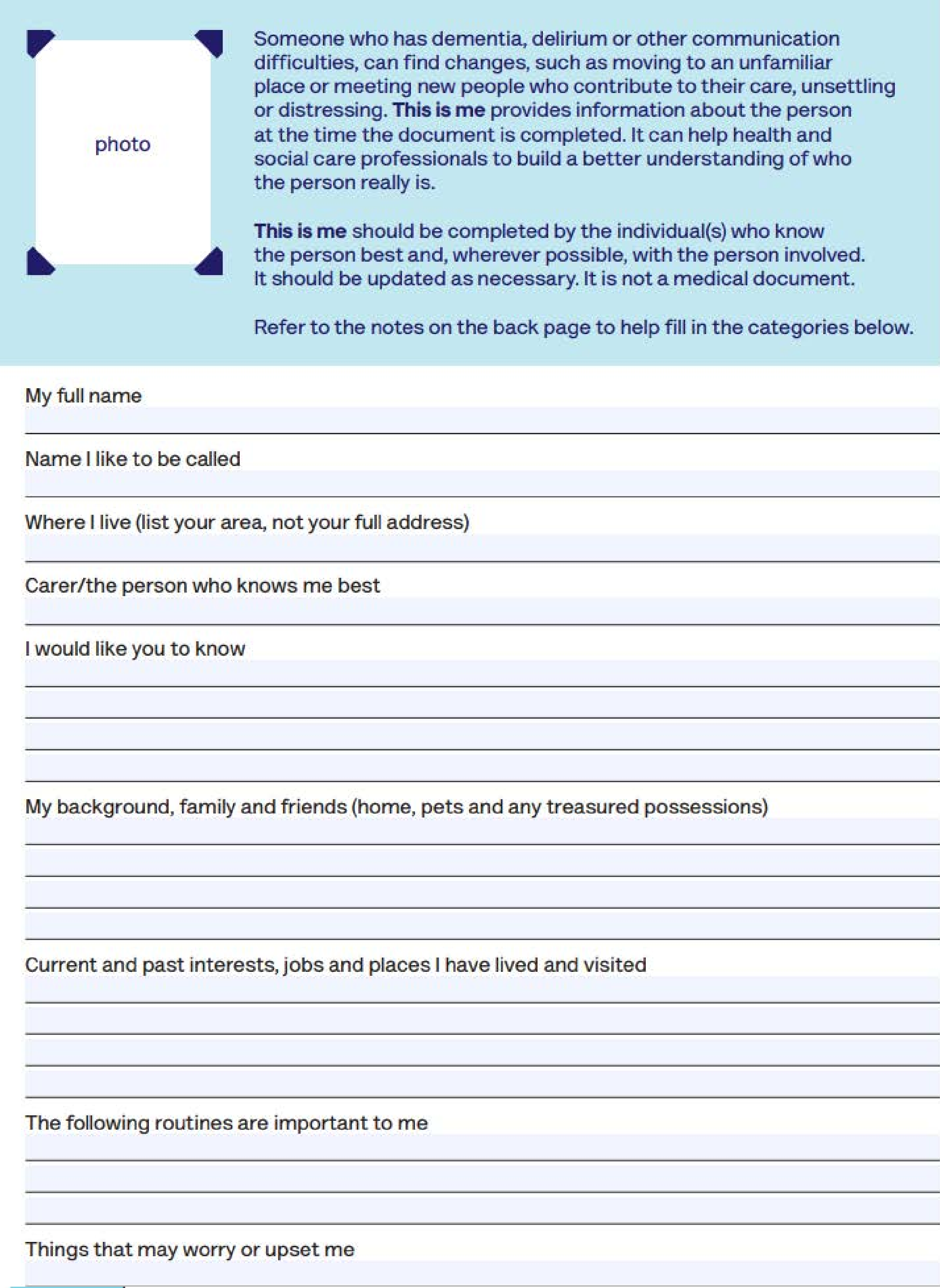
Royal College of Nursing

This is me

This leaflet will help you support me in an unfamiliar place.

My full name is

- Please place a photograph of yourself in the space provided.
- Turn to the back page of this form for guidance notes to help you complete **This is me**, including examples of the kind of information to include.
- Keep the completed form in a suitable place so that all care staff can see it and refer to it easily.



photo

Someone who has dementia, delirium or other communication difficulties, can find changes, such as moving to an unfamiliar place or meeting new people who contribute to their care, unsettling or distressing. **This is me** provides information about the person at the time the document is completed. It can help health and social care professionals to build a better understanding of who the person really is.

This is me should be completed by the individual(s) who know the person best and, wherever possible, with the person involved. It should be updated as necessary. It is not a medical document.

Refer to the notes on the back page to help fill in the categories below.

My full name

Name I like to be called

Where I live (list your area, not your full address)

Carer/the person who knows me best

I would like you to know

My background, family and friends (home, pets and any treasured possessions)

Current and past interests, jobs and places I have lived and visited

The following routines are important to me

Things that may worry or upset me

“I am the one whom I can decide”

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THIS IS 我是 ME我

第①冊

我是我・生命日誌本

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與耆同行腦退化症支援計劃

i 我想 PREFER說

第②冊

我想說・家屬自助手冊

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Dementia Care
Programme
賽馬會
與耆同行腦退化症支援計劃

i 我 CAN可以

第③冊

我可以・組員手冊

Jockey Club
Post-diagnostic
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Dementia Care
Programme
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與耆同行腦退化症支援計劃

我的意願 預設照顧計劃

?

你可預先在仍有決定能力時，與家人及醫護人員商討日後的醫療及照顧護理計劃（預設照顧計劃），表達自己對治療及個人照顧的意向，及日後決定會否簽署「預設醫療指示」（詳見後文）。

- 讓自己和家人更了解晚期照顧
- 思考合適的照顧方法
- 避免接受自己所不願接受的醫療程序
- 預早與家人溝通，讓家人較明白及尊重自己的意願
- 讓家人代你作醫療決定時更輕鬆、安心

?

為何要預先計劃？

?

有曾經試過患上重病嗎？當時的情況是怎樣？感受？之後，自己有沒有對一些事情有所改觀？

預設照顧計劃（續）

?

試想象當遇到以下情況，自己會想有怎麼樣的安排，好讓家人和醫護人員尊重和執行我的意願？

當有嚴重危疾或病情到了末期，希望醫生或家人 ...

○ 向我如實告知病情以及往後可能的進展

○ 不需要向我告知病情，並由他們為我作醫療決定

當失去自決能力 ...

- 我希望授權於 ____________（家人／親友／其他人的姓名），成為我的照顧代理決策人。我希望醫生可以與他／她商量有關我的任何醫療照顧決定，並請他／她代我作出最合適的決定。
- 他／她的個人資料：

姓名 ____________

關係 ____________

電話 ____________

地址 ____________

「持久授權書」

持久授權書必須採用《持久授權書（訂明格式）規例》（香港法例第 501A 章） 附表所載的訂明表格。

- **表格 1** 適用於指定一名受權人
- **表格 2** 適用於指定多於一名受權人

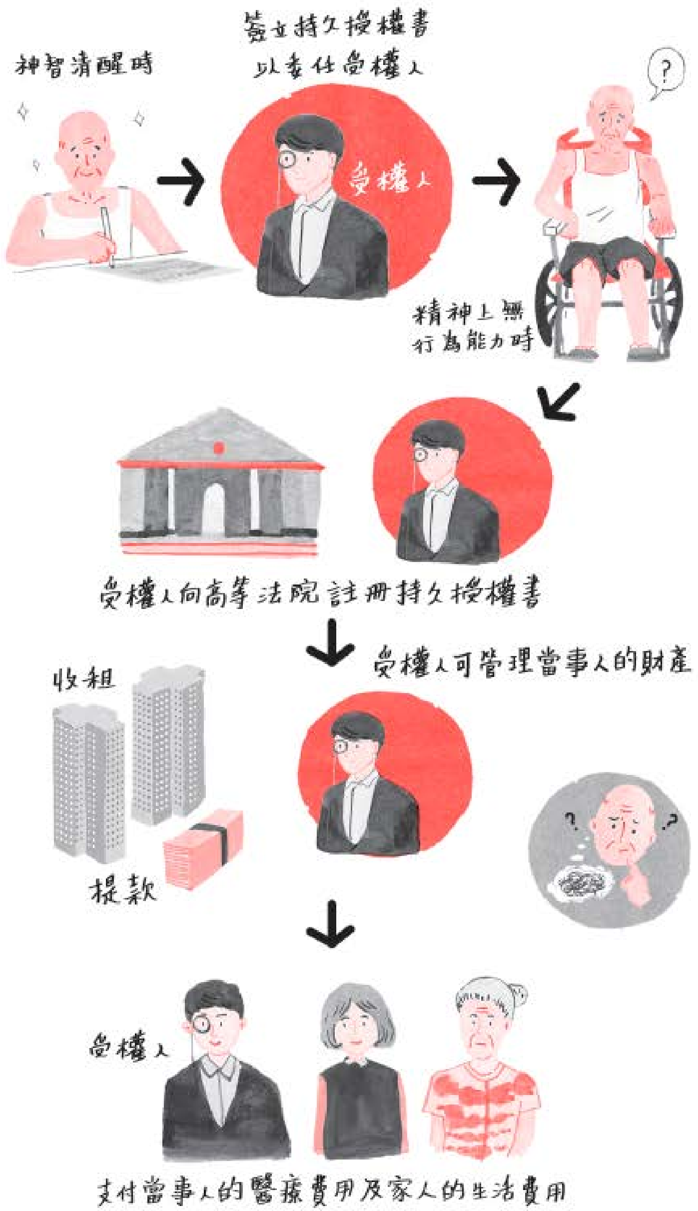
?

容許授權人在精神上有能力時，委任受權人（家屬）。授權人日後精神上無能力執行指令時，受權人便能協助處理授權人的財務，這對腦退化症人士尤其重要。

「持久授權書」例子

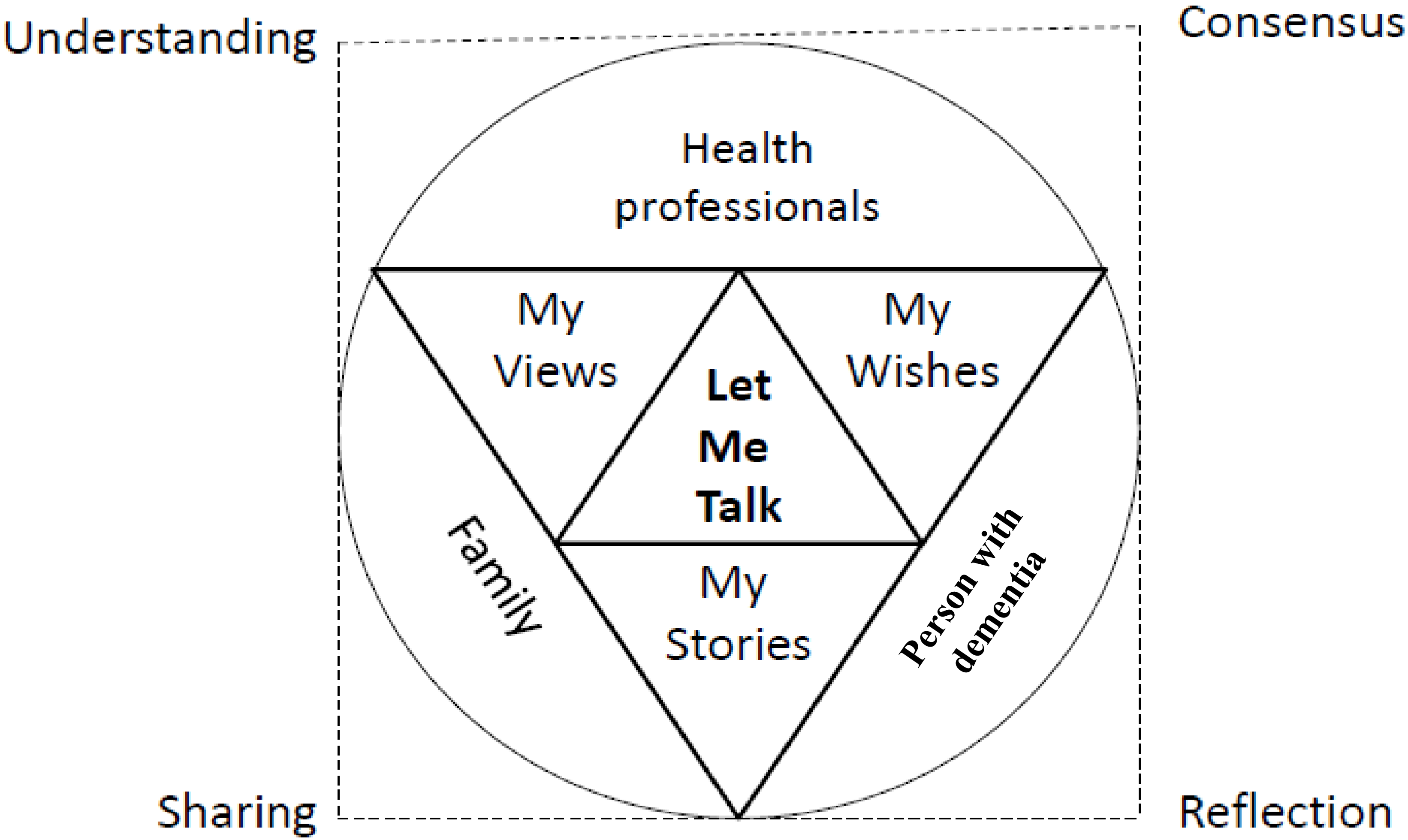
當我因腦退化症或因病重而變得神志不清，不能處理自己的財產時，我希望由 __________ 成為我的「持久授權書」的受權人，代我處理財政事宜，繼續用我的財產照顧本人及家人。因為：

- 「持久授權書」必須在一位醫生及一位律師見證下簽署，以證明當事人在簽署時「精神上有能力行事」。見證的醫生及律師兩人可以不必同時在場，但醫生見證之後，律師需要在 28 日內見證。
- 為避免嫌疑及利益衝突，以下人士即使本身是醫生或律師，也不可擔任該「持久授權書」的見證人：1. 當事人的配偶 2. 當事人的親屬 3. 受權人或其配偶或親屬
- 關於「持久授權書」的內容和詳情，請向相關律師查詢，並作最終決定。



Psychosocial model to ACP

Chan, H. Y., & Pang, S. M. (2010). Let me talk–an advance care planning programme for frail nursing home residents. *Journal of Clinical Nursing*, *19*(21-22), 3073-3084.



Online Caregiver Platform and E-learning

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Dementia Care Programme

專職及
前線同工

公眾人士

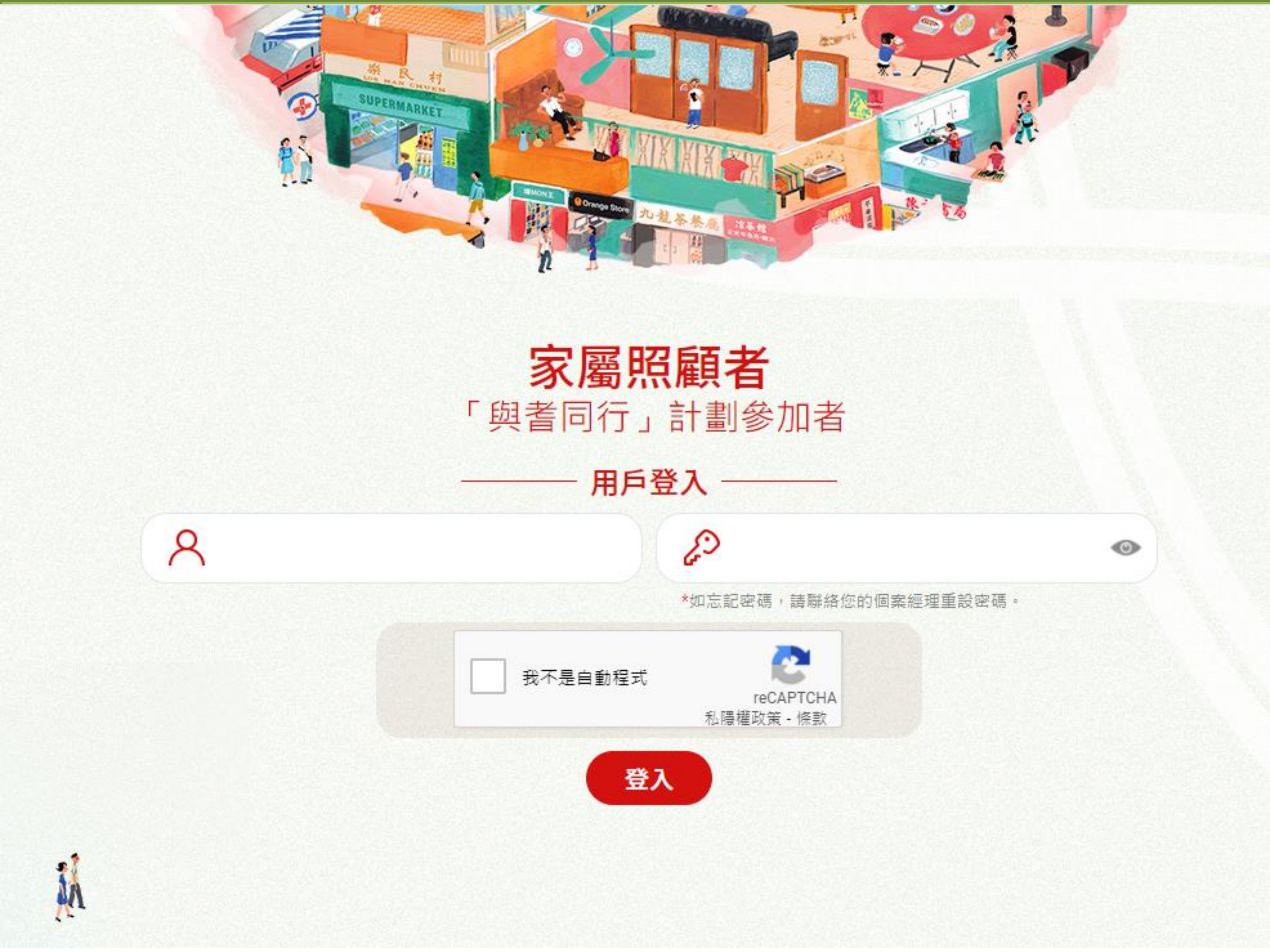
家屬照顧者

捐助機構：
香港賽馬會慈善信託基金
The Hong Kong Jockey Club Charities Trust
同心同步同進 RIDING HIGH TOGETHER

主辦機構： 賽馬會耆智園 Jockey Club Centre for Positive Ageing
香港中文大學醫學院 CU Medicine Faculty of Medicine The Chinese University of Hong Kong

合辦機構： 基督教香港信義會社會服務部 Evangelical Lutheran Church Social Service - Hong Kong
靈實協會 HAVEN OF HOPE
九龍樂善堂

https://pdsp.hk/tc/home/index.html



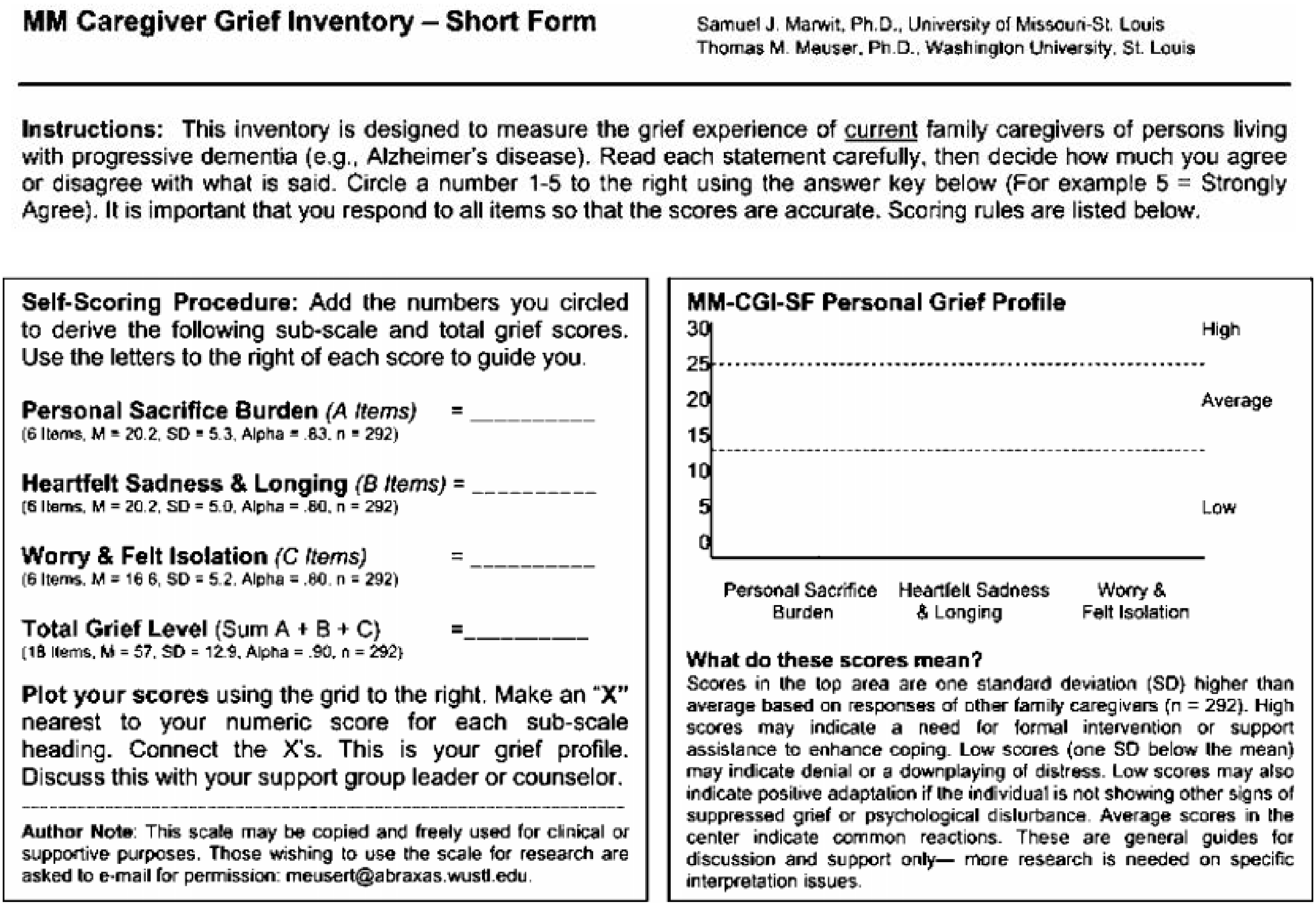
家屬照顧者

「與耆同行」計劃參加者

用戶登入

*如忘記密碼，請聯絡您的個案經理重設密碼。

TABLE 1 Marwit-Meuser Caregiver Grief Inventory–Short Form (MM-CGI-SF)



MM Caregiver Grief Inventory – Short Form

Samuel J. Marwit, Ph.D., University of Missouri-St. Louis
Thomas M. Meuser, Ph.D., Washington University, St. Louis

Instructions: This inventory is designed to measure the grief experience of current family caregivers of persons living with progressive dementia (e.g., Alzheimer's disease). Read each statement carefully, then decide how much you agree or disagree with what is said. Circle a number 1-5 to the right using the answer key below (For example 5 = Strongly Agree). It is important that you respond to all items so that the scores are accurate. Scoring rules are listed below.

Self-Scoring Procedure: Add the numbers you circled to derive the following sub-scale and total grief scores. Use the letters to the right of each score to guide you.

Personal Sacrifice Burden *(A Items)* = __________
(6 Items, M = 20.2, SD = 5.3, Alpha = .83, n = 292)

Heartfelt Sadness & Longing *(B Items)* = __________
(6 Items, M = 20.2, SD = 5.0, Alpha = .80, n = 292)

Worry & Felt Isolation *(C Items)* = __________
(6 Items, M = 16.6, SD = 5.2, Alpha = .80, n = 292)

Total Grief Level (Sum A + B + C) =__________
(18 Items, M = 57, SD = 12.9, Alpha = .90, n = 292)

Plot your scores using the grid to the right. Make an "X" nearest to your numeric score for each sub-scale heading. Connect the X's. This is your grief profile. Discuss this with your support group leader or counselor.

Author Note: This scale may be copied and freely used for clinical or supportive purposes. Those wishing to use the scale for research are asked to e-mail for permission: meusert@abraxas.wustl.edu.

MM-CGI-SF Personal Grief Profile

What do these scores mean?
Scores in the top area are one standard deviation (SD) higher than average based on responses of other family caregivers (n = 292). High scores may indicate a need for formal intervention or support assistance to enhance coping. Low scores (one SD below the mean) may indicate denial or a downplaying of distress. Low scores may also indicate positive adaptation if the individual is not showing other signs of suppressed grief or psychological disturbance. Average scores in the center indicate common reactions. These are general guides for discussion and support only— more research is needed on specific interpretation issues.

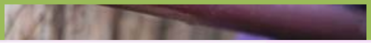
ANSWER KEY

1 = Strongly Disagree // 2 = Disagree // 3 = Somewhat Agree // 4 = Agree // 5 = Strongly Agree

1	I've had to give up a great deal to be a caregiver.	1	2	3	4	5	A
2	I feel I am losing my freedom.	1	2	3	4	5	A
3	I have nobody to communicate with.	1	2	3	4	5	C
4	I have this empty, sick feeling knowing that my loved one is “gone”.	1	2	3	4	5	B
5	I spend a lot of time worrying about the bad things to come.	1	2	3	4	5	C
6	Dementia is like a double loss…I've lost the closeness with my loved one and connectedness with my family.	1	2	3	4	5	C
7	My friends simply don't understand what I'm going through.	1	2	3	4	5	C
8	I long for what was, what we had and shared in the past.	1	2	3	4	5	B
9	I could deal with other serious disabilities better than with this.	1	2	3	4	5	B
10	I will be tied up with this for who knows how long.	1	2	3	4	5	A
11	It hurts to put her/him to bed at night and realize that she/he is "gone"	1	2	3	4	5	B
12	I feel very sad about what this disease has done.	1	2	3	4	5	B
13	I lay awake most nights worrying about what's happening and how I'll manage tomorrow.	1	2	3	4	5	C
14	The people closest to me do not understand what I'm going through.	1	2	3	4	5	C
15	I've lost other people close to me, but the losses I'm experiencing now are much more troubling.	1	2	3	4	5	B
16	Independence is what I've lost…I don't have the freedom to go and do what I want.	1	2	3	4	5	A
17	I wish I had an hour or two to myself each day to pursue personal interests.	1	2	3	4	5	A
18	I'm stuck in this caregiving world and there's nothing I can do about it.	1	2	3	4	5	A

腦退化症患者家屬照顧者的哀傷情緒自助手冊

Chinese Version of the Marwit–Meuser Caregiver Grief Inventory



兩位學者經多年來走訪不同配偶照顧者及子女照顧者，研發了以下的評估工具，可讓照顧者以自行填寫的方式去了解自己現時的照顧哀傷程度及範疇。

以下的句子都是來自腦退化症照顧者敘述的經歷，請在閱讀每一句後，根據自己有多認同句子描寫的感受圈出分數，(1)表示「非常不同意」，(5)表示「非常同意」。

句子	非常唔同意(1)	唔同意(2)	有啲同意(3)	同意(4)	非常同意(5)	範疇
1. 為咗照顧患者，我要放棄好多嘢。	1	2	3	4	5	A
2. 我覺得自己逐漸失去自由。	1	2	3	4	5	A
3. 我同唔到任何人傾訴。	1	2	3	4	5	C
4. 當我知道我親愛嘅人（患者）已經「唔再係以前嘅佢」，我就覺得好空虛，好難過。	1	2	3	4	5	B
5. 我成日擔心啲可能會發生嘅壞事。	1	2	3	4	5	C
6. 腦退化症令我有雙重損失，既令我同我親愛嘅人（患者）唔再咁親近，又令我同屋企人疏遠咗。	1	2	3	4	5	C
7. 我啲朋友根本唔明白我而家嘅經歷。	1	2	3	4	5	C
8. 我好掛住以前，掛住我哋曾經一齊擁有過、分享過嘅嘢。	1	2	3	4	5	B
9. 換轉係另一啲頑障，我可以應付得好啲。	1	2	3	4	5	B
10.呢樣嘢將會一直纏擾住我，唔知幾時先完。	1	2	3	4	5	A
11.夜晚睇住佢瞓，諗到佢已經「唔再係佢」，我就好傷心。	1	2	3	4	5	B
12.呢個病所造成嘅影響令我好難過。	1	2	3	4	5	B
13.我好多晚都瞓唔着，擔心發生緊嘅事，同埋我聽日可以點算。	1	2	3	4	5	C
14.我至親嘅人都唔明白我經歷緊嘅嘢。	1	2	3	4	5	C
15.我曾經失去過啲好親嘅人，但而家呢種「失去」嘅經歷更加令人困擾。	1	2	3	4	5	B
16.我失去咗獨立同自由，做唔到我想做嘅嘢，去唔到我想去嘅地方。	1	2	3	4	5	A
17.我好想每日都有番一，兩個鐘做吓自己鍾意做嘅嘢。	1	2	3	4	5	A
18.我個世界只剩低要照顧患者，我覺得好困身，但又無可奈何。	1	2	3	4	5	A

現在，你可以依據句子右面的英文字母指示，將你已圈的分數加總，以計算哀傷情緒的程度。

(A) 個人犧牲的負擔(共6句) = ____________分

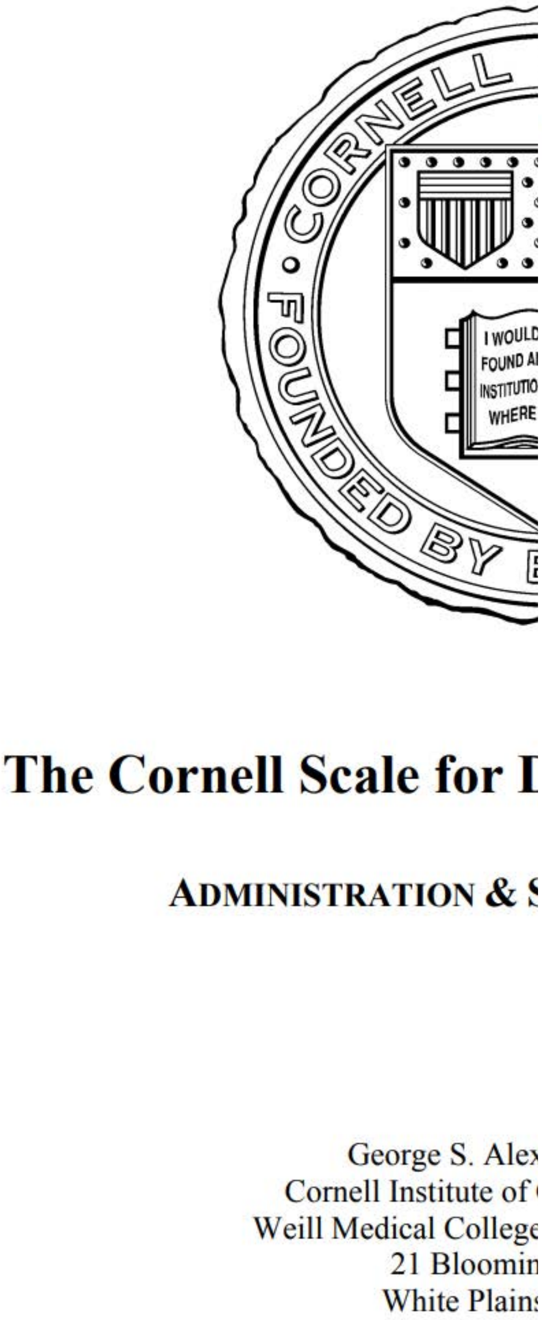
(B) 憂傷及懷緬(共6句) = ____________分

(C) 擔憂及孤獨感(共6句) = ____________分

(A+B+C) 哀傷總分 = ____________分

外國的研究顯示，西方的腦退化症患者家屬的分項(A或B或C項)分數在11至26分之間，總分分數在44分至70分之間；香港或華人的分數可能有所不同，尚需進一步研究。

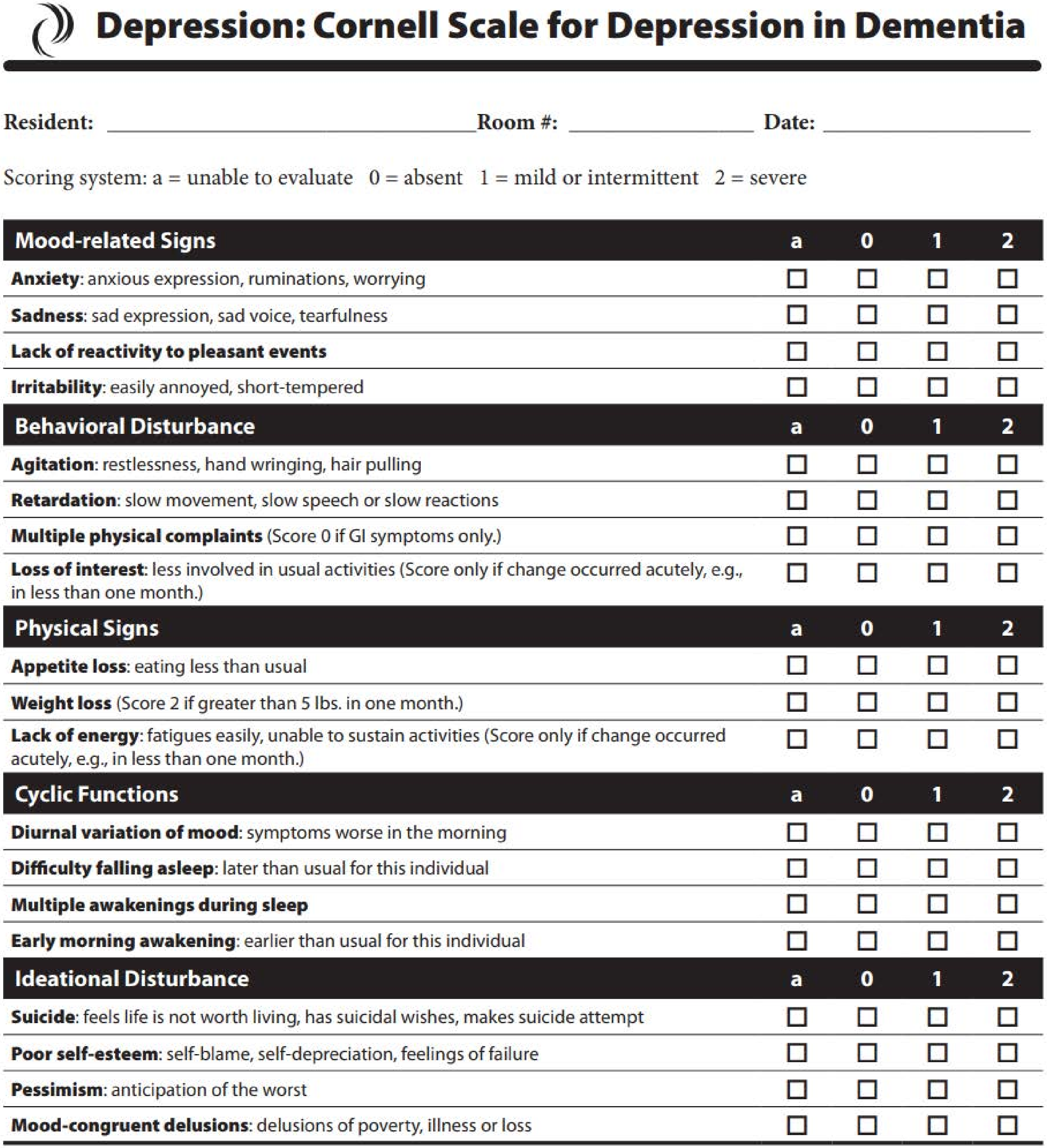
若你覺得你在照顧親人的過程中有哀傷的情緒，我們希望以下的介紹及小練習能夠協助你從回顧與前瞻中尋找哀傷的意義。



The Cornell Scale for D

ADMINISTRATION & S

George S. Alex
Cornell Institute of
Weill Medical College
21 Bloomin
White Plain



Depression: Cornell Scale for Depression in Dementia

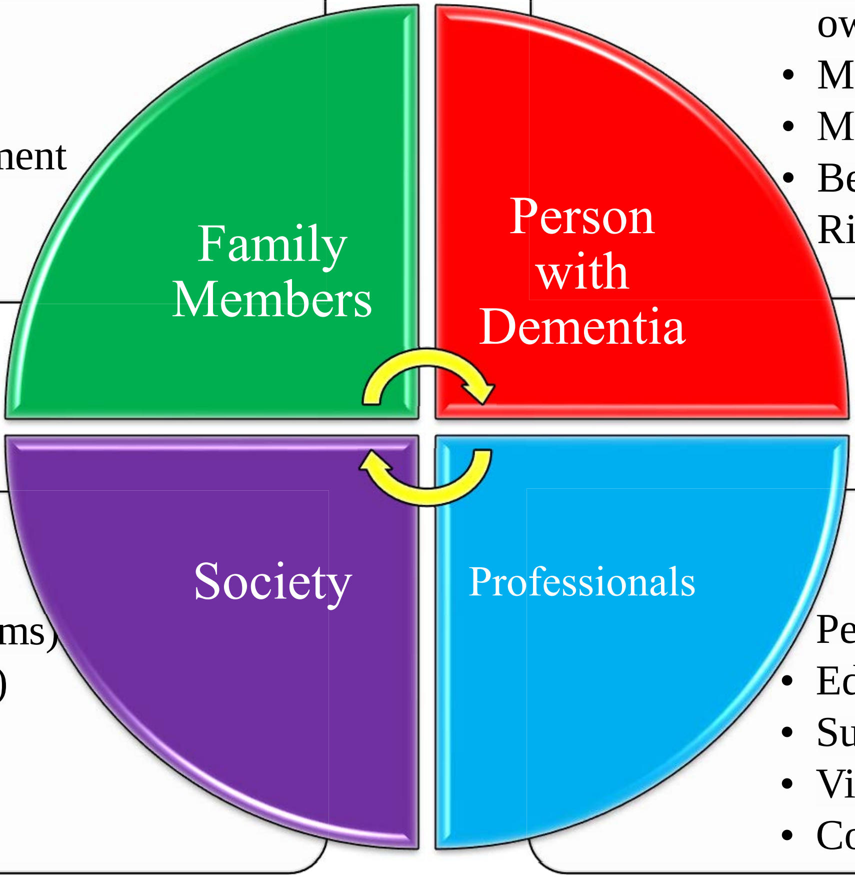
Resident: ______________________ **Room #:** __________ **Date:** ____________

Scoring system: a = unable to evaluate   0 = absent   1 = mild or intermittent   2 = severe

Mood-related Signs	a	0	1	2
Anxiety: anxious expression, ruminations, worrying	☐	☐	☐	☐
Sadness: sad expression, sad voice, tearfulness	☐	☐	☐	☐
Lack of reactivity to pleasant events	☐	☐	☐	☐
Irritability: easily annoyed, short-tempered	☐	☐	☐	☐
Behavioral Disturbance	**a**	**0**	**1**	**2**
Agitation: restlessness, hand wringing, hair pulling	☐	☐	☐	☐
Retardation: slow movement, slow speech or slow reactions	☐	☐	☐	☐
Multiple physical complaints (Score 0 if GI symptoms only.)	☐	☐	☐	☐
Loss of interest: less involved in usual activities (Score only if change occurred acutely, e.g., in less than one month.)	☐	☐	☐	☐
Physical Signs	**a**	**0**	**1**	**2**
Appetite loss: eating less than usual	☐	☐	☐	☐
Weight loss (Score 2 if greater than 5 lbs. in one month.)	☐	☐	☐	☐
Lack of energy: fatigues easily, unable to sustain activities (Score only if change occurred acutely, e.g., in less than one month.)	☐	☐	☐	☐
Cyclic Functions	**a**	**0**	**1**	**2**
Diurnal variation of mood: symptoms worse in the morning	☐	☐	☐	☐
Difficulty falling asleep: later than usual for this individual	☐	☐	☐	☐
Multiple awakenings during sleep	☐	☐	☐	☐
Early morning awakening: earlier than usual for this individual	☐	☐	☐	☐
Ideational Disturbance	**a**	**0**	**1**	**2**
Suicide: feels life is not worth living, has suicidal wishes, makes suicide attempt	☐	☐	☐	☐
Poor self-esteem: self-blame, self-depreciation, feelings of failure	☐	☐	☐	☐
Pessimism: anticipation of the worst	☐	☐	☐	☐
Mood-congruent delusions: delusions of poverty, illness or loss	☐	☐	☐	☐

Advance care planning in psychosocial perspectives

Understanding the needs of different stakeholders



Family Members

- Release the burden of decision making
- Build-up closer relationship
- Expectation management
- Grief, loss and bereavement

Person with Dementia

- Understand further his/her own condition
- Minimize uncertainty
- Make one’s own choice
- Being listened (Empower)
- Rights and dignity

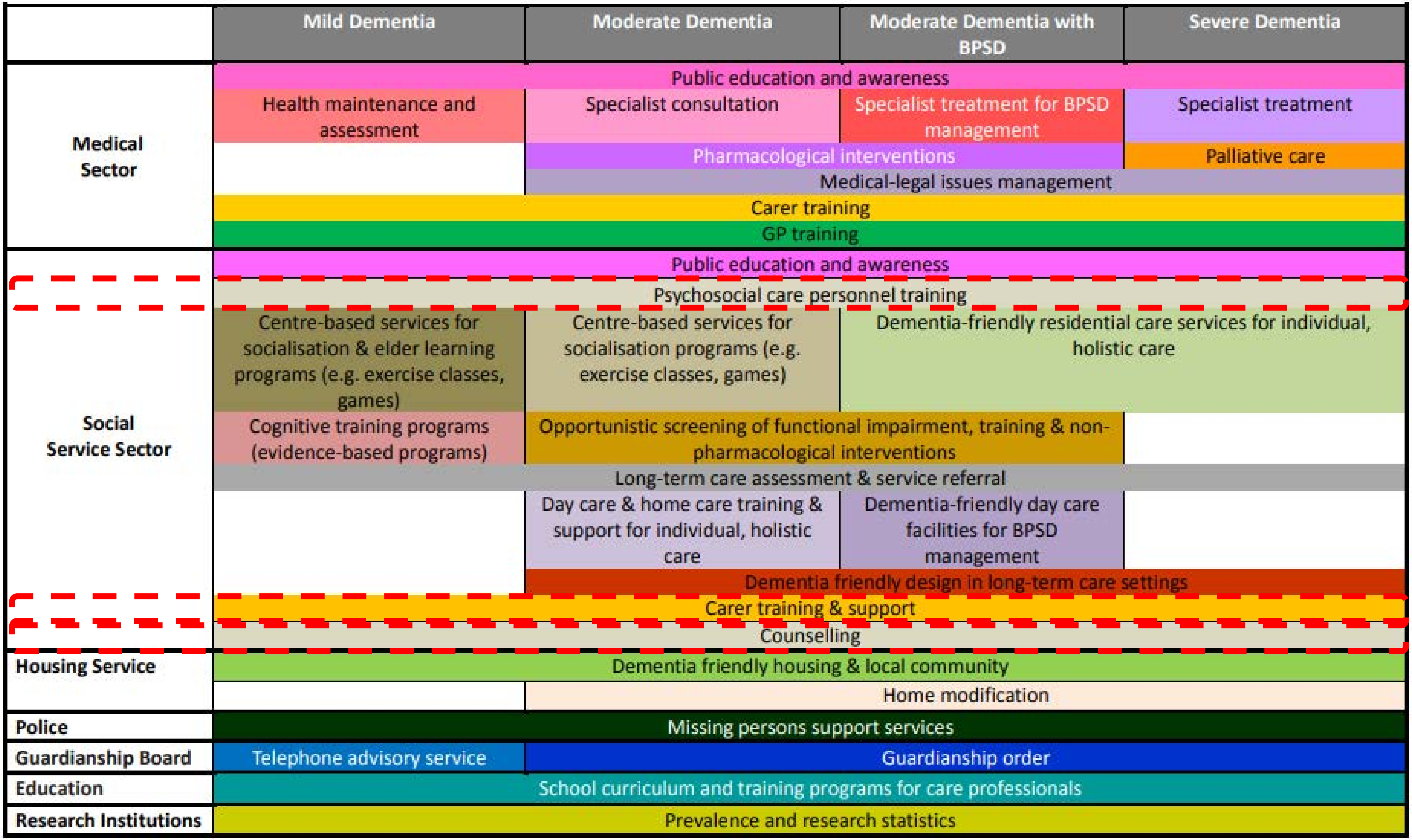
Society

- Public education (norms)
- Open-minded (Taboo)
- Transparency of information (culture)
- Integrate with policy

Professionals

- Person-centred care
- Education and familiar to
- Sufficient Time (Facilitate)
- Vital interactions (Enable)
- Co-ordinate stakeholders

Figure 4.16 Typical Service Components for Persons with Dementia



<table>
<tr><th></th><th>Mild Dementia</th><th>Moderate Dementia</th><th>Moderate Dementia with BPSD</th><th>Severe Dementia</th></tr>
<tr><td rowspan="6">Medical Sector</td><td colspan="4">Public education and awareness</td></tr>
<tr><td>Health maintenance and assessment</td><td>Specialist consultation</td><td>Specialist treatment for BPSD management</td><td>Specialist treatment</td></tr>
<tr><td></td><td colspan="2">Pharmacological interventions</td><td>Palliative care</td></tr>
<tr><td></td><td colspan="3">Medical-legal issues management</td></tr>
<tr><td colspan="4">Carer training</td></tr>
<tr><td colspan="4">GP training</td></tr>
<tr><td rowspan="9">Social Service Sector</td><td colspan="4">Public education and awareness</td></tr>
<tr><td colspan="4">Psychosocial care personnel training</td></tr>
<tr><td>Centre-based services for socialisation & elder learning programs (e.g. exercise classes, games)</td><td>Centre-based services for socialisation programs (e.g. exercise classes, games)</td><td colspan="2">Dementia-friendly residential care services for individual, holistic care</td></tr>
<tr><td>Cognitive training programs (evidence-based programs)</td><td colspan="2">Opportunistic screening of functional impairment, training & non-pharmacological interventions</td><td></td></tr>
<tr><td colspan="4">Long-term care assessment & service referral</td></tr>
<tr><td></td><td>Day care & home care training & support for individual, holistic care</td><td>Dementia-friendly day care facilities for BPSD management</td><td></td></tr>
<tr><td></td><td colspan="3">Dementia friendly design in long-term care settings</td></tr>
<tr><td colspan="4">Carer training & support</td></tr>
<tr><td colspan="4">Counselling</td></tr>
<tr><td rowspan="2">Housing Service</td><td colspan="4">Dementia friendly housing & local community</td></tr>
<tr><td></td><td colspan="3">Home modification</td></tr>
<tr><td>Police</td><td colspan="4">Missing persons support services</td></tr>
<tr><td>Guardianship Board</td><td>Telephone advisory service</td><td colspan="3">Guardianship order</td></tr>
<tr><td>Education</td><td colspan="4">School curriculum and training programs for care professionals</td></tr>
<tr><td>Research Institutions</td><td colspan="4">Prevalence and research statistics</td></tr>
</table>

賽馬會耆智園
Jockey Club Centre for Positive Ageing

(Food and Health Bureau, 2017)

Conclusion

DemenTitude - The proper caring attitude to people with dementia

- Persons with dementia could not do?
- Persons with dementia could not say?
- Persons with dementia could not express?

Or actually…

- Persons with dementia were not being trusted;
- Persons with dementia were not being respected;
- Persons with dementia were not being listened to;

So…

- It is a matter of meaningful engagement but not being engaged only
- It is a matter of living but not a matter of lives only;
- It is a matter of caring but not a matter of care only!

Truly listen to their voice and synchronize with their perception of world~~~

Think over what people with dementia "CAN" but not only what they "CAN'T" !

Chui, K. C. M., & Lam, C. M. (2019). " DEMENTITUDE" from the Voice of Dementia: Promoting Proper Caring Attitude to the Person with Dementia in Chinese Society, *Alzheimer's and Dementia, 15*(7), P1562-P1563.

ACP is a matter of “CHOICE” !

https://www.ioa.cuhk.edu.hk/zh-tw/casebook/themes

賽馬會安寧頌

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Thanks for your attention

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