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

International Conference on
Community End-of-Life Care
Sustainable Development and New Frontier
June 17-18, 2021 (Hong Kong Time, GMT+8) | Virtual Conference

"Listen to Our Voice"

Subjective Views of People with Dementia and their Caregivers for Implementation of Advance Care Planning in Hong Kong

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賽馬會耆智園
Jockey Club Centre for Positive Ageing

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.

Scoring can be referenced to p.51

Dementia Innovation Readiness in Cities

Overall Scores

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


Access to Care Scores
HK is ranked at the 25th
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

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

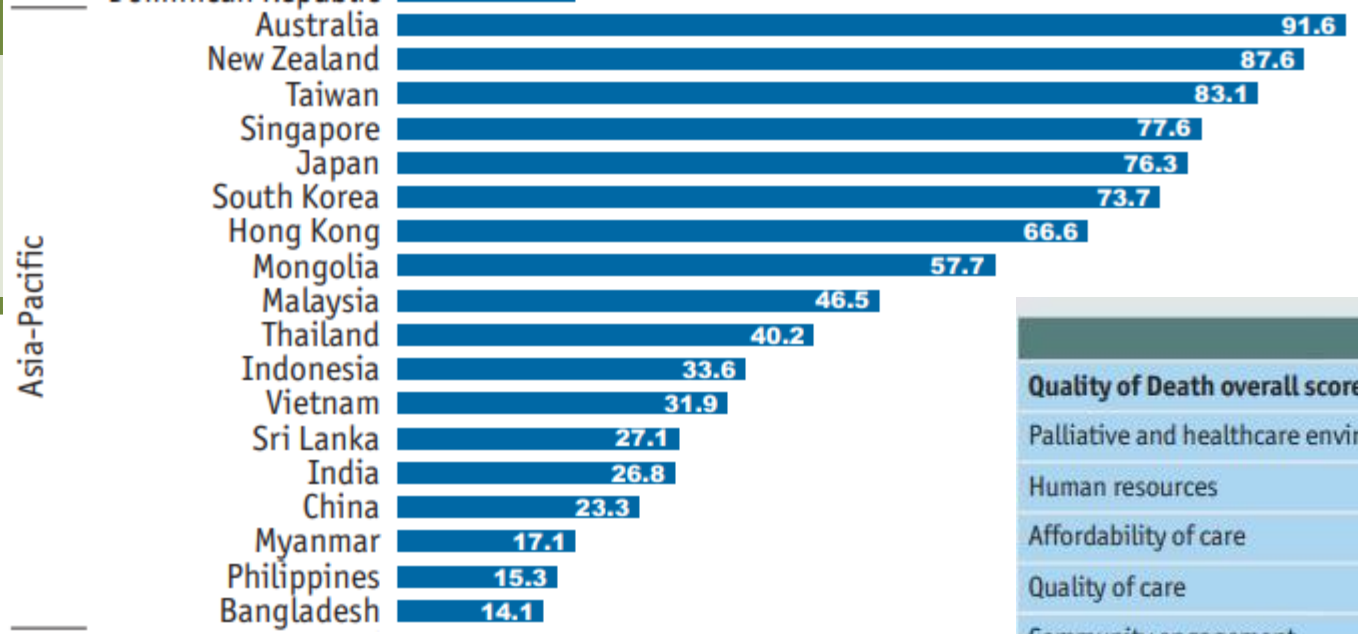
Figure 1.2

2015 Quality of Death Index—Overall scores

Rank	Country	
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

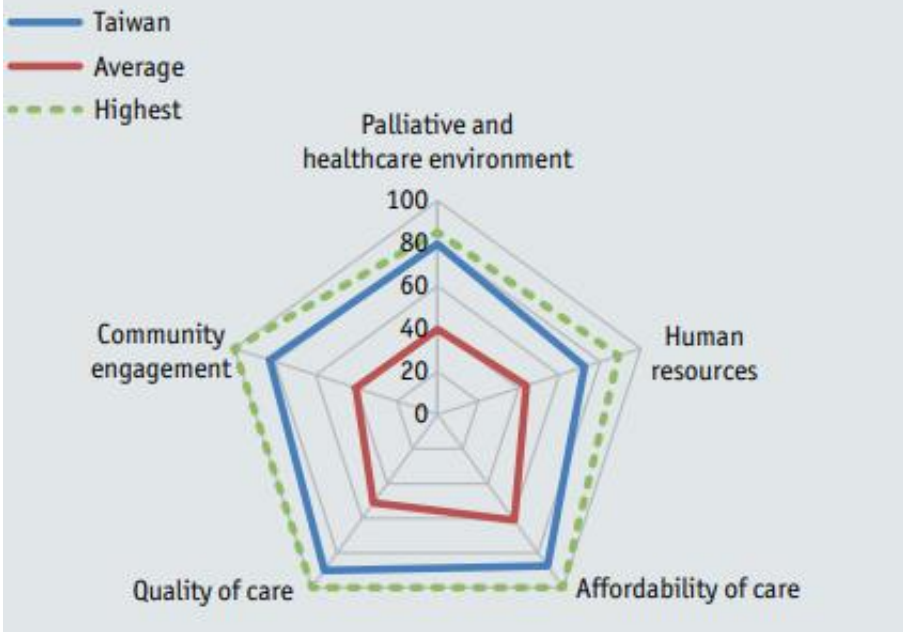
Hong Kong is ranked at

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



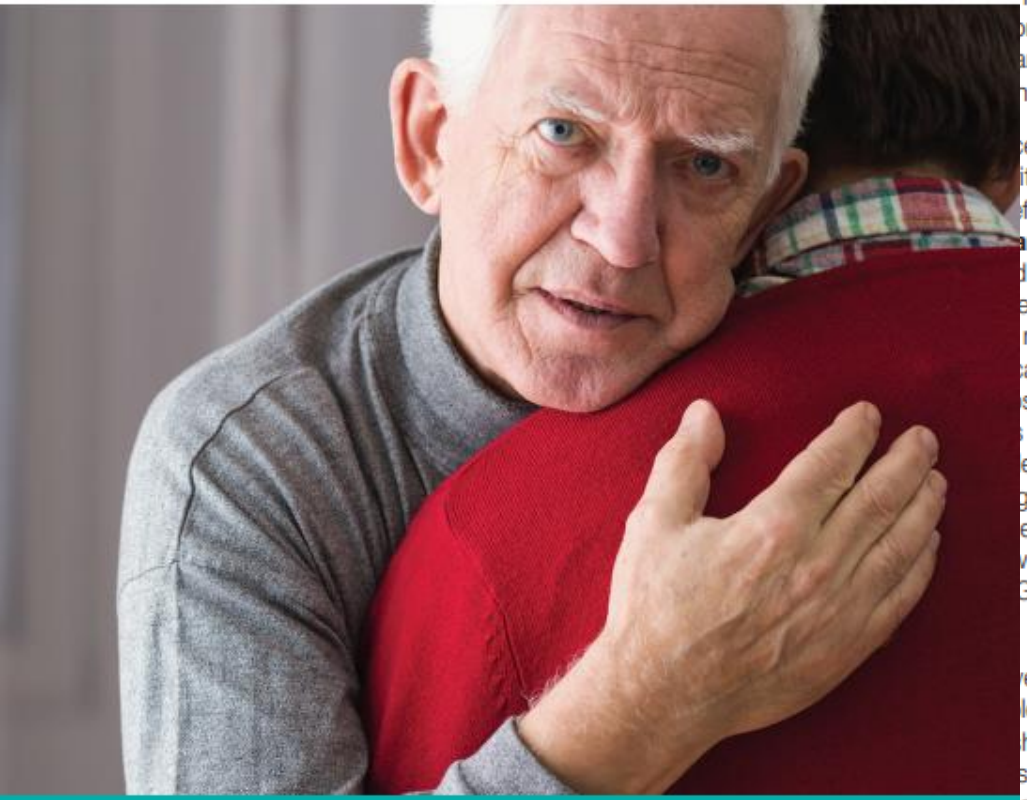
① Palliative and healthcare environment category (20% weighting) → 28th in rank
② Human resources category (20% weighting) → 20th in rank
③ Affordability of care category (20% weighting) → 18th in rank
④ Quality of care category (30% weighting) → 20th in rank
⑤ Community engagement (10% weighting) → 38th in rank

Figure 4.16 Typical Service Components for Persons with Dementia

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

(Food and Health Bureau, 2017)

Palliative Care
AND DEMENTIA



Dementia Australia

Paper Number 43

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

dementia australia

Advance care planning

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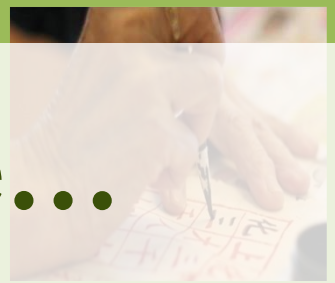
People with dementia may require care in different settings. It is important that a person's ACP is transferred to all relevant settings. A range of strategies can assist with this including:

- 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…

(1) Good and trustful relationship between stakeholders

- ✓ *I am doing something related to "Relationship building and not task-oriented"*
- ✓ *I am ready to have a family meeting when you are here…*
- ✓ *Please trust my mental capacity in a changing mode rather than a static mode, I am not always in confusion and chaos…*
- ✓ *Voice out my wishes list and insisted in my end-of-life decisions (AD)*

(2) Clear and easy-to-understand information with professional advice

- ✓ *I want to have a professional consultation in this part…*
- ✓ *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 am just in front of you…*
- ✓ *Clarify with me about my awareness of understanding my progress of dementia and my choices…*

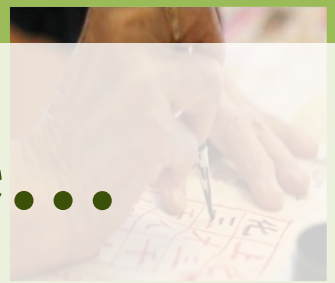
(Bram et al., 2018; Chui, 2018; Piers et al., 2018)

Listen to me…

(3) Special communication skills and preparation of visual materials;

- ✓ *Stop going on while I am not in a good condition…*
- ✓ *It will be good if you can provide me with suitable levels of information and rhythm as well as relevant materials to facilitate our discussion…*
- ✓ *Please kindly give me enough time to discuss and think over that…*
- ✓ *Structured implementation of discussed parts and clarify with my preference/decision whenever is possible…*
- ✓ *Ongoing detect me any fears or concerns in Advanced Care Planning..*
- ✓ *I am happy if you can walk around with me so that I can remember what I should tell you…*

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


Listen to me…

(4) Systematic records and ongoing documentation

- ✓ *Support me to initiate the topic and talk to me at the right time in my journey living with dementia…Start as soon as possible when I am OK…*
- ✓ *Get my consent with mutual agreement* as we should *consider with ethical considerations, right?... at least my professional reminded me…*
- ✓ *Help me documented and ask me back later on whenever is necessary. Show me the records when time goes by…*

(5) Relaxed places and dementia friendly environment

- ✓ *Understand my emotional status and my readiness of me as well as my family members…show empathy to what I am experiencing (context)…*
- ✓ *I preferred to make it at home or familiar places, don't you…*
- ✓ *I love talking ACP with a relax atmosphere…*
- ✓ *Consider my personality and my background again, like getting through my life story and please look at this (This is ME)…*

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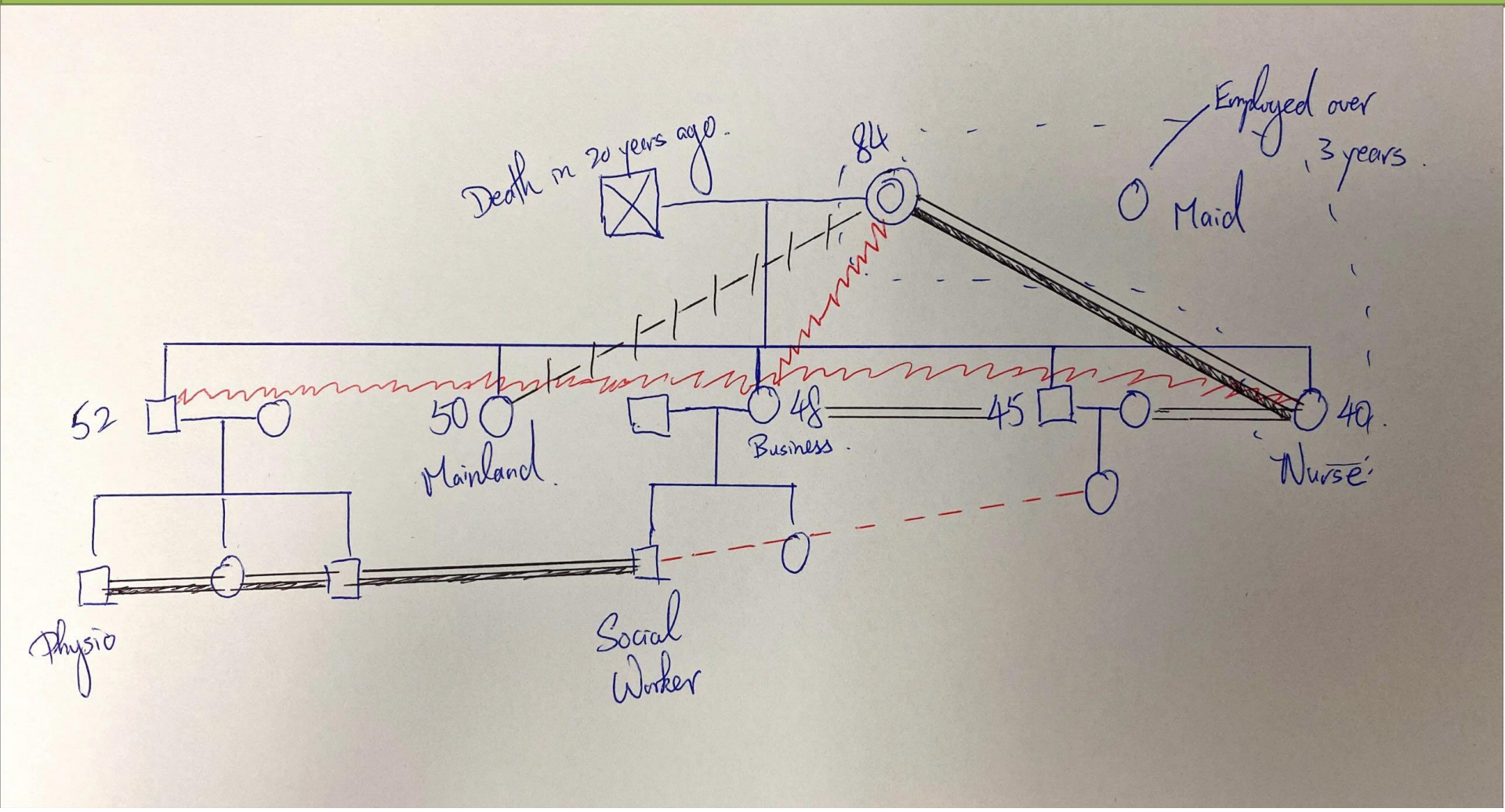
(Bram et al., 2018; Chui, 2018; Piers et al., 2018)

Listen to them (family members)

- What is ACP and how can I access this application…
- Mention 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 our dynamics before the discussion…

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

Example: Genogram and family functioning with dynamics



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)

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.*

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(HA, 2020)

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.*

(HA, 2020)

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

(HA, 2016)

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.

Tan Tock Seng HOSPITAL

https://www.ttsh.com.sg/Patients-and-Visitors/Medical-Services/advance-care-planning/Pages/default.aspx

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

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appointment line: Tel: 6359 6100
Fax: 6359 6101

Tan Tock Seng HOSPITAL

PECC-GRM-ED-2018-441-v1

CENTRE FOR GERIATRIC MEDICINE

ADVANCE CARE PLANNING IN DEMENTIA

賽馬會耆智園 Jockey Club Centre for Positive Ageing

(Tan Tock Seng, 2020)

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

(Department of Justice, 2020)


賽 馬 會 耆 智 園
Jockey Club Centre for Positive Ageing
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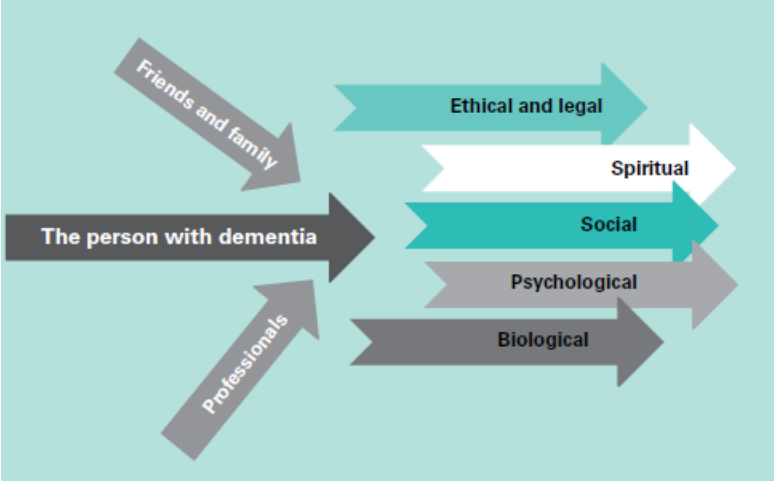
Discuss in Post-diagnostic Package

Discuss in Post-diagnostic Package

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

In partnership with

Royal College of Nursing

Alzh
So

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”

賽馬會
與耆同行
腦退化症支援計劃
Jockey Club
Post-diagnostic Support in
Dementia Care Programme

目錄

好好認識我自己

我們邀請你創作這本日誌，讓大家知道：你的故事、你的背景、你的喜好、你的意願……也鼓勵你邀請與你同行的家人，一起參與這本書的創作。

我們相信，當你完成這本日誌，你會發現，自己重整了過去的你，認識了現在的你，計劃了將來的你！

回望自己的人生，學習欣賞自己曾付出的努力，以感恩平安的心去看待人生中的好與壞，接納自己的限制，用平常心去看待所遇的人和事，可以幫助我們更坦然地面對生老病死與困境。

期望你保留這本日誌，與身邊關懷你的人和醫療護理團隊分享，讓其他人更了解你和你的意願。

在人生不同階段中，你和家人可適時更新這本書的內容。

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）。

為何要預先計劃？

- 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

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

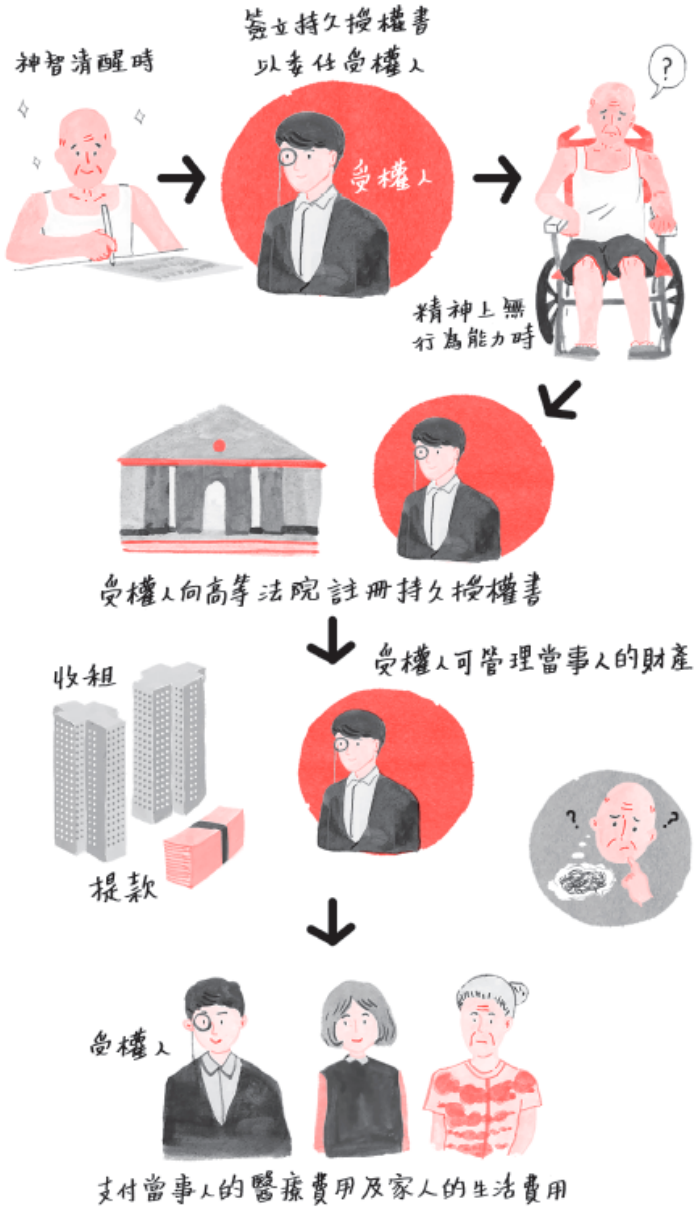
?

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。



我想 PREFER說

我想說・家屬自助手冊

第2冊

Jockey Club Post-diagnostic Support in Dementia Care Programme

賽馬會與耆同行腦退化症支援計劃

目錄

賽馬會耆智園 Jockey Club Centre for Positive Ageing

i 我 CAN可以

我可以．組員手冊

第3冊

Jockey Club Post-diagnostic Support in Dementia Care Programme

賽馬會
與耆同行腦退化症支援計劃

目錄

Online Caregiver Platform and E-learning

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

家屬照顧者

「與者同行」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。

我不是自動程式

reCAPTCHA
私隱權政策 - 條款

登入

家屬照顧者

「與者同行」計劃參加者

每一位腦退化症人士都是獨特的。在診斷腦退化症後，腦退化症人士和家屬／照顧者一起安排日常起居和積極面對生活上的困難，是十分重要的。賽馬會耆智團在香港賽馬會慈善信託基金的捐助及支持下，聯同基督教香港信義會社會服務部、基督教靈實協會、及九龍樂善堂推行賽馬會「與者同行」腦退化症支援計劃。本計劃以蘇格蘭國家腦退化症策略為本，採用蘇格蘭政府認可的「診斷後支援服務五大支柱」作藍本，為腦退化症人士及其家屬提供優質而適切的介入。國際上實證研究已證明，診斷後的支援服務能有效延緩腦部退化，及為腦退化症人士的未來作好準備，保持他們的生活質素。

蘇格蘭阿茲海默症協會診斷後支援計劃五大支柱

如何使用此網站

本網站為早期腦退化症人士及其家人而設，針對回應家人在親人確診後在知識、照顧技巧、及感受上的各種疑問，以及和家人一起制訂照顧方案。本網站中每個單元都設有「知識」及「行動計劃」兩部份，本計劃的個案經理會按你的需要，透過電話或網上留言提供適當的指導，讓你更能掌握本書的知識及實踐有效的照顧方案。我們鼓勵你向腦退化症親人及其他家庭成員分享及實踐你在本計劃所學的知識，好讓整個家庭能齊心在照顧的道路上同行，更有信心面對腦退化症。

A的網上學習單元

1 — 2.2 — 2.3 — 2.4 — 3.2 — 4.1 — 5.1 — 8.2

恭喜你完成以上學習單元，我們還提供以下高階學習單元，以助你對腦退化症有更進一步了解！

2.1 — 3.1 — 4.2 — 5.2 — 5.3 — 6 — 7 — 8.1

Our case manager can make the interactive advice and comments to empower the caregivers through the online platform (Summary Report and Care Planning)

學習總結

你的照顧壓力程度：
低

eegeg的認知能力：
早期腦退化症

eegeg的行為表現：
繼續觀察

謝謝你抽出寶貴的時間參與賽馬會「與者同行」腦退化症支援計劃之家屬支援篇，你已完成了以下的單元：

1 「以人為本」照顧模式的概念

2.2 早期腦退化症人士的日常生活改變

2.3 延緩腦退化的方法

2.4 良好溝通和關係建立的重要性

3.2 認知友善家居

4.1 我健康嗎？

5.1 照顧者的情緒

8.2 財政規劃與預設照顧計劃

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 impact of 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.

Conclusion of ACP in Dementia Care

- Advance care planning is a 'process' rather than a 'result' in the experience of people with dementia and their family members
- Apply person-centred care model in whatever means and build up a proper care attitude (DemenTitude®) in dementia care
- The case management model facilitates the discussion of the expectation of care and supports mood variation during the journey of dementia.
- Cultural difference and consideration should be addressed. Advanced care planning could be step-by-step and divided into the social parts as well as the medical parts
- Hence, there is an urge to highlight advance care planning as one of the critical elements in designing the post-diagnostic support dementia care services in Hong Kong.


Thanks for
your attention

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