

Advanced Care Planning in Canada

Putting it into Practice

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Congress Track #: Enter Info Here

Disclosure of interest: None declared

Affiliated organisation: Canadian Partnership Against Cancer

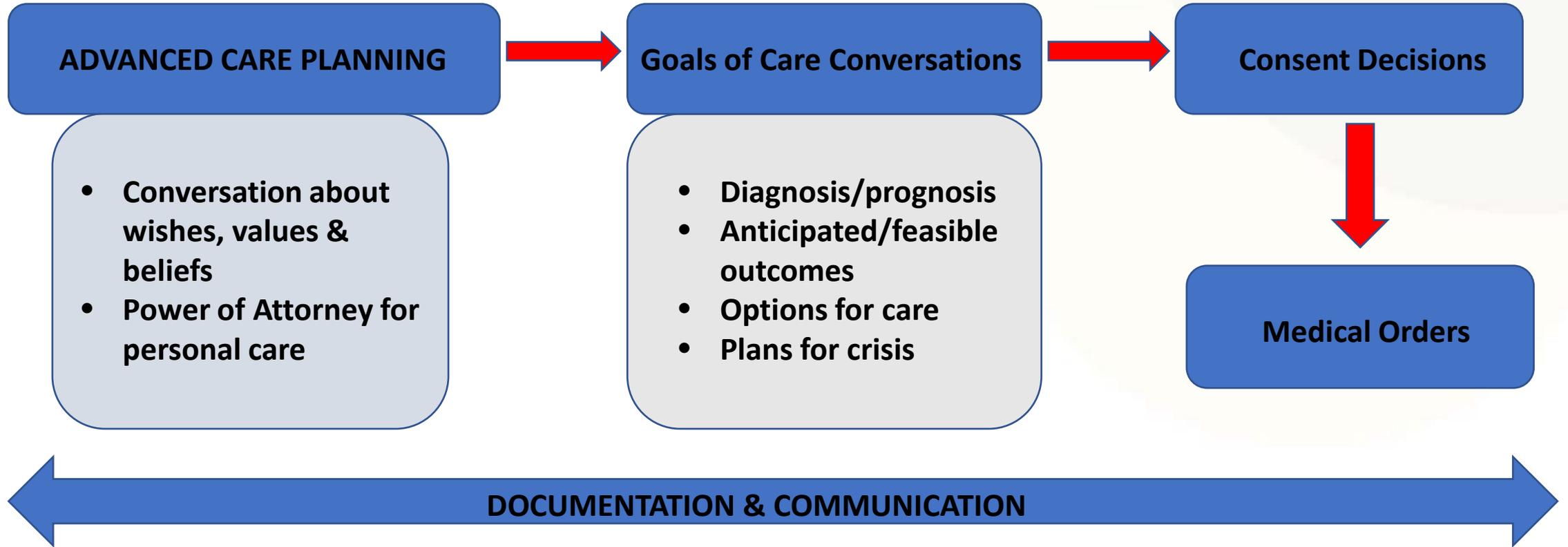


World Cancer Congress
Kuala Lumpur, Malaysia
1–4 Oct 2018

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End-of-Life Communication & Decision Making



End of Life...

*It's Everyone's Business
Start the conversation*

Advanced Care Planning

- **What are your values, wishes, goals for health care?**
- **Do you have personal beliefs that influence your goals?**
- **Are there conditions under which you do or do not want a certain treatment?**
- **Where would you want to live and receive treatment?**
- **When you are nearing death, are there things that you are worried about or would wish?**
- **When you are nearing death, are there things that you would like family and friends to know?**

Health PEI

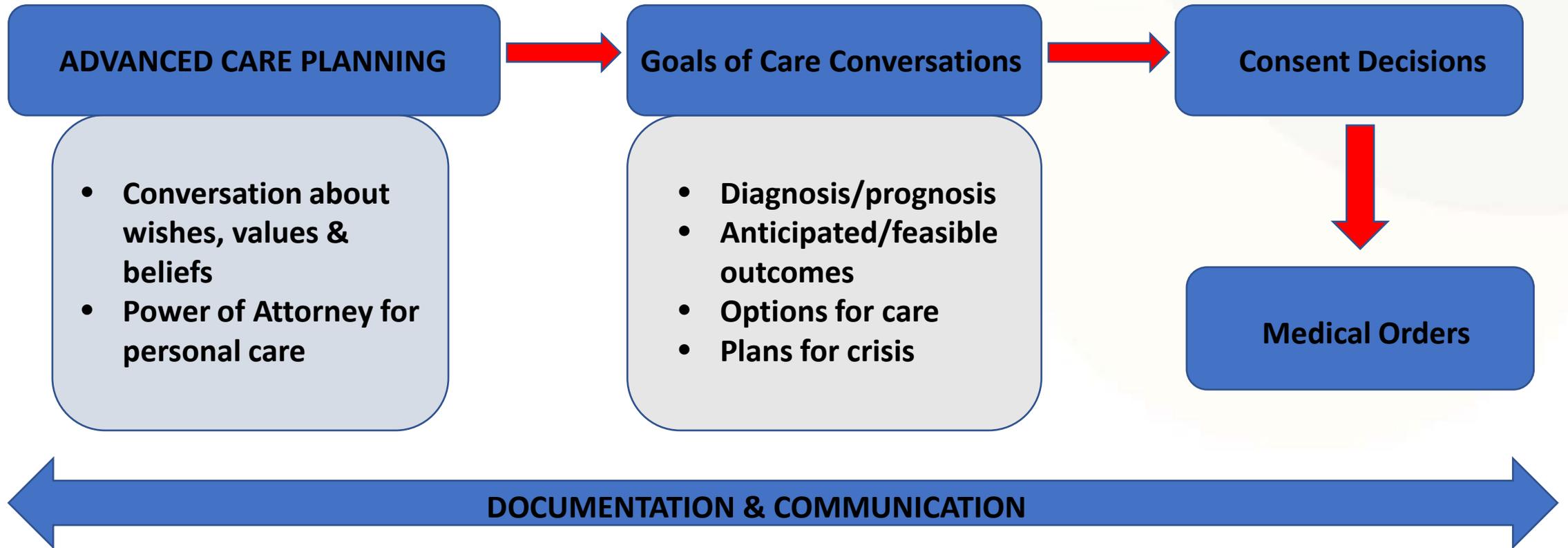


Respecting Patient Choices

Goals of Care

- **Health Care Directives, Living Wills, Advanced Care Directives:**
 - Documents that explain a person's wishes about health care and treatment in case he/she is unable to make decisions or communicate them at a future time
- A proxy or another person to make health care decisions can be appointed for when/if the person can't themselves

End-of-Life Communication & Decision Making



Identification Triggers



- **“Would you be surprised if this patient were to die in the next year?”**
- **Does the patient have general or specific indicators of decline?**
 - **Decreasing activity, poor response to treatment, metastatic disease, progressive weight loss, no further disease-oriented treatment**
- **Has the patient indicated a preference or need for palliative care?**

A Palliative Care Approach for Oncology, CCO

A Palliative Care Approach for Oncology

- **PPS \geq 70** (normal activity with effort, some evidence of disease) – **Advanced Care Planning with patient and SDM**
- **PPS \leq 60** (a few times a week needs assistance with at least 1 of transfer out of bed, walk, wash, toilet, eat) – **End-of-Life Care Planning with patient and SDM**
- **PPS \leq 50** (mainly sits in chair or lies in bed. Needs help every day with listed activities) - **urgent assessment of understanding, goals of care and EOL Care Plan**

CCO Integrate Project

Did You Know?

100% of Canadians will die



8 out of 10 Canadians have never heard of Advance Care Planning



Advance Care Planning is a process of reflecting on and communicating your wishes for end of life care with your family, friends and health team

Only about half of Canadians have had a discussion with a family member or friend about what they would want or not want if they were ill and unable to communicate

That means 50% of their families don't know their loved one's wishes — and may have some very difficult decisions to make



Make your wishes known today

Speak Up

Start the conversation about end-of-life care

www.advancedcareplanning.ca



www.advancedcareplanning.ca

Thank you to our project funders:



Advanced Care Planning

Putting it into Practice

As You Wish



ADVANCE CARE PLANNING

- **Important to distinguish between ACP, Goals of Care and consent**
- **Need to know the law in your region**
- **Establish processes for identification of people who would benefit from these conversations**
- **Documentation and communication are essential**
- **Utilize and adapt on-line resources that are available**

Thank you!



FOR MORE INFORMATION:

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Advance Care Planning in Australia

Sondra Davoren, Manager – Treatment & Supportive Care
McCabe Centre for Law and Cancer



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Track 4 -11

Disclosure of interest: None declared

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An orange graphic element consisting of two curved lines that meet at a central point, resembling the spine of an open book or a stylized bracket.

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Overview

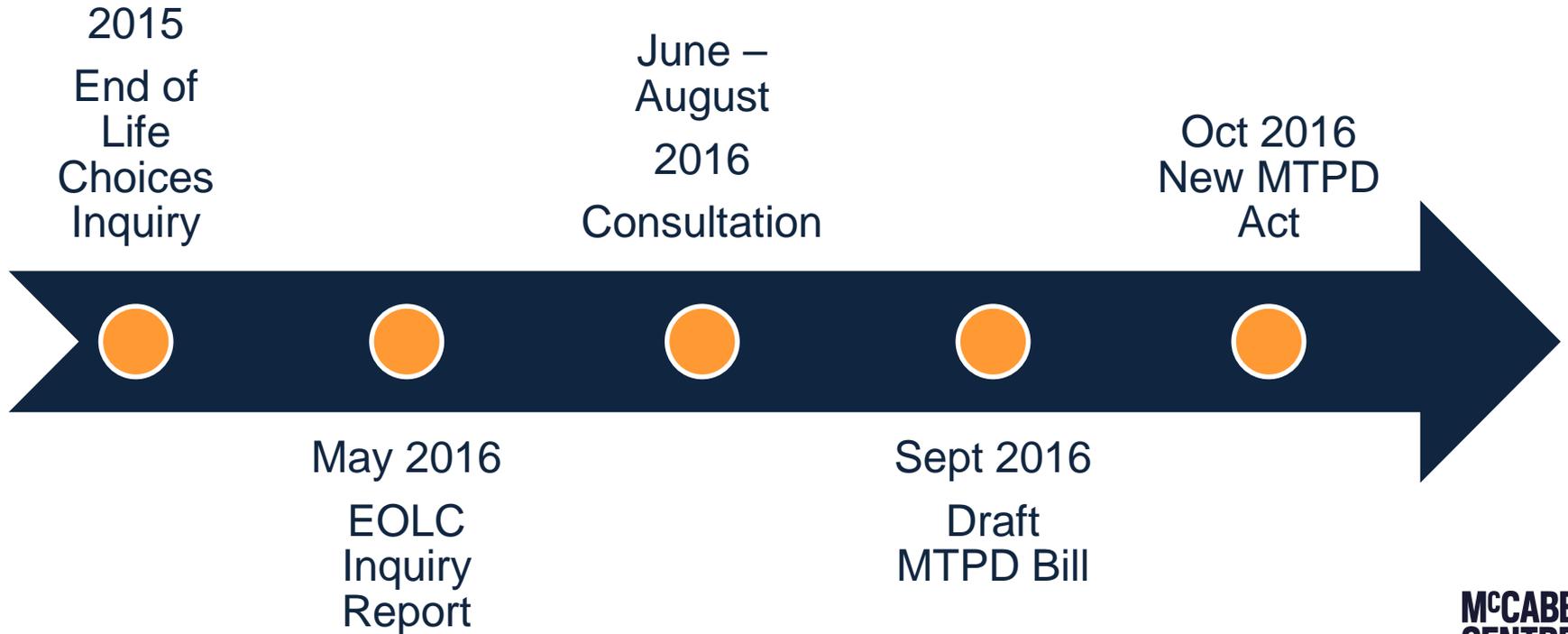
- Recent law reform in Australia – what were the key drivers for change?
- The law reform process – consultation, legislation drafting, passage through Parliament
- What are the key changes?
- What does this mean for health professionals, people affected by cancer and their carers?

Confusion and uncertainty

- Multiple overlapping Acts
- Limited to current condition
- Doctors confused about who could make a decision
- No ability to make binding future decisions
- Common law uncertainty – unclear whether doctors had to follow advance care plans
“Statement of Choices”



Law reform process



Key reforms

- New legally binding advance care directives can be made by anyone with capacity
- Changes to substituted decision making process

Key reforms: advance care planning

- Advance care planning now in two options:
 - Instructional directive
 - Allows specific directives about treatment a person would consent to or refuse
 - Values directive
 - Details a person's preferences, values, wishes, which medical treatment decision makers and health professionals must consider in making decisions.

Advance care planning: Instructional directives

- Provide specific directives about treatment a person consents to or refuses
 - E.g. consent to heart bypass in specific circumstances; refuse CPR
- Takes effect as if the person who gave it has consented to or refused treatment

Advance care planning: values directives

- Statement of preferences and values as the basis on which you would like any medical decisions to be made about you:
 - *If I am unable to recognise my family and friends, and cannot communicate, I do not want any medical treatment to prolong my life.*
 - *If a time comes when I cannot make decisions about my medical treatment, I would like to receive any life prolonging treatments that are beneficial. This includes receiving a medical research procedure to see if the procedure has any benefit for me.*

Key reforms: medical treatment decision making

- All decision makers have the same powers to consent to and refuse treatment
- The list of decision-makers has been simplified
- Those in the list must have a “close and continuing relationship”
- From ‘best interests’ to ‘consistent with a person’s preferences, values and personal and social wellbeing’

Making a medical treatment decision:

A medical treatment decision maker must...

- Consider any **values directive**
- Consider **other relevant preferences**
- Consider that person's values
- Act in good faith and with due diligence
- Consult



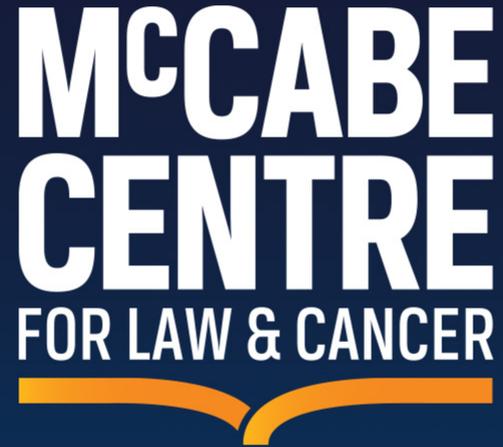
New responsibilities for health practitioners

- All must make reasonable efforts in the circumstances to ascertain whether a person has an advance care directive or medical treatment decision maker
- If a health practitioner is aware of an ACD they must comply with it – except in very limited circumstances.
- Medical practitioners have particular responsibilities as authorised witnesses to the completion of ACDs

What does this mean for health professionals, people affected by cancer and their carers?

- Health professionals: new responsibilities – must ‘have the conversation’.
- People affected by cancer: can express their wishes for medical treatment, as well as their values and preferences.
- Carers and medical treatment decision makers – greater certainty about what a person might want if they lose capacity.

Thank you for your attention.



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Communicating Future Care Plans with Cancer Patients in Malaysia



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Legal, clinical and supportive care perspectives on
advance care planning

Disclosure of interest: None declared

32.4 million population (annual growth rate 1.1 %)



Population by ethnic group:

Bumiputera 69.1%
Chinese 23%
Indians 6.9%
Others 1.0%

Life expectancy
75years

Percentage of old age increases from 5.0% in the year 2010 to 14.5% in the year 2040

Principle cause of death:

Male

Ischaemic heart disease 13.2%
Pneumonia 12.5%
Cerebrovascular diseases 6.9%
Transport accidents 5.4%
Lung cancer 2.2%

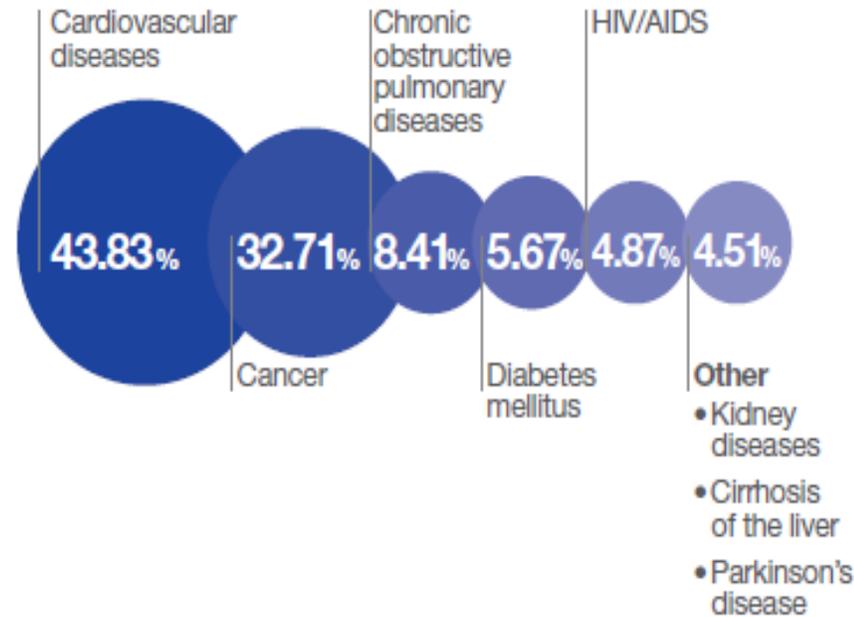
Female

Pneumonia 14%
Ischaemic heart disease 9.9%
Cerebrovascular diseases 7.6%
Breast cancer 3.8%
Transport accidents 2.2%

Needs Assessment for Palliative Care in Malaysia



are in need of palliative care*

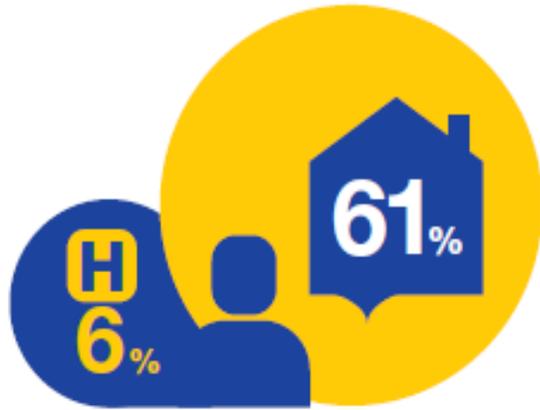


Causes of death in adults needing palliative care*

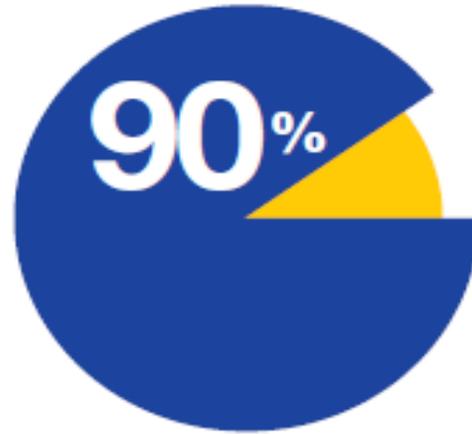


From the Public Perceptions survey

Needs Assessment for Palliative Care in Malaysia



61% indicated home as the preferred place of death as compared to 6% in hospitals



felt that end-of-life care discussions are important



53% indicated home as the preferred place of care if they had a life-limiting illness compared to 22% for hospitals

Advance Care Planning (ACP) – local context

- No legislation to govern ACP and advance medical directive
- No standardised practice

Local studies on patients' views

- Majority have no knowledge but receptive to end-of-life discussion and planning for the future
- Patients want doctors to initiate discussion
- Family members' involvement in EOL decision-making

Htut et al 2007, Hing et al 2016

Advance Care Planning (ACP) – What do palliative care patients living in Malaysia want in future care planning? unpublished data

Table 1. Patient Demographics and Clinical Diagnosis

Participants	Sex	Age	Cultural Background	Religion	Past/Present Occupation	Clinical Diagnosis
P1	F	46	Chinese/Eurasian	Catholic	Teacher	Breast Cancer
P2	M	78	Chinese	Buddhism	Construction	Pancreatic Cancer
P3	M	71	Chinese	Buddhism	Electrician	Lung Cancer
P4	M	62	Chinese	Taoism	Lawyer	Hepatocellular Cancer
P5	F	54	Chinese	Christianity	Restaurant owner	Ovarian Cancer
P6	F	67	Chinese	Christianity	Clinic nurse assistant	Multiple Myeloma
P7	F	39	Chinese	Buddhism	Part-time sales promoter	Ovarian Cancer
P8	F	61	Malay	Islam	Dental nurse	Breast Cancer
P9	F	50	Chinese	Christianity	Property agent	Motor Neurone Disease
P10	F	61	Malay	Islam	Ministry of education	Breast Cancer
P11	F	87	Chinese	Buddhism	Housewife	Breast Cancer
P12	M	65	Malay	Islam	Security guard	Renal Cell Cancer
P13	M	72	Filipino	Christianity	Retired	End Stage Renal Failure
P14	F	80	Chinese	Buddhism	Babysitter/Cleaner	Lung Cancer
P15	F	36	Chinese	Buddhism	Mechanical engineer	End Stage Renal Failure

M = male F = female

Advance Care Planning (ACP) – What do palliative care patients living in Malaysia want in future care planning? unpublished data

- **Information needs**

- i. Information on diagnosis and prognosis
- ii. Information on hospice and palliative care service
- iii. Information on different agencies and organizations that can provide social support and financial planning

Advance Care Planning (ACP) – What do palliative care patients living in Malaysia want in future care planning? unpublished data

- **Psychosocial concerns**

‘Worried about the future... with this illness, I will be paralysed. I am worried that no one will look after me... I don't want to be a burden to my family’

‘It is quite scary when I think about the future... I am worried and I hope that I get into a home where they are compassionate’

Advance Care Planning (ACP) – What do palliative care patients living in Malaysia want in future care planning? unpublished data

- **Health care experiences**

‘ Every patient would not want to have tubes because I have witnessed my mother in-law, my own daughter died with many tubes in the body’

‘ This hospital, they practice locking the medicine... but by the time I wait for them (referring to the nurses) to come and to call the doctor, my pain is already so bad...I wait for like 10, 20, 30minutes...that’s why I feel they can’t help much’

Advance Care Planning (ACP) – What do palliative care patients living in Malaysia want in future care planning? unpublished data

- **Spirituality and religion**

‘ All humans have to die once in their lifetime’

‘ I have never thought about the future. Live one day at a time’

‘ I am a Buddhist. I myself witnessed, after one passed away, one still has their senses for few hours... can still hear, can still feel. So, if I am at home, at least I know all my family can handle my body. In hospital, I do not know how the staff, how the doctor, where they put me, do they put me into the very cold box?... the feeling is scared’

Summary

- Malaysia is a long way from implementation of ACP
- Medical culture is a barrier in meaningful discussions on future care planning including end-of-life care.
Communication skills training is essential as patients want doctors to initiate discussion.
- Hospice organization can be an advocate for palliative care patients in planning for the future
- Raising awareness amongst the public and health care team is important

THANK YOU

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For more information on Hospis Malaysia, please visit

www.hospismalaysia.org



Advance Care Planning: Law & Policy in Singapore

Sumytra Menon



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Singapore – A Snapshot

Land Area
719.2 km²

Population
5.61 million
60.8% Singapore Citizens
9.4% Permanent Residents
29.9% Non-Residents

Ethnicity
74.3% Chinese
13.4% Malay
9.1% Indian
3.2% Others

Life expectancy
82.7 years

Ageing
Residents aged >65
12.4%

Total fertility rate
1.2

Number of doctors per 100,00 population
23

Percentage GDP spent on healthcare
4.6%

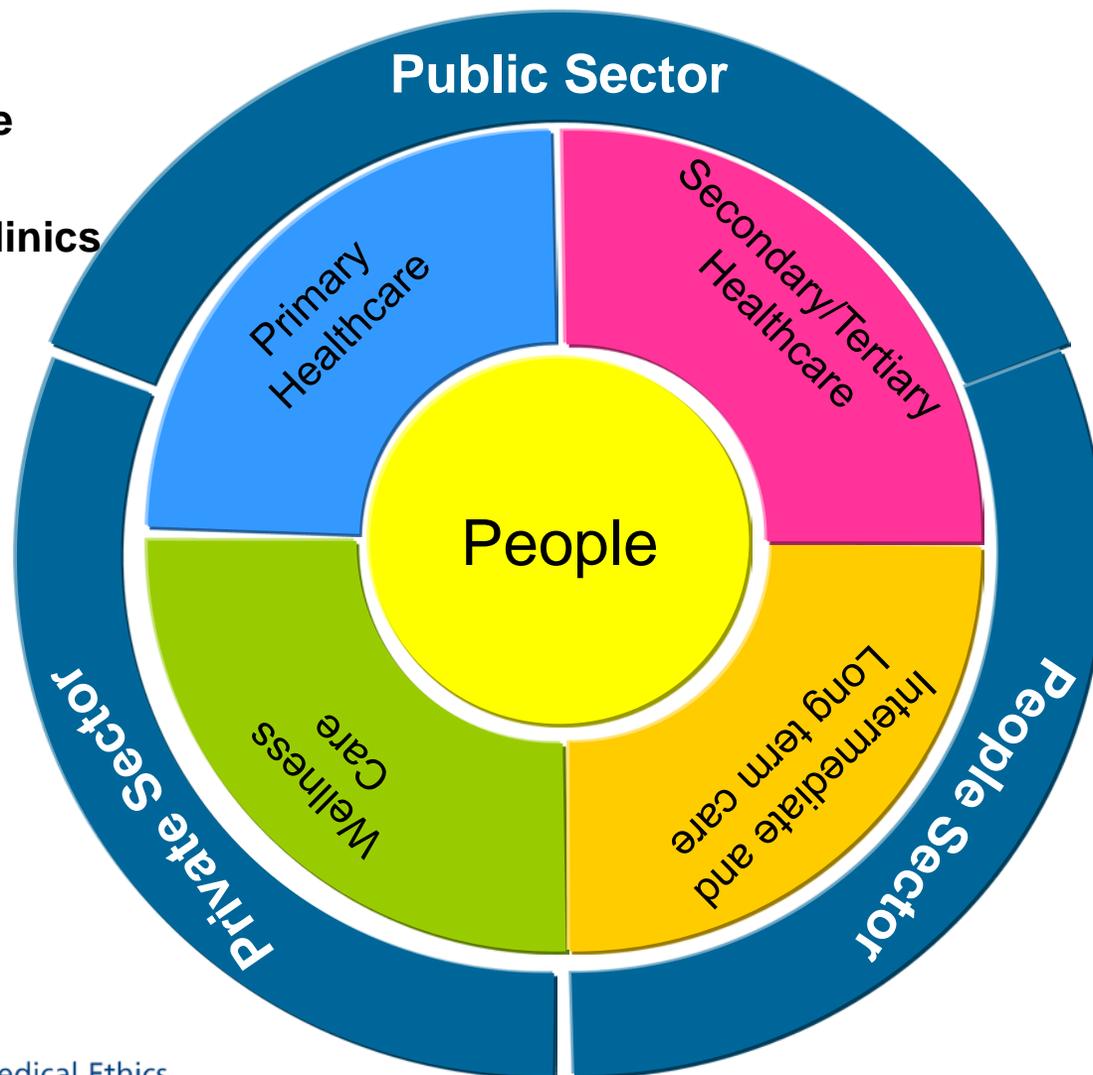
Overview of Healthcare Services in Singapore

Primary Care

80% Private primary care clinics (GPs)
20% Public sector polyclinics

Wellness Care

Mainly private sector
Some public sector involvement
E.g. Health Promotion Board



Secondary/Tertiary Care

80% Public sector run acute hospitals

20% Private

Hospital care comprising of multi-disciplinary inpatient and specialist outpatient services, and 24-hour emergency services.

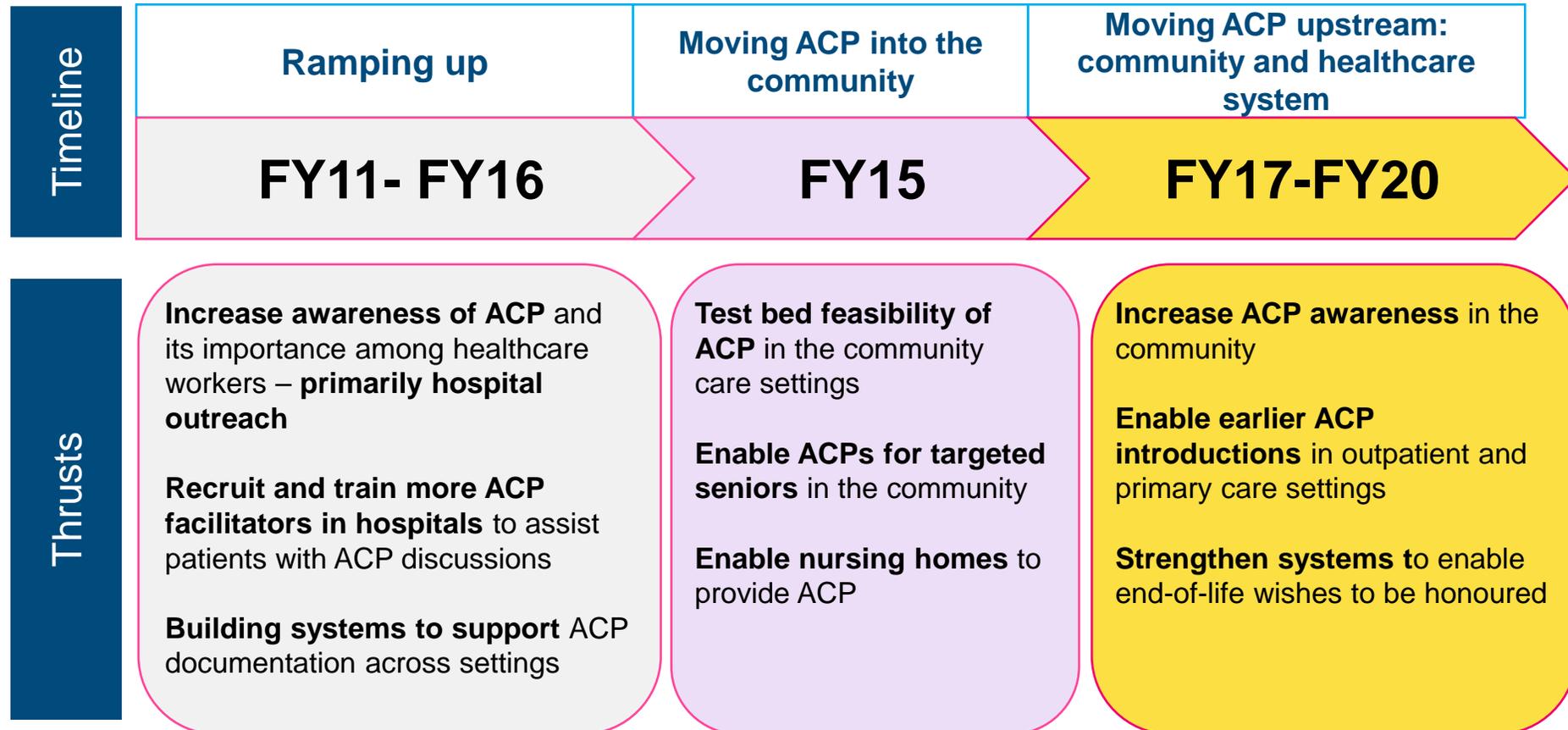
Intermediate & Long-term Care

80% Public sector run acute hospitals

20% Private

Hospital care comprising of multi-disciplinary inpatient and specialist outpatient services, and 24-hour emergency services.

ACP Implementation in Singapore



Singapore's "Living Matters" ACP Model

General ACP

Nominate Healthcare Spokesperson and consider when a serious neurological injury would change goals of treatment

Early onset & medically stable patients

Disease Specific (DSACP)

Determine what goals of treatment should be followed if complications result in "bad" outcomes

Patients with progressive, life-limiting illness, suffering frequent complications

Preferred Plan of Care (PPC)

Establish a specific plan of care expressed in the PPC form

Patients with < 12 months prognosis and/or require long-term institutional care

Based on Respecting Choices

ACP & Singapore Law

Advance Medical Directive Act (AMDA) 1996

- AMD made under AMDA can complement ACP.
- Prescribed document – **very narrow** application.
- Allows someone with capacity to **refuse in advance extraordinary life sustaining treatment** if they lack capacity to decide, are terminally ill and three doctors have confirmed this, and are at imminent death.
- Palliative care cannot be withdrawn or withheld.
- Healthcare professionals cannot ask a patient whether they have made an AMD – it is a **criminal offence** punishable with fine and/or imprisonment!

ACP & Singapore Law

Mental Capacity Act 2008

- Covers all decisions made on behalf of persons who lack capacity, including decisions made by the decision-maker in accordance with an ACP and LPA (lasting power of attorney).
- Allows a person to appoint a proxy to make decisions on their behalf, including healthcare decisions.
- But, proxy appointed under LPA can only decide on **non-serious treatment**.
- Doctor is the final decision-maker on **life-sustaining treatment or treatment to prevent a serious deterioration** in the patient's health.
- Decision must be made the patient's **best interests**.

Best interests – patient centered clinical and non-clinical factors

- Must consider likelihood person will regain capacity in future regarding the specific matter and when that is likely to happen
- The person's past and present wishes, values, beliefs, culture and other relevant matters important to that specific decision (**i.e. ACP considered under this domain**)
- Should consult anyone named by the person for inclusion in discussions, any caregivers, anyone interested in the person's welfare (such as family members, close relatives and friends), any donees (appointed proxies under a LPA) and court-appointed deputies.
- **The bottom line** - To determine best interests you have to weigh the benefits, burdens and the views of relevant parties – taking in account the clinical and non-clinical factors.

Barriers to ACP

- Taboo subject – death and dying.
- Confusion about the different healthcare decision-making tools – LPAs, AMDs, and wills.
- Concern that ACP may burden loved ones.
- Perception that loved ones will know what to do when the time comes.
- Fear of making anticipatory decisions, which may not be able to be changed in the future.
- Some defer decisions to relatives because they don't think they have the right to decide if the relative is paying for treatment.

Menon S, Kars MC, Malhotra C et al. Advance Care Planning in a Multicultural Family Centric Community: A Qualitative Study of Health Care Professionals', Patients', and Caregivers' Perspectives. *J Pain Symptom Manage.* 2018 Aug;56(2):213-221.e4.

Summary & Next Steps



Advance Care Planning

Your Stories

Start the Conversation

Voice Your Choice

John is in the pink of health and a firm believer in Advance Care Planning. In this video, he shares what it means to live well.



- Singapore has developed a national ACP system to promote patient autonomy and encourage future planning for healthcare.
- More efforts on developing awareness, reduce taboo culture and normalize these conversations.
- Amend AMDA to reflect policy and promote LPA and ACP as complementary decision-making tools to empower individuals.

Thank you

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