Advance Care Planning in practice

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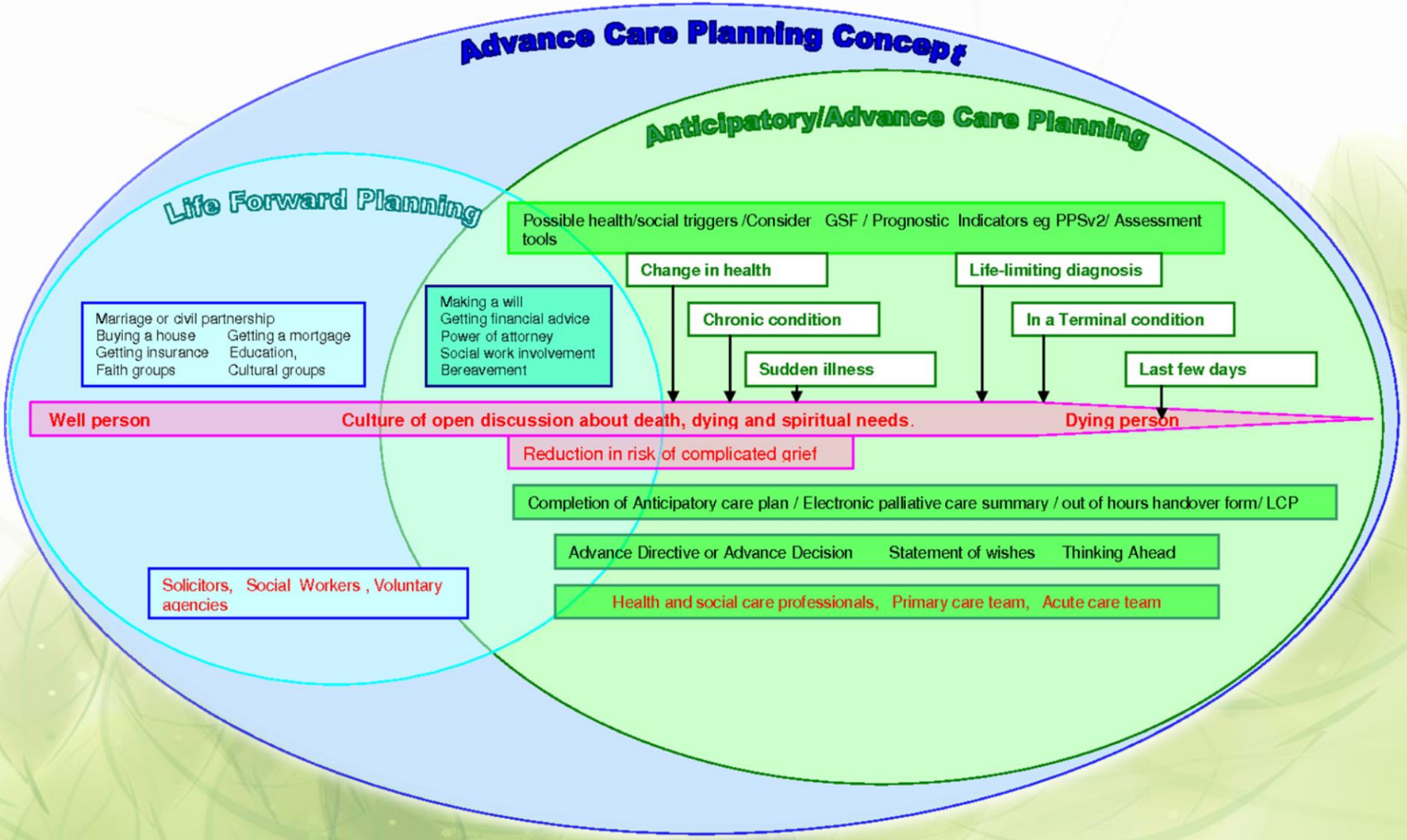
Advance Care Planning

- A process of assisting individuals in ***understanding***, ***reflecting*** & ***communicating*** future medical treatment ***preferences***, including end-of-life care.

(Gundersen Lutheran, 2014)

Concept of ACP



What is ACP?

- ***A communication process***
- Among health care team, patients & family members
- Regarding patient's
  - ***wishes***
  - ***preferences***
  - ***values***
  - ***Beliefs***
- About ***future care*** in the event the patient has lost capacity to make decision
- ***Emotional preparation*** of patients & families for future crises

Emphasizing on ***comprehensive communication process*, rather than on document

Trends

Traditional model

Purpose

- Prepare for incapacity

Focus

- Advance Directive

Context

- Doctor & patient relationship

Developing model

Purpose

- Prepare for death
- Achieved control in health system
- Relieve burden
- Strengthen relationships

Focus

- **Written advanced statement** & advance directive

Context

- **Involve patient, family & healthcare professionals**

(Thomas, 2011)

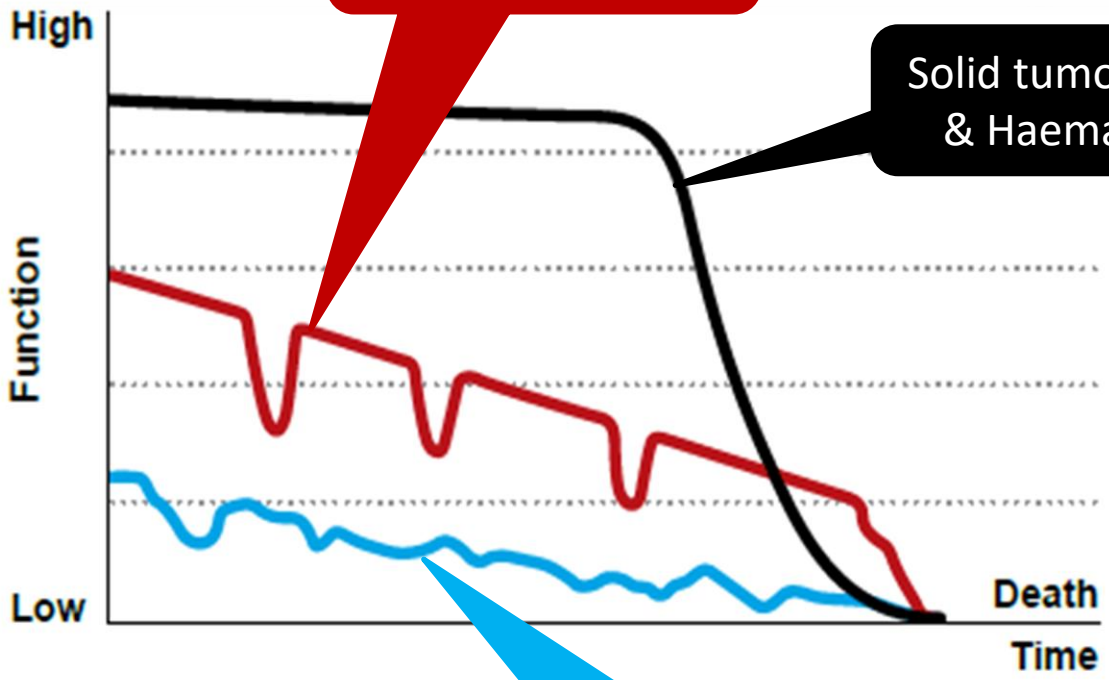
Why?

- Builds ***trust & teamwork*** between patient, physician & decision maker
- Uncertainty & anxiety reduced
- Avoids future confusion & conflict
- Permits ***peace of mind*** for patient, decision maker & patient's family

Who?

- All patients with ***incurable*** illnesses
  - Advanced cancer
    e.g. metastatic cancer
  - End-stage organ failure
    e.g. ESRF, ESHF
  - Degenerative illness
    e.g. Motor neuron disease

Illness trajectories



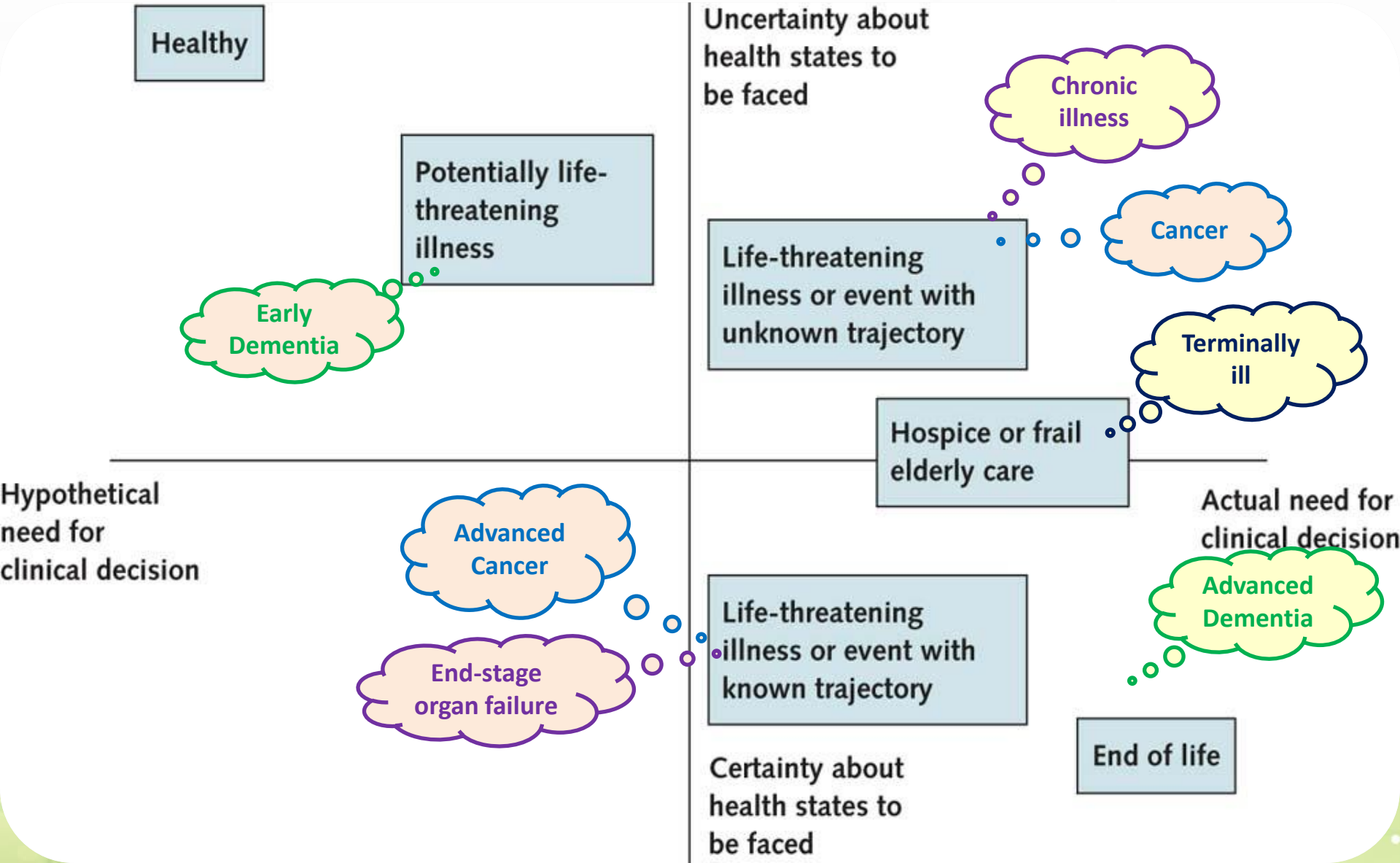
Paediatric Palliative

When?

- Retirement
- ***Life changing event*** e.g death of spouse
- Following a ***new diagnosis*** of life limiting condition
- ***Assessment*** of a person's need
- In conjunction with ***prognostic*** indicators
- ***Multiple hospital admissions***
- Mark increase in ***level of dependency***

  e.g. admission to an institution / care home

When to start?



Triggers

- Retirement
- ***Life changing event*** e.g death of spouse
- Following a ***new diagnosis*** of life limiting condition
- ***Assessment*** of a person's need
- In conjunction with ***prognostic*** indicators
- ***Multiple hospital admissions***
- Mark increase in ***level of dependency***

  e.g. admission to an institution / care home

Impacts

Patient & carer

- Speak to him/herself
- Peace of mind
- Improve quality of life
- Reduce family stress
- Relieve family burden in making choice
- Patient's choice are respected

Organization

- Improve care, ***not*** to save money
- Maintaining high-quality planning
- Ensuring the plans are available & reasonably followed
- More palliative-focused
- Person-centered health care delivery

Gaps

Talk

- ***Misconception*** of Advance Care Planning
- ***No*** involvement in patient's decision in some cases
- Focus on Life-sustaining treatment ***only***

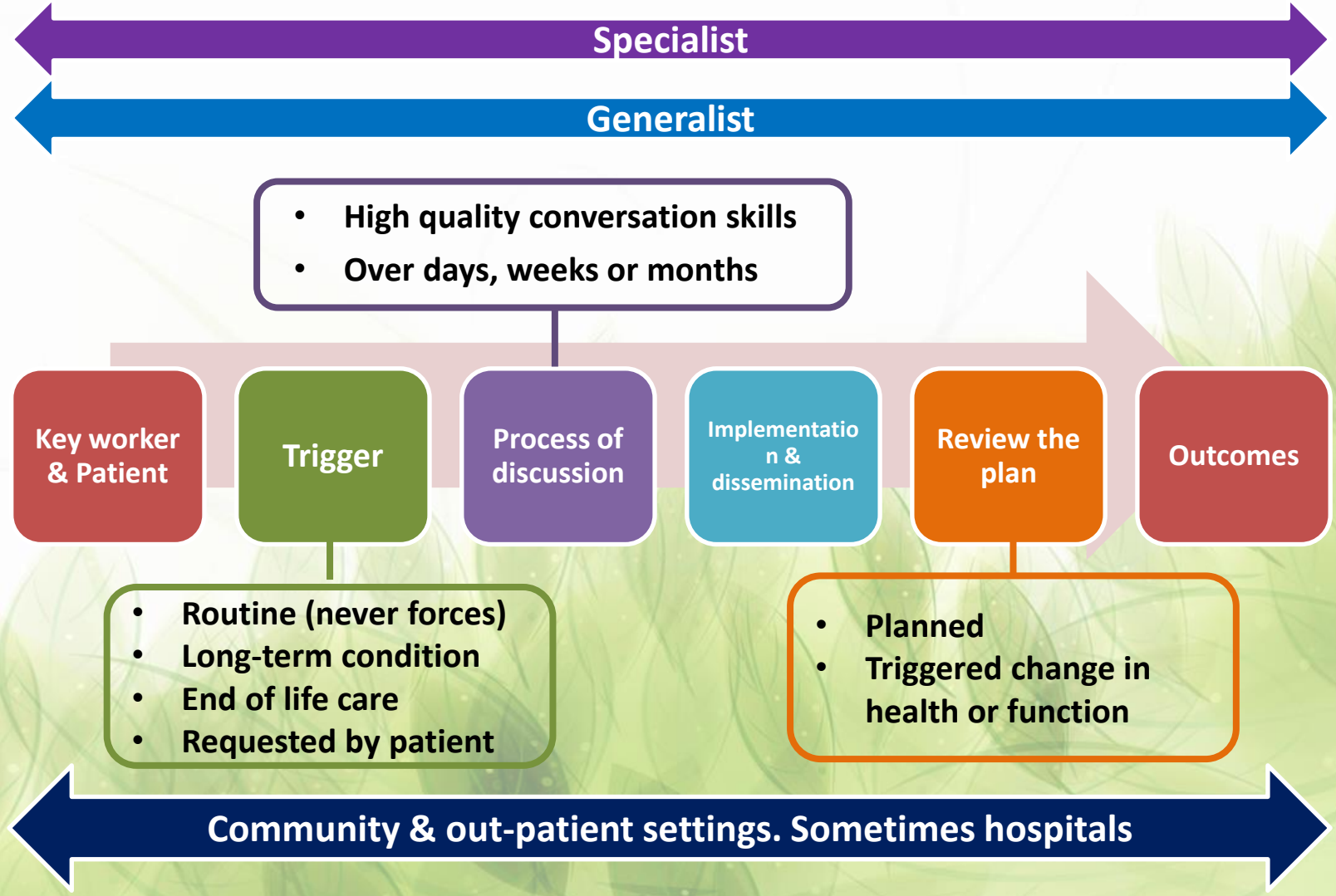
Write

- ***Lack of standardized tool***

Share

- Patient's preference ***not*** communicate well
- ***Lack of sensitivity*** to patient & family emotional needs
- ***Unclear logistic*** for effective communication between teams

Model for ACP



(Conroy, 2011)

Process of discussion

Shared decision making

Advance care planning process

- Conversation about values, goals & preferences
- Substitute decision maker
- Documentation

Patient-centered care

- Understanding
- Reflection
- Discussion

ACP discussion

What do you want to happen?

- Statement of wishes & preferences

What you do not want to happen?

- Advance decisions to refuse treatment

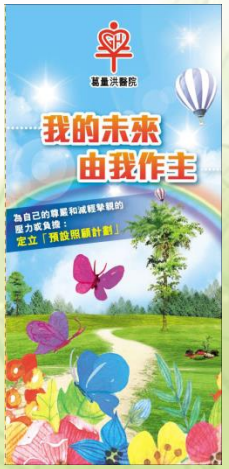
Who will speak for you?

- Substitute decision maker

ACP Pamphlet & Booklet

1. Health status
2. Quality of life
3. Preferable care
4. Preferable treatment
5. Dying process
6. Funeral Arrangement

- ✓ Who can help to make the decision?
- ✓ Who should keep the duplicate copies?



心肺復甦術

何謂「心肺復甦術」？

「心肺復甦術」是指對瀕死或無生命徵象的病人，進行體外按壓心臟、插入氣管導管、注射急救藥物、電擊心臟、心臟人工調頻、人工呼吸或其他緊急救治。

為甚麼需要「心肺

當病者的心搏驟停、
「心肺復甦術」以保持

「心肺復甦術」之常

「心肺復甦術」之常見
氣管和食道受損等。
受眾多因素影響。對於
器官衰竭等，「心肺復
成疑問。

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人工呼吸機

何謂「人工輔助呼吸」？

「人工輔助呼吸」主要分為「入侵性」及「非入侵性」兩種

- 入侵性　：指將一條膠質的喉管，從口或鼻孔插入至氣管中，再接駁到人工呼吸機，輔助病人的呼吸。
- 非入侵性：通過鼻罩或面罩接駁到人工呼吸機，輔助病人呼吸。

**入侵性人工呼吸機

為甚麼需要「人工

當病人有呼吸衰竭
吸機。

使用「人工呼吸

使用人工呼吸機的
度，以免喉管鬆脫
止痛藥以鬆弛肌肉
吸機相關性肺炎。
罩太緊貼或長期使用

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人工餵食

何謂「人工餵食」？

「鼻胃管餵」是其中一種最常見的「人工餵食」，它是以一條膠質的喉管，由鼻腔插至胃部，將液體食物（營養配方）送到消化系統（胃腸道）內。

為甚麼需要「人工

為不能用口進食普遍
營養，如嚴重中風、

「人工餵食」之常

當病人插入鼻胃管時
不適；甚至引起黏膜
有機會增加病人之身

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液體輸注

何謂「液體輸注」？

「液體輸注」是以針刺引入喉管經靜脈或皮下進入身體內。輸注液體以補充水份或平衡電解質，如鹽水或葡萄糖溶液等。

- 靜脈輸注：把輸液直接輸入靜脈。
- 皮下輸注：把輸液注入皮下施用。

為甚麼需要「液體輸注」？

病人因疾病或身體情況引致暫時不能用口進食，可考慮給予液體輸注，以補充水份、電解質和糖份等，使身體回復正常狀況。

「液體輸注」之常見風險

常見的風險包括感染（輸注穿刺部位）、引起腫脹和疼痛；若液體超出負荷，可引致肢體水腫，甚至心和肺臟衰竭等。

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PMUBK014D

Grantham Hospital
Palliative Medical Unit
Brief summary of "Advance Care Planning"

Patient Name	Name of Facilitator (Staff)
Name of relative who join the discussion & relationship	Date

Patient's preference

Health Status	Patient/ family understand present health status and prognosis		
	☐ Yes (Please refer to "More understanding" 「了解多一點」 for details)		☐ No
Quality of life	Patient's value has been shared with his/her family		
	☐ Yes (Please refer to "More understanding" 「了解多一點」 for details)		☐ No
Preferable care	Patient has expressed his/her wishes of preferable care in late stage of life		
	☐ Yes (Please refer to "More understanding" 「了解多一點」 for details)		☐ No
	What kind of life-sustaining treatment that you do not want to receive?		
	Cardiopulmonary resuscitation	☐ Yes	☐ No
	Invasive / Non-invasive artificial ventilation*	☐ Yes	☐ No
	Hemodialysis / Peritoneal Dialysis*	☐ Yes	☐ No
	Antibiotics	☐ Yes	☐ No
	Intravenous / Subcutaneous infusion*	☐ Yes	☐ No
	Artificial tube feeding	☐ Yes	☐ No
	expressed his/her wishes of preferable environment of dying		
	Please refer to "More understanding" 「了解多一點」 for details)		☐ No
	wish about funeral arrangement is known to his/her family		
	Please refer to "More understanding" 「了解多一點」 for details)		☐ No

Emergency	Relationship	Contact number
	Relationship	Contact number

I have a duplicate copy of "Advance Care Planning"

	Relationship	Contact number
	Relationship	Contact number

Case sharing

History:	• ***Repeated admission*** for blood stained urine, retention & fever
03 Jan:	• ***In-pt consultation*** & initial assessment. • Pt's value & belief explored. Pt's family seen.
06 Jan:	• ***First home visit*** & ***ACP discussed***, then weekly home visit
16 Jan:	• Phone FU with pt's niece for care plan discussion • ***SOPD*** appointment scheduled on 18 Jan
17 Jan:	• Admitted to ***QMH AED*** because of haematuria before first SOPD appointment. Transferred back to ***GH PMU*** on the same day.
18 Jan:	• Stabilization of pt's condition. ***AD signed***. • Offer ***24 hrs admission slip*** on discharge
26 Jan:	• Discharged home with long-term plan
27 Jan:	• Early home visit & settle pt's care @ home
17 Feb:	• Pt's GC further deteriorate. Offer in-patient care. • ***Patient's prefer stay @ home*** after explanation & supported by family.
21 Feb:	• Patient found unarousable & attended ***RH AED***. Then certified ***dead***

此小冊子乃個人財物，如拾獲，請交還

_____(姓名)(電話：_____)或

葛量洪醫院 紓緩治療科 (電話：_____)

Name & contact of case manager

前言

在人生旅程中，我們常為不同階段的重要事情與目標，作出計劃及準備。但當面對生老病死，人難免會出現不安或感到擔憂，對這階段的種種事情作出規劃，往往令人感到難以啟齒，甚至有些人選擇避而不談，留待日後當事情發生時再作打算，或失去能力時由醫生或家人作決定，最終因未能表達個人的需要及意願而產生遺憾。

家人在未清楚明白病人的意願下，要代為決定，更變得左右為難；同時，背負著沉重的壓力。「預設照顧計劃」希望病人、家屬及醫護人員之間透過有效的溝通，在病人仍有能力作出決定時，為自己未來的醫治療照顧預先表達意願及作出決定，確保病人日後無法為自己作出決定時，其意願可執行和得到尊重。

當走到人生旅途的最後一程時，「預設照顧計劃」可作為生命的嚮導，讓愛我們的人了解個人心靈需要，讓你的意願得以尊重，生命有尊嚴地結束，為人生旅程劃上圓滿的句號。

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目錄

「預設照顧計劃」好處

「預設照顧計劃」是一個溝通過程。透過這個過程，病者表達他的價值觀、信念及喜好；讓醫護人員及家人更明白自己的需要。不少病者在得知將來的安排及自己的想法被受尊重後，會感到安心及輕鬆得多。訂定「預設照顧計劃」的好處包括：

減少病人的憂慮

協助病人了解自己的病況及預期的病情變化，選擇對自己最有利的治療方向，並可定期回顧以作出修訂，確保其預先作出的決定及意願於任何情況下可得到尊重，並落實執行。

紓緩家屬的心理負擔

了解病人臨終照顧意願，免卻家人面對生死時要作出決定而感到壓力，有助減低日後可能出現的衝突、焦慮、矛盾和內疚感。

改善病人的生活質素

透過病人、家屬和醫護人員的討論，掌握到病人理想中的照顧，加強互信和了解，為病人減輕痛楚和紓緩病徵，讓他們在餘下的日子，能夠按自己喜歡的方式舒適和有尊嚴地過活。

臨終照顧意願受尊重

訂立過程中，病人可坦誠地與家人、醫護人員溝通，表達對晚期照顧意願。於任何情況下能夠遵照其意願，病人可以掌握自己的生命，有尊嚴地走完人生最後旅程。

了解多一點

合適的「預設照顧計劃」需要透過探討、分享及個人選擇來決定，並清楚記錄下來。當病者日後未能為自己的照顧及治療計劃作出決定時，這計劃便會自動生效及作為參考。

1 健康狀況

i. 以你所知你現時的健康狀況如何？

Health condition?

- *Deteriorate since 2016*

ii. 你覺得你的病情未來發展將會如何？

Prognosis?

- *Pressure sore*
- *Repeated retention of urine*
- *On long-term urinary catheter*
- *Decrease mobility*
- *Poor appetite*
- *May further deteriorate*

了解多一點

2 生活質素

i. 你想與所愛的人做些什麼有意思的事？

- Nothing special
- Just want to have comfort care

Meaningful activities?

ii. 你想約會什麼家人或朋友？

Time spending with the loved one?

- Family member

iii. 你想參與什麼活動？

- Sit out of bed
- Doing exercise

Daily activities?

iv. 你最想食什麼食物？

- Sweetie

Favorable food?

了解多一點

v. 你需要一些寧靜的時間祈禱或靜思嗎？

Time for praying / thinking?

- Yes. In Indian way

vi. 你最重視的/價值觀是甚麼？

Believes & values?

- Family oriented person

vii. 你有什麼需要很希望讓關心你的人知道？

Things to let family know?

- Stay at home as long as possible

了解多一點

3 晚期照顧

Any worries?

i. 在晚期照顧的期間，你最擔心什麼事情？

- ☐ 痛楚
- ☐ 失禁
- ☐ 無自由
- ☐ 氣喘
- ☐ 不能自理
- ☐ 無人照顧
- ☐ 噁心嘔吐
- ☐ 經濟困難
- ☑ 讓家人憂心
- ☑ 其他(請例明)
  - *Blockage of urinary catheter*
  - *Poor appetite*

ii. 在晚期的時刻，你最想在那裡接受照顧？

- ☑ 自己的家中
- ☐ 朋友的家中
- ☐ 老人院
- ☐ 親人的家中
- ☐ 修道院/寺院
- ☐ 其他(請例明)

Place of care?

Preferable carer?

iii. 你希望誰人在這段時間照顧你？

- ☑ 家人
- ☐ 好朋友
- ☐ 院舍職員
- ☐ 其他(請例明)
  - *Maid*

了解多一點

4 末期治療

你覺得你會接受/拒絕怎樣的維持生命治療？

CPR?

i. 心肺復甦術？ ☐ 接受 ☑ 不接受 ☐ 未能決定

Artificial ventilation?

ii. 人工輔助呼吸？

- 侵入性呼吸 ☐ 接受 ☑ 不接受 ☐ 未能決定
- 非侵入性呼吸 ☐ 接受 ☑ 不接受 ☐ 未能決定

Dialysis?

iii. 透析？

- 血液透析 ☐ 接受 ☑ 不接受 ☐ 未能決定
- 腹膜透析 ☐ 接受 ☑ 不接受 ☐ 未能決定

Antibiotics?

iv. 抗生素？ ☑ 接受 ☐ 不接受 ☐ 未能決定

Infusion?

v. 液體輸注？

- 靜脈輸注 ☑ 接受 ☐ 不接受 ☐ 未能決定
- 皮下輸注 ☑ 接受 ☐ 不接受 ☐ 未能決定

vi. 人工餵食？ ☐ 接受 ☑ 不接受 ☐ 未能決定

Artificial tube feeding?

了解多一點

5 臨終安排

At the moment of death?

i. 在接近生命終結時，你想那時的環境如何？

☐ 寧靜　☐ 床邊播放音樂　☐ 誦經
☐ 親戚朋友陪伴　☐ 神職人員為你祈禱
☑ 其他(請例明)

- Stay at home if everything okay

ii. 在接近生命終結時，你想誰人在你身旁？

Surrounded by people?

- Family members

6 身後事安排

i. 生命終結後，你希望怎樣被悼念？

Remember?

- Indian way

ii. 你想你的悼念儀式是怎樣？

- 在那裡進行？

Ritual ?

- Temple
- 有什麼意願？

- Indian ritual

了解多一點

iii. 你期望遺體放在那裡？

Body storage ?

- Temple

iv. 你期望安葬儀式是怎樣？

Funeral arrangement?

- Indian ritual

v. 你有沒有特別的事情要交托？

Message to leave?

- All done

vi. 需否訂立遺囑？

Any wills?

- Already completed

與關心你的人溝通

讓關心你的人明白你晚期照顧的意願，透露你期望的優先次序及重要性，使他們更加了解你的選擇。

i. 你認為誰人最明白你？

Person understand you most?

- *Sister-in-law, then sister*

Surrogate?

ii. 當你未能為自己作決定時，誰人能夠代表你的意願去作決定？

- *Sister-in-law*

In reality, niece

「預設照顧計劃」與「預設醫療指示」的分別

「預設照顧計劃」

ACP

「預設照顧計劃」是著重病人、家人與醫護人員之間的溝通過程，讓病人為自己未來的醫療照顧預先作出決定及表達意願，以確保當病人無法作出任何醫療上的決定時，其預先訂定的意願亦能被尊重。「預設照顧計劃」討論範圍包括：病情預測及預後、可提供的選擇、好處和風險、對治療的期望、對治療限度的意向、病人對個人照顧的意向、希望達成的個人目標、家人價值觀及關注、未成年病人父母的看法和意向、無能力自決病人事先表達的願望或意向等。

「預設醫療指示」

AD

填寫「預設醫療指示」，需要有兩個見證人，其中一人必須是醫生。討論內容及方向大多與「預設照顧計劃」相似。醫生須確實病人精神上有能力理解「預設醫療指示」的性質和作用，由病人簽署確認。

「預設醫療指示」具法律效力，而有關個人照顧意向的表述則不具法律效力，但有助醫護人員日後制訂個人化照顧計劃。

定期回顧及更新

「預設照顧計劃」會隨著情況變化及你的意願而更改，若你改變先前所訂立的文件，只需重新填寫新的「預設照顧計劃」或「預設醫療指示」並將副本交予付每一位擁有舊「預設照顧計劃」或「預設醫療指示」的人便可。

參考資料

1. HA Clinical Ethics Committee (2014). Guidance for HA Clinicians on Advance Directives in Adults. HAHO
2. Working Group on Modular Review of HA Guidelines on Life-Sustaining Treatment (2015). HA Guidelines on Life-Sustaining Treatment in the Terminally Ill. HAHO

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紓緩醫學部
「預設照顧計劃」概要

病人姓名	協助人(職責)姓名
參與討論家屬姓名與關係	日期

病人意願

健康狀況	病者/家屬*已清楚明白現時的健康狀況及病情未來發展。 □ 有（詳情請參閱「了解多一點」） □ 沒有		
生活質素	病者所重視的價值觀已讓家人明白。 □ 有（詳情請參閱「了解多一點」） □ 沒有		
晚期照顧	病者已清楚考慮及表達希望所得到的晚期照顧。 □ 有（詳情請參閱「了解多一點」） □ 沒有		
末期治療	病者決定接受/拒絕以下各種維持生命治療？		
	心肺復甦術	□ 接受	□ 不接受
	侵入性/非侵入性*人工輔助呼吸	□ 接受	□ 不接受
	血液/腹膜*透析	□ 接受	□ 不接受
	抗生素	□ 接受	□ 不接受
	液體(靜脈/皮下*)輸注	□ 接受	□ 不接受
	人工餵食	□ 接受	□ 不接受
臨終安排	病者已向家屬/醫護*人員清楚表達對臨終時的環境安排。 □ 有（詳情請參閱「了解多一點」） □ 沒有		
身後事安排	病者已向家屬交代身後事宜及安排。 □ 有（詳情請參閱「了解多一點」） □ 沒有		

誰人能夠代表你的意願去作決定？

緊急聯絡姓名	與病人關係	聯絡電話
代言人姓名	與病人關係	聯絡電話
1.姓名	與病人關係	聯絡電話
2.姓名	與病人關係	聯絡電話

*請刪除不適用的

Name of relative

Name of staff

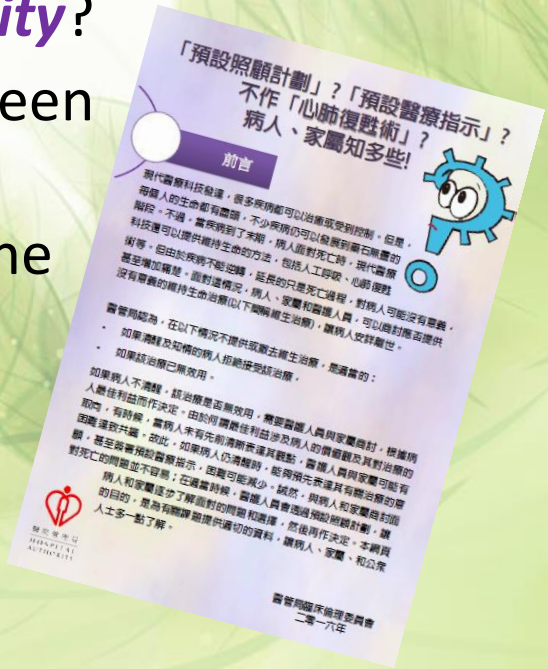
Date of completion

Name of relative

Name of surrogate

Still a challenge

- What ***ACP models*** to use?
- ***Who*** should initiate ACP?
- How to ***initiate*** with patient?
- How can ***family*** be properly involved in ACP?
- How can we make sure that the family members ***understand their responsibility***?
- How well is ***flexibility negotiated*** between patient & his/her family?
- How can ACP be ensured throughout the ***continuity of care***?


「預設照顧計劃」？「預設醫療指示」？不作「心肺復甦術」？病人、家屬知多些!

前言

現代醫療科技發達，很多疾病都可以治癒或受到控制，但是，每個人的生命都有盡頭，不少疾病仍可以發展到毫無康復的階段。不過，當疾病到了末期，病人面對死亡時，現代醫療科技還可以提供維持生命的方法，包括人工呼吸、心肺復甦術等，但由於疾病不能逆轉，延長的只是死亡過程，對病人可能沒有意義，甚至增加痛楚，面對這情況，病人、家屬和醫護人員，可以商討應否提供沒有意義的維持生命治療(以下簡稱維生治療)，讓病人安詳離世。

醫管局認為，在以下情況不提供或撤去維生治療，是適當的：

- 如果病人不清醒，該治療是否無效用，需要醫護人員與家屬商討，根據病人最佳利益而作決定。由於病情變化和治療可以是複雜的，有時候，當病人未有先前清晰表達其觀點，醫護人員與家屬可能有困難達致共識。故此，如果病人仍清醒時，能夠預先表達其有關治療的意願，甚至簽署預設醫療指示，困難可能減少。就然，與病人和家屬商討應對死亡的問題並不容易；在適當時候，醫護人員會透過預設照顧計劃，讓病人和家屬達成了解面對的問題和選擇，然後再作決定。本網頁的目的，是為有關課題提供適切的資料，讓病人、家屬、和公眾人士多一點了解。

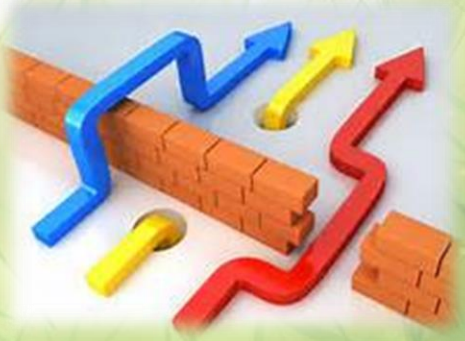
醫管局臨床倫理委員會
二零一六年

Difficulties

- Prognostication
- Difficult discussions
- Death anxiety of staff
- Making time
- Sensitivities & sadness
- May require extra communication skills

Patient barriers

- General ***anxiety*** regarding death
- Perceives only important to others, but ***irrelevant*** to them
- Believes it is ***unnecessary***, because family & physician know what to do.
- ***Lack of knowledge***
- Perceives it ***cannot be changed*** once completed
- Checklist – ***not meet patient changing wishes & needs***
- Past ***negative experience*** with dying friends & family



Health professionals barriers

- Too idealistic
- Time-intensive & too busy
- Lake of time
- Perceives low health literacy of patients
- Patient is not sick enough
- Lack of necessary communication skills & expertise

Avoiding Common Pitfalls

1. Failure to plan
2. Surrogate absent for discussions
3. Unclear patient preferences
4. Narrow focus on a specific treatment or scenario
5. Communicative patients are ignored
6. Not reading the advance directive

Avoiding Common Pitfalls

1. Failure to plan

- Do not avoid advance care planning
- Be pro-active
- It is easy to forget the central role of the patient, and easy to forget the importance of the proxy. Involve both early and often

2. Surrogate absent for discussions

- Do not leave the proxy decision-maker(s) out of the initial discussions with the patient

3. Unclear patient preferences

- Vague statements can be dangerously misleading
- Be sure to clarify patient preferences if they do not seem clear to you or to the proxy
- For instance, patients who make statements such as "I never want to be kept alive on a machine" should be asked to clarify whether their wishes would change if their condition were readily reversible, or if their prognosis were unclear

Avoiding Common Pitfalls

4. Discussion focused too narrowly

- Avoid isolated DNACPR discussions
- A DNACPR discussion is usually an indication that other palliative goals & measures should be considered in the context of a range of scenarios

5. Communicative patients are ignored

- Not to assume what patient wants in the present is what he/she indicated for future possible scenarios
- As long as the patient is competent, talk to him or her
- An impaired patient may still be able to express wishes at some level, take AD & the patient's current wishes into account

6. Not reading the Advance Directive

- Always read advance directives
- Do not assume
- Remember that AD can be for aggressive intervention, comfort care, or a wide range of specific views

Benefits of ACP

Speak to him/herself

Improve quality of life

Relieve family burden in making choice

Peace of mind

Reduce family stress

Patient's choice are respected

ACP enhancers & barriers

Enhancers

- Old age
- Personal encounter with poor death qualities of significant others
- Perceived as a priority e.g. failing health
- Death not a taboo
- Available support e.g. family & community
- Higher education level

Barriers

- Lack of knowledge
- Poor relationship with family
- Lack of support
- No faith in autonomy
- Death as a taboo

(Chan, 2010)

Key to success

Case manager factors

- ☐ Initiate ACP discussion
- ☐ Health status discussion
- ☐ Patient's value discussion
- ☐ Life-sustained treatment discussion
- ☐ Dying process & funeral discussion

Ward staff factors

- ☐ Initiate communication during dying process
- ☐ Management of pain & other symptoms
- ☐ Management of agitation
- ☐ Recognizing dying
- ☐ Use of Care plan of dying (optional)

Staff reflection

- Did I ask my patient about preferences for end-of-life care?
- Do I know who to contact if the patient cannot communicate their wishes?
- Did I include the family?
- Do I feel confident that I know my patient's wishes for care?
- Did I accurately document the nature of the conversation?

Thank you