End of Life Care
A difficult conversation

8 May 2018
HA Convention 2018

Masterclass 15:
Interactive case discussion &
Use of Applied Mediation Skills
to resolve conflicts in End-of-life Care

End-of-life Care
- A difficult conversation

An awareness of

1. End-of-life care issues – feeding.
2. End-of-life care conversation
3. Applied mediation skill to resolve conflicts.

Interactive discussion
Role play
75 minutes only

五福臨門
第五福？

五福臨門

出於《尚書·洪范》。

第一福是“長壽”
第二福是“富貴”
第三福是“康寧”
第四福是“好德”
第五福是“善終”。

善終是生命即將結束時，
沒有遭到橫禍，
身體沒有病痛，
心裏沒有挂礙和煩惱，
安詳而且自在地離開人間。

Good Life All the Way to the End

WHEN THE TIME COMES, MAKE IT A 'GOOD DEATH'

Researchers are now looking at personalising a person's death to ensure that those last few moments are as comfortable and meaningful as possible

Associated Press

What do you see when you picture an ideal death?

Are you surrounded by friends and family, or is the setting more intimate? Are you at a hospital or at home? Are you pain free? Were you able to feed yourself up until your death? Is there a spiritual element to your experience?

"We talk about personal medicine, but there should be personalised death too," said Dr Dilip Jeste, director of the Sam and Rose Stein Institute for Research on Ageing at the University of California, San Diego School of Medicine. "Finding out what kind of death a person would like to have should not be a taboo topic."

To help open up the conversation in our death-phobic culture, Jeste and his colleagues are working on a broad definition of a "good death" that will help health care workers and family members ensure that a dying person's final moments are as comfortable and meaningful as possible.

"You can make it a positive experience for everybody," Jeste said. "Yes, it is a sad experience, but knowing it is inevitable, let us see what we can do that will help."

The group's first step was to look at previously published studies that examined what constitutes a good death according to people who are dying, their family members and health care workers. The results were published this week in the *American Journal of Geriatric Psychiatry*.

The researchers searched through two large research databases – PubMed and PsycINFO – but they were able to find only 36 articles in the last 20 years that were relevant to their work.

Jeste said the lack of studies on a good death was not surprising.

religiosity and spirituality. Also on the list were life completion, treatment preferences, preference for dying process, relationship with health care provider, and "other".

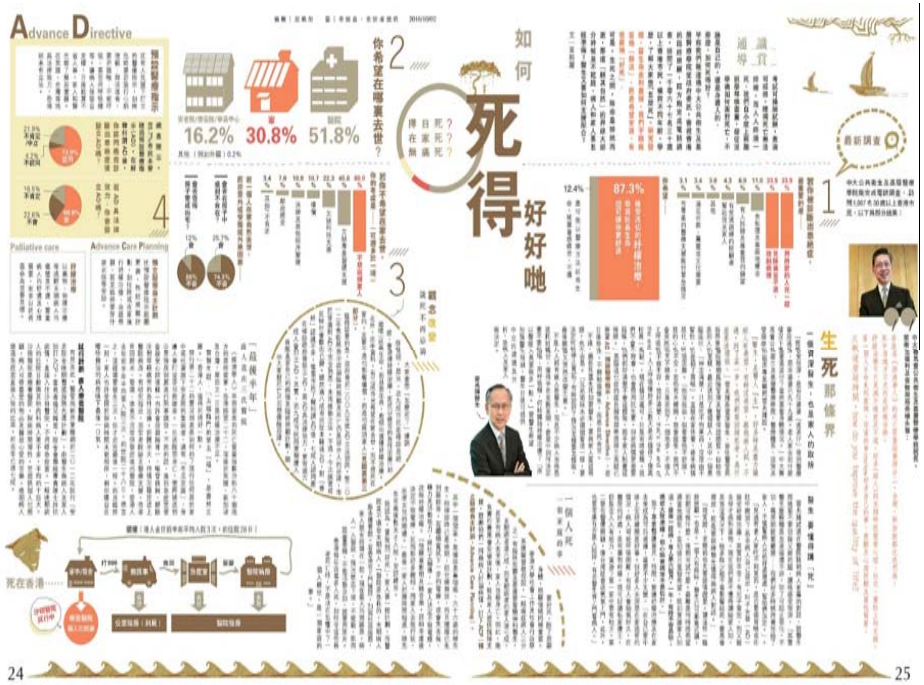
The authors reported that the most important elements of a good death differed depending on whom you asked, but there was agreement on some of them.

One hundred per cent of patients and family members as well as 94 per cent of health care workers said preference for the dying process – defined as getting to choose who is with you when you die, as well as where and when – was an important element

Finding out what kind of death a person would like should not be a taboo topic

DR DILIP JESTE

Hong Kong
SCMP
April 2016



HA CONVENTION
Hospital Authority Convention 2016

Chief Executive's Speech
Hospital Authority Convention 2016 – 3-4 May 2016

Travelling Life's Journeys Together

In planning for a 'good death', we can create better lives for ourselves and our loved ones by reducing uncertainty and fear. HA's mission to help people stay healthy is underpinned by a belief in whole life well-being – from birth to death.

With the strong support of our dedicated staff, patients and the broader Hong Kong community, we will help current and future generations of people in Hong Kong enjoy rich, active and fulfilling lives & **when the time comes, to experience a good death that is just the last of many blessings in one's life.**

http://ha.org.hk/haho/ho/admin/HAC2016_CE_speech_EN.pdf

Leaders

How to have a better death

What matters

… these medicalised deaths do not seem to be what people want.

… too often patients receive drastic treatment in spite of their dying wishes - by default, when doctors do "**everything possible**", as they have been trained to, without talking through people's preferences or ensuring that the prognosis is clearly understood.

When to let go, to allow
a serene (安祥) passing away?

A challenge, a dilemma for

- healthcare professionals
  … always to do the best & more.

- Family members on the care of
  their love one.

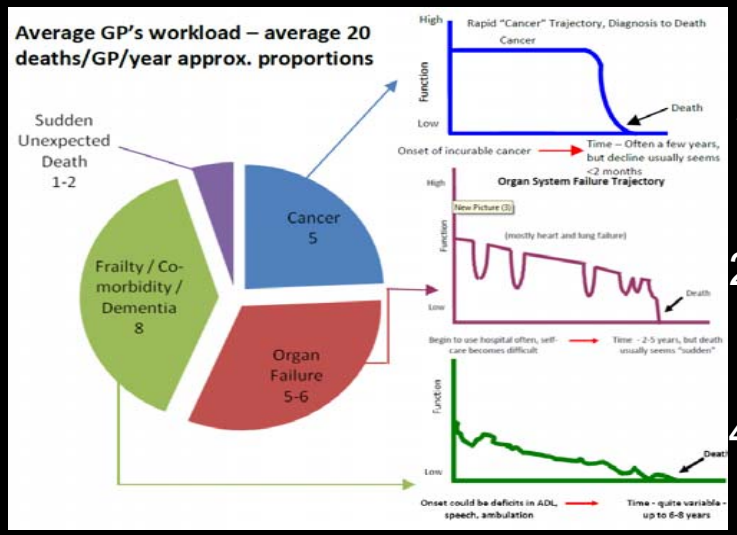
The beginning and the end of

THE END

is a <u>continuum</u>

of conditions, care

& conversation.



25%

25%

40%

人生最後的路程 - 死亡
是合時的、不早不遲的、
是安祥的、是五福「善終」。

The final journey of life - DEATH,
is timely, not early, nor too late,
is serene, is a 5th blessing.
A good life to the very end.

A Reflection…
Lui Siu Fai 18.5.2016

End of Life Care

There is a time towards the later phase
of our care for a patient,
to reassess his/her situation
for a different mode of care
(end of life/palliative care).

NOT a case of stopping treatment.

A case of starting / escalating good
EOL (palliative) care

End of Life Care

Many aspects:

- Physical (weakness, frailty)
- Mental
- Organ failure / symptoms

Feeding difficulty

Feeding issues

- Oral feeding
- Difficulty in swallowing / inadequate intake

=> Tube feeding?
Other options?

Decision by who?

- Healthcare professionals
- Patient/ relative
- Dispute ?

Doctor pushing for tube feeding …

M/76歲，長期卧床，與家人同住，由工人照顧，已家人同意不作心肺復甦法。入院後，家人拒絕插置胃管餵飼，三餐一直是工人由口餵飼。但出現發燒情況，再轉介言語治療師評估，結果建議插置胃管。

主診醫生致電其二女傾談言語治療師建議，
醫生說:「你不許病人插置胃管，太殘忍。」
二女聽了，回覆要與家人商討此情況。
及後其二女回電病房，表示同意插胃管，請告知主診醫生。

那天星期五下午插置胃管，零晨開始管飼。但星期六早上七時發現有胃出血情況，停止管飼，只給予藥物。
星期日下午二時病人突然離世。通知家人，其二女到病房不接受離世，說要投訴至醫院管理局，說:「插胃喉插死病人，要交代病人死因。」

Family pushing for tube feeding …

016年10月25日 星期二

「醫師，幫爸爸放鼻胃管好不好，我不想看他餓死……」

者：朱為民

… 他真的吃東西愈吃愈少。有一天查房時，他兒子說：「醫師，我們幫爸爸放鼻胃管好不好？他真的吃很少，我很擔心。」於是，我走到病床前，握著余爺爺的手，問他：「爺爺，你都沒有吃東西，我們在鼻子放一條管子給你喝牛奶好不好？」爺爺搖搖頭。
看到爸爸搖頭，他兒子趕緊衝過來跟老爸說；「爸！你都沒有吃耶！這樣怎麼會有體力？放個管子，好不好？」他說服了好久，令人驚訝的是，爺爺後來點頭了。於是我們幫爺爺插上了鼻胃管。
隔天，我又去查房，發現爺爺的鼻胃管不見了，我趕緊問：「怎麼了？」護理師才說：「爺爺半夜一直拔管子，在清晨時還是不小心被他得手了。」兒子在旁邊很自責的樣子，說：「唉！都是我不好，上個廁所，管子就被他拔掉了！」我拍拍他肩膀，安慰他：「沒關係，爸爸不喜歡，我們就不要勉強，可以試著從嘴巴吃一點布丁類的食物，比較好吞。」他點點頭。

又過了一周，爺爺的呼吸開始變得很喘，使用了嗎啡才稍微好些，到這時，爺爺完全無法再進食任何東西了。我跟護理師點點頭，彼此都知道，爺爺即將要離開了，沒想到，他的兒子說了一句讓我們很驚訝的話：「醫師，幫爸爸放鼻胃管好不好，我真的很怕他會這樣餓死……」說完，二行眼淚就這樣留下來。我拍拍他的肩膀，跟他說：「這真的很難吧！」他愈哭愈厲害，只好轉身到病房外面走廊。過了沒多久，他回來了，他走到爸爸身邊問他說：「爸！你都沒有吃，我們再放個管子，好不好？」爺爺沒有表示，沒力氣了。
儘管我們試圖同理兒子的心情，也說了很多關於現在的狀況不適合再放鼻胃管的理由，他仍然堅持要幫爸爸放鼻胃管。放了鼻胃管之後，爺爺就開始掙扎，但是他沒有力氣把管子拔掉了，只好不停扭動頭部。過了二小時，兒子請我們把管子拔掉。隔天，爺爺過世了。

Family members with different views…

小 大

瓊瑤拒絕悲劇結局　流行小說

2017年9月3日 第31卷 35期

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七十九歲的台灣流行小說女王瓊瑤，最近因反對讓九十歲的失智丈夫平鑫濤繼續插鼻胃管治療，而與繼子女失和，演繹痛苦人生。她的新書《雪花飄落之前》，描述與平鑫濤的感情，並希望藉她照顧丈夫的心路歷程，呼籲華人社會重視「死的尊嚴」，帶動社會實踐「善終權」的新觀念——「生之時如火花般燃燒到生命盡頭，死之際如雪花般飄然落地」，拒絕悲劇結局。

瓊瑤（圖：天下文化）

台灣流行小說女王瓊瑤最近成了社會版的焦點，她因反對讓失智的丈夫、被評為「台灣邵逸夫」的平鑫濤插鼻胃管跟繼子女們公開失和，一樁家務事鬧到不可開交，引起社會關注。

今年七十九歲的瓊瑤和九十歲的平鑫濤鶼鰈情深，結縭三十九年，兩人相依為命，二零一五年他失智後身體日衰，去年三月大中風，醫生確定他不會再醒來，瓊瑤傷心欲絕，面對老伴說不出的苦，她反對讓他插鼻胃管，認為這只是「加工活著」，徒增折磨，但他的三名子女堅持要插管，認為他們父親是個鬥士，只要有一點機會就不會放棄，何況他只是「失智」，還不到「病危」。

瓊瑤孤掌難鳴，只能屈服，但此舉她認為是對夫婿的「背叛」，氣得要跳樓，但被秘書和媳婦強拉住。一場繼母和繼子女的衝突，最終演變成家變，她夢見平鑫濤要她把這段遭遇寫出來，但平家子女對她違諾寫書，極力反對，她為呼籲「善終權」，忍痛用生命來書寫最後的悲劇，自認自己做了一件「很對的事」，堅持不屈，這充滿戲劇張力的情節宛若「瓊瑤小說」再現，她攪進了被自己小說情節還痛苦的糾結。


賽馬會安寧頌

個案：陳先生

簡介 個案 背景資料 主題

The case was originally presented by Dr. Wong Che Keung on 23 April 2016 in the Clinical Ethics Day held in HA Head Office Lecture Theatre.

陳先生

- 84歲，患有高血壓、糖尿病、 復發性中風、認知障礙症
- 去年開始，需要臥床，大小便失禁，依靠他人餵食
- 兩個兒子和一個女兒，皆住在香港
- 妻子數年前去世 ，之後他和次子一家同住，由媳婦瑪莉照顧
- 過去幾個月，他愈來愈虛弱，瑪莉無法再獨自扶他下床。他現在被送到安老院居住

- 他因吸入性肺炎多次入院
- 經言語治療師評估，陳先生有吞嚥困難，食物容易誤入氣管，引起肺炎，建議他使用胃喉
- 次子說：「爸爸不想被插入胃喉，他在安老院見過很多使用胃喉的院友，只能整天躺在床上，這不是他想要的生活。」
- 女兒也同意， 決定選擇用人手小心餵食
- 他們明白陳先生有肺炎和死亡的風險

- 數個月後，陳先生發燒、昏睡，被送入醫院
- 發現有嚴重的肺炎。次子和女兒得知父親的病情惡化，並會很快離世。 他們同意使用保守治療（注射抗生素、不使用胃喉）
- 長子在第二天到醫院，堅持要使用胃喉。他說：「我爸爸臨終前要有吃飽，這很重要！我不想他成為餓鬼。」

How should the situation be managed?

By the healthcare professionals and the family?

You would support

Younger son

Careful feeding

Elder son

Tube feeding

An awareness of the feeding options for end of life care

=> Dr. Carolyn Kng

HA Convention 2018 Masterclass 15
Difficult End-of-Life Care and Conversation
- Interactive case discussion. Applying mediation skill to resolve conflict

晚程關顧服務 - 舒適餵食

Careful Hand (Comfort) Feeding for End-Of-Life Care

康佩玲醫生
港島東醫院聯網基層及社會醫療服務總監
律敦治及鄧肇堅醫院老人科部門主管

Date: Tuesday 8 May 2018

餵食問題 - 趨勢

- 人口老化
- 增加腦認知障礙症，柏金遜症和中風的發病率
- 以上病者病情於較嚴重階段遇到餵食問題非常常見

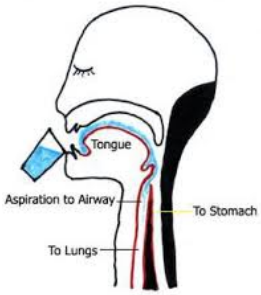
餵食的常見問題

攝取食物量不足

- 脫水及營養不良

吞嚥困難

- 70%長者患有吞嚥困難 [1]
- 吸入性肺炎



[1] Leder SB, Gerontology 2009

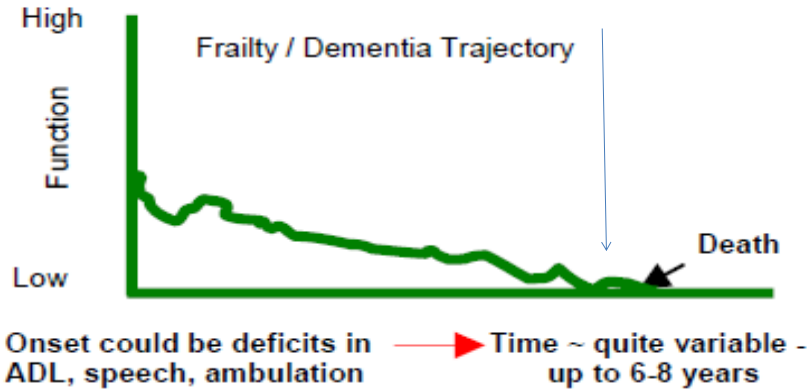
餵食問題 - Poor Prognosis

- 晚期認知障礙症

85% 患者在臨終前的1.5年內有餵食問題

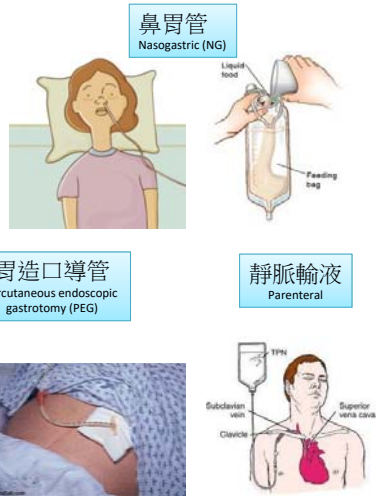
發生餵食問題後6個月內死亡率高達39%

Mitchell S, NEJM, 2009



餵食選項 - Feeding Options

- 口服餵養
  Oral Feed
- 人工營養及流體餵養
  Artificial Nutrition & Hydration (ANH)



? 仔細餵食 (手餵)
? Careful Hand Feeding

? 舒適餵食
? Comfort feeding

HA Guidelines on life sustaining treatment in terminally ill , v2015

舒適餵食選項 Careful Hand Feeding Option

- 仔細餵食技巧
  Careful hand feeding - Techniques

姿勢
position
食物稀稠程度
Food consistency
提示吞嚥，每口食物讓患者吞嚥數次
Swallow reminder, multiple
小口份量進食
Small bolus size

Li, 2002, Sherman 2003, DiBartolo 2006

- 舒適餵食的照顧目標
  Comfort feeding – Goals of care
  - 舒適為本 (減低入侵性)
    comfort-orientated (least invasive)
  - 份量不是重點
    quantity not main focus
  - 能享用喜愛的食物，注重餵食時的交流
    taste favorite foods, touch
  - 吸入性肺炎的風險
    risk of aspiration

Palacek E, JAGS 2010, RCP 2010

臨床個案: 非口腔方式餵食 Clinical Scenario : "Non- Oral Feed"

黃女士

- 晚期認知障礙症
- 多次感染肺炎
- 建議非口腔方式餵食 "Non-oral feed"
- 兒子詢問什麼是最佳餵食方案

1.平衡得益及負擔
Balance benefits & burdens of options

2.甚麼是病人的最佳利益
What is best interests of the patient

3.病人闡明期望、建立共識
Clarify expectations, build consensus

1.平衡得益及負擔 Balance Benefits & Burdens

	管飼餵食 Tube Feeding	舒適餵食/仔細餵食 (手餵) Comfort/Careful hand Feeding
目標 Goals	食物份量 Quantity of feed (reliable)	質素及份量 "Quality" vs quantity (variable)
方法 Means	人工方式 Artificial	食物天然的味道 Natural taste food, touch
考慮因素 Concerns	身體約束/激動/拔去喉管 Restraint, agitation, pull out tube	吸入性肺炎及餵食時間較長 Aspiration, pneumonia, time consuming for carer
證明 Evidence	沒有科學證明管飼餵食比手餵優越 No evidence tube feed is superior to hand feed . It does not • 延長壽命 [1,2] Prolong survival • 避免吸入性肺炎[3] Prevent aspiration • 改善生活質素 [4] Improve quality of life or function • 減少飢餓,口渴 Reduce hunger/thirst sensation	

[1,2]mortality in tube fed elderly 63% at 1 year, median survival 7.5 months

[3] Tube does not prevent aspiration of oral secretions, food reflux from stomach, affect sphincter function

[1] Mitchell S, Arch Int Med 1997 [2] Rabeneck L, J Gen Int Med 1996 (3) Finucane T, Lancet, 1996 (4) Callahan CM, JAGS 2000

2.甚麼是病人的最佳利益 ? What is best interests for patient ?

醫院管理局末期病人使用維生治療指引|2015 HA Guidelines on life sustaining treatment in terminally ill,V2015

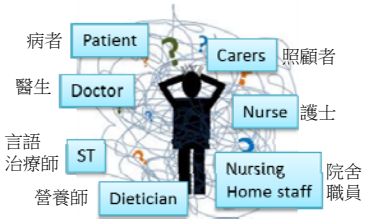
- 第8章:人工營養及流體餵養 Section 8 : Artificial Nutrition & Hydration
- 附件4:晚期認知障礙症病人餵食的道德討論 Appendix 4 : Ethical discussion on feeding in advanced dementia

- **病人意願, 例如: 拒絕管飼餵食**
  Patient's wish
  - 清醒的病人的意願
    Decision by mentally competent patient
  - 持有有效的預設醫療指示
    Valid advance directive
  - 代理人的決擇, 例如: 家人
    Surrogate decision maker eg family
  - 患者的最佳利益
    Best interest
  - 臨終期或當死亡不可避免
    Death is imminent/inevitable

- **仔細餵食有吸入性肺炎的風險**
  Careful hand feed with aspiration risk
  - 「知情同意」的共識
    "informed consent' consensus
  - 所有治療均有潛在的風險和效益
    all treatments have potential risk and benefit
  - 減低風險的方法、記錄
    measures to reduce risks, documentation

3. Clarify expectations & build consensus with families/carers

合作
Teamwork



考慮
Considerations

醫療風險評估 **Medical risk assessment**
可逆轉? 末期? Reversible ? Terminal ?
保護氣道 Airway protection
營養 Nutrition
困難 - 拒絕使用喉管,約束Distress – resist tube, restraint

病人意願及最佳利益
Patient's wish & best interest
信念及意願 Values & wishes
預設醫療指示 Advance care plan
照顧目標 Goals of care

溝通期望
Clarify expectations
仔細餵食的技巧 + 時間
Skills & Time for careful hand feeding
家人顧慮
Family concerns
醫院及院舍職員
Hospital & residential home staff

Approach to Decision Making for Feeding Options

- 「全人照顧」的考慮
  Holistic considerations
- 溝通及與家人的共識 (調解技巧)
  Communication & consensus (mediation skills)
- 餵食方案
  Feeding plan
- 培訓
  Training
- 記錄
  Documentation

End of life conversation

A difficult and challenging conversation
for Patient / Family
& Healthcare professionals.

We need a EOL conversation to guide the EOL care for a better death, 第五福 “善終”

End of life conversation

A Challenging & Difficult Communication

Enhance communication
with mediation skill

MEDIATION

調解 [三口六面]

A structured process whereby
two or more parties to a dispute
attempt by themselves,
on a voluntary basis,
to reach an agreement on
the settlement of their dispute
with the assistance of a mediator.

MEDICAL PRACTICE

The practice of mediation to resolve clinical, bioethical, and medical malpractice disputes

Danny WH Lee *, Paul BS Lai

ABSTRACT

Mediation is a voluntary process whereby a neutral and impartial third party—the mediator—is present to facilitate communication and negotiation between the disputing parties so that amicable settlements can be agreed. Being confidential and non-adversarial in nature, the mediation process and skills are particularly applicable in clinical practice to facilitate challenging communications following adverse events, to assist bioethical decision making and to resolve disputes. Mediation is also a more effective and efficient means of dispute resolution in medical malpractice claims when compared with civil litigation. Health-care mediation teams should be set up at individual facilities to provide education and consultation services to frontline staff and patients. At a community level, the Government, the mediation community, and the health-care professionals should join forces to promote mediation as a means to settle medical malpractice claims outside of the courtroom.

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Day to day operation / simple dispute

Healthcare professionals
with Patient / Family
with staff between colleagues
Front line staff & management

Complaint management
Difficult situation
Adverse event

Front line management:
Ward Manager, AC/CON
Department level:
Team head, / DOM / COS
Hospital Management Level:
PR / Senior Admin

Challenging Patient Communication

Communication with negotiation & applied mediation skill

Handling conflicts, complaints, care planning

Half day forum for Frontline staff

Full day workshop for HA mid-level / senior staff

9 MEDIATION SKILLS
調解技巧: 5策略 9步驟

1. Manage emotion 情緒管理
2. Clarify issues 澄清問題
3. Refocus issues 重新聚焦問題
4. Understand 理解
5. Explore 探索

- Empathy 同理心
- Anger management 憤怒管理
- Active listening 積極的傾聽
- Deep questioning 深層的訊問
- Reframe 重構
- Paraphrase 釋義
- Summarize 總結
- Position / Interest 立場 / 利益
- OPTIONS 可選方案

1. Manage emotion
情緒管理

1. Empathy
同理心

- The action of understanding, being aware of, being sensitive to, and experiencing the feelings, thoughts, and experience of another
- Feel how they feel,
  Feel what they feel.

1. Manage emotion
情緒管理

2. Emotion (Anger) Management
憤怒管理

- Feelings are part of the conflict, often not articulated but run deep
- Anger, hurt, resentment.

2. Clarify issues
澄清問題

3. Listening (active)
積極的傾聽

- The listener to feed back what they hear to the speaker, by way of **re-stating** or **paraphrasing** what they have heard in their own words, to confirm what they have heard and moreover, to confirm the understanding of both parties. (Wikipedia)
- **Interactive listening:**
  encourage to express their INC

Source: Norris Yang

2. Clarify issues
澄清問題

4. Questioning (deep)
深層的訊問

- What? What is the problem?
- Why? Why are we doing this?
- Who? Who should be involved?
- When? When should we do this?
- Where? Where should we do this?
- hoW? How are we going to do this?
- Why not? Why can we not do it that way?
- **Work Smart**

Source: Norris Yang

3. Refocus issues
重新聚焦問題

5. Reframe
重構

result in a phrase/ sentence that is more

- **M**utual
- **N**eutral
- **N**ormal
- **S**imple

3. Refocus issues
重新聚焦問題

6. Paraphrase
釋義

- Restate what speaker has said in your own words
- Explain and clarifying the text, communicate understanding to others

3. Refocus issues
重新聚焦問題

7. Summarize
總結

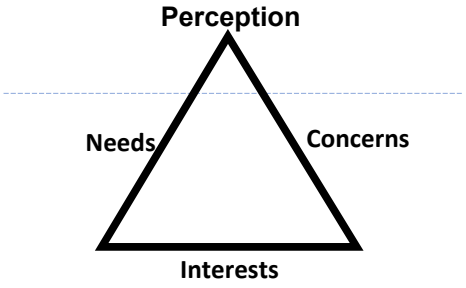
- **Act of intervention :**
  In order to make sure that I understand you correctly, let me summarize you have just said ……..
- **Facilitating <u>active listening</u> :**
  Let's recap…….

4. Understand
理解

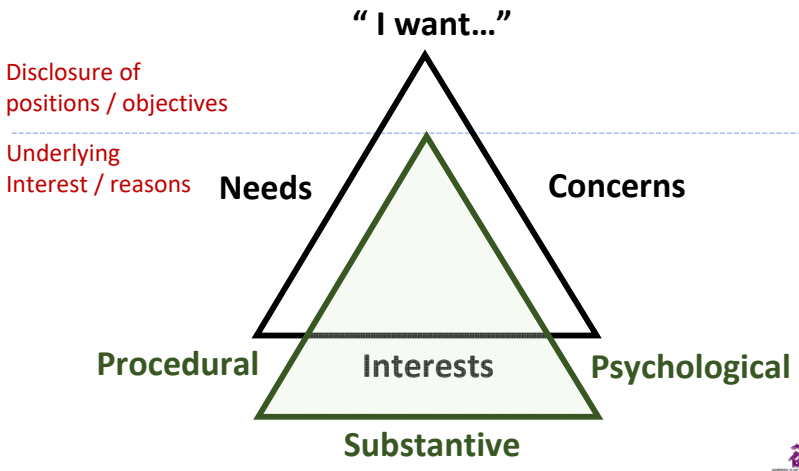
8. Interest behind the position 立場 / 利益

- What is "**position**" ?
  "I want……"
- What is "**interest**"?
  "Why I want……"

Interest, Needs, Concern (INC)



"Position" and "Interest"



5. Explore options
探索 可選方案

9. Options 方案

- General options - Interest base negotiation
- Interests behind the position
  Options are to address the interests
- **BATNA**
  Best **A**lternative **T**o a **N**egotiated **A**greement
- **WATNA**
  Worst **A**lternative **T**o a **N**egotiated **A**greement)

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調解技巧: 5策略 9步驟

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有 傾
有 講
mediation
有 商
有 量

人物介紹

- **大仔背景：**
  客貨車司機，收入微薄，
  有孫兒會在幾個月後出生。
  個人主觀地不太信任醫護人員。

- **細仔背景：**
  貿易公司經理，家庭環境較好，
  有妻子及1位兒子。

1. 兄弟的爭拗

2.醫生的討論

3. 調解

Discussion

Moderators: Dr. SF Lui, Dr. KS Tang

Panel:
Dr. Carolyn KNG
Dr. Jacqueline Yuen
Dr. KM Chow
Mr. Charlie Yip
Mr. Yuen Siu Lam
Prof. Paul Lai

Session Chairperson

Mr. Charlie Yip
Board member, Hospital Authority
Vice Chairperson, Patient Voices.

Moderators

Dr. Tang Kam Shing
Co-Chairman HA Central Committee PR&E
HCE(DKCH/FYKH/MMRC

Dr. LUI Siu Fai
Adjunct Professor, Jockey Club Institute of Ageing &
Clinical Professional Consultant,
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Speakers* / Panel members#

Dr. LUI Siu Fai*#

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Dr. Jacqueline Yuen*#
Clinical Lecturer, Department of Medicine & Therapeutics, CUHK

Dr. Carolyn KNG*#
HKEC SD(P&CHC) / RTSKH Cons(IMS),
Head of Department (Geriatric)

Prof. Paul Lai#
Department of Surgery, CUHK

Mr. Charlie Yip#

Mr. Yuen Siu Lam#
Chairperson, Hong Kong Alliance of Patient Organization

Role play

Dr. Tang Kam Shing
HCE(DKCH/FYKH/MMRC

Dr. David Sun
HCE, NDH

Ms. Mok Yi Tan
DKCH WM(OTS)

Dr. Chow Kai Ming
NTEC CC(PR&E) /PWHMED COS(MED)

Dr. Lui Siu Fai

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