


佛光山綜合醫院  
BUDDHIST TZU CHI GENERAL HOSPITAL

# Community Engagement in EoL care


Yingwei Wang M.D. DrPH  
Tzuchi University/ Tzuchi General Hospital  
Heart Lotus Hospice

志為人醫 守護愛



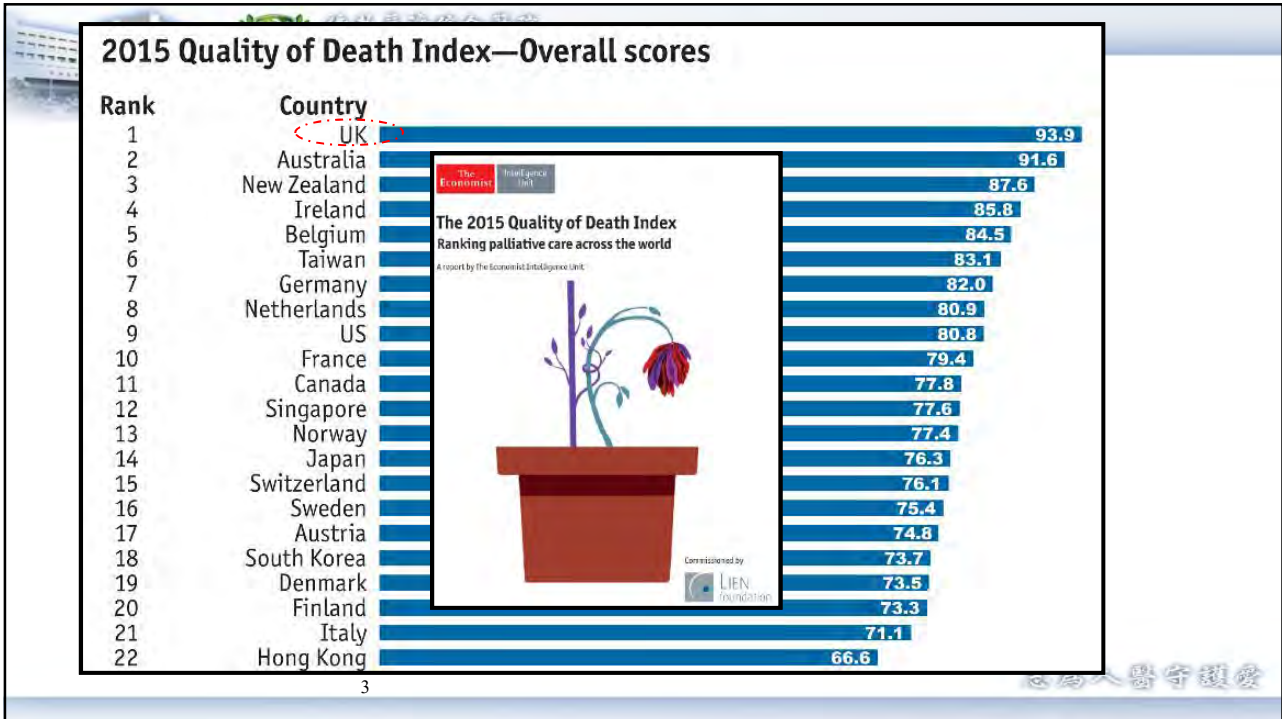
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In the past one and half day, we spent a lot of time on looking at

half empty →  ←

Now this time we start to look at the other side - half full -

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	Rank/80	Score/100
Quality of Death overall score (supply)	1	93.9
Palliative and healthcare environment	1	85.2
Human resources	2	88.2
Affordability of care	=1	100.0
Quality of care	1	100.0
Community engagement	=3	92.5

**SNAPSHOT**  
A pioneer in palliative care, the United Kingdom maintains cutting-edge services and is the world's best location to receive terminal care and pain-alleviating treatment.


**IN DETAIL**  
Dame Cicely Saunders was an early advocate of




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The Economist Intelligence Unit		The 2015 Quality of Death Index Appendix II: Quality of Death Index Methodology	
Indicator	Unit Year	Weight	Description
<b>Community engagement</b>		<b>10%</b>	
Public awareness of palliative care	EIU rating 2014	70%	Public awareness and information around of palliative care. 5= Public has a strong understanding and awareness of palliative care services. Readily available information on palliative care is available from government portals and community mechanisms. 1= Public no understanding and awareness of palliative care services. There is no information on government portals and community mechanisms on palliative care.
Availability of volunteer workers for palliative care	EIU rating 2014	30%	Availability of volunteer workers for the care of palliative care patients. 5=There are sufficient volunteer workers to meet the needs of the country's palliative care system; volunteer workers are mostly in the care of patients and they receive regular training in the care of patients. 1= There are very few volunteer workers in palliative care services, and they are mostly not well-trained in the care of patients.

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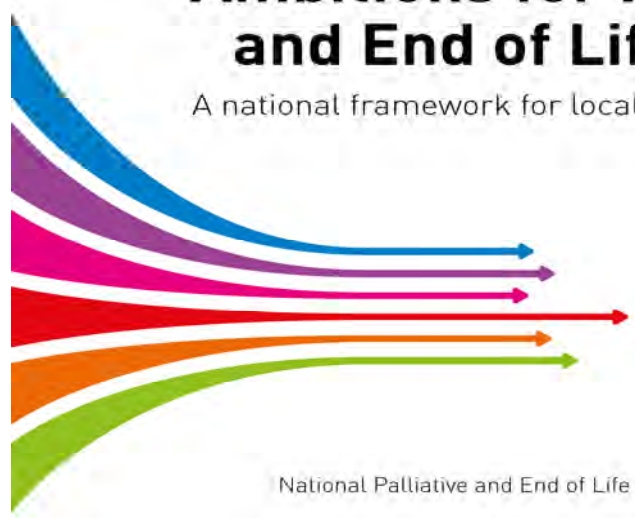




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## Ambitions for Palliative and End of Life Care:

A national framework for local action 2015-2020



National Palliative and End of Life Care Partnership

醫守護愛

01 德華國際綜合醫院

***“The will, determination and innovation of organisations working collaboratively to find new ways of delivering better care will, and must, make a difference”.***

*The Foreword: Ambitions for Palliative and End of Life Care*



National Palliative and End of Life Care Partnership  
www.endoflifecareambitions.org.uk

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01 德華國際綜合醫院

**Six ambitions to bring that vision about**

- 01 Each person is seen as an individual
- 02 Each person gets fair access to care
- 03 Maximising comfort and wellbeing
- 04 Care is coordinated
- 05 All staff are prepared to care
- 06 Each community is prepared to help


*“I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s).”*



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www.endoflifecareambitions.org.uk


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## Each community is prepared to help

*I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways.*



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## Each community is prepared to help

<p><b>Compassionate and resilient communities</b></p> <p>Public health approaches to palliative and end of life care need to be accelerated and support given to people and communities who can provide practical help and compassion.</p>	<p><b>Public awareness</b></p> <p>Those who share our ambition should work to improve public awareness of the difficulties people face and create a better understanding of the help that is available.</p>
<p><b>Practical support</b></p> <p>Local health, care and voluntary organisations should find new ways to give the practical support, information and training that enables families, neighbours and community organisations to help.</p>	<p><b>Volunteers</b></p> <p>To achieve our ambition more should be done locally and nationally to recruit, train, value and connect volunteers into a more integrated effort to help support people, their families and communities.</p>

[www.endoflifecareambitions.org.uk](http://www.endoflifecareambitions.org.uk)

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## The Way Forward National Framework 2015

- **At all stages of frailty or chronic illness**, not just at the end of life
- To give individuals and families **a greater sense of control**.
- Hospice palliative care as less of a discrete service offered to dying persons ....simultaneous or **integrated approach** ....quality of life ...the course of their illness or the process of aging.




## The Need for a **System-wide Shift**

1. Promote a Culture Shift
2. Establish Common Language and Terminology that supports dying as part of living
3. Educate and Support Providers
4. Engage Canadians **in Advance Care Planning**
5. Create **Caring Communities**
6. Adapt an Integrated Palliative Approach to Provide Culturally-Safe Care, including with and for Canada's First Peoples
7. Develop Outcome Measures and Monitor the Change

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## New Movements in Hospice and Palliative Care

The Ministry of Health and Welfare organized a taskforce to develop hospice and palliative care in 1995.

**First**

- Development of Hospice concept
- Focus on cancer
- Development of hospital care, shared care and home care

**Second**

- Non-cancer on Hospice
- ACP / Shared decision making SDM
- ICU, ES care

**Third**

- The elderly and children of Hospice Care
- Early palliative Care
- Hospice of Long-Term Care and community
- New Technology in community Palliative care
- Patient Self-Determination Act
- **Compassionate cities/compassionate community**

Start      Present      Future

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### Indicator scores

	Rank / 80	Score / 100	Data	Unit
<b>SUPPLY ENVIRONMENT</b>	<b>6</b>	<b>82.1</b>		0 - 100 where 100= best and 0=worst
<b>1) PALLIATIVE AND HEALTHCARE ENVIRONMENT</b>	<b>7</b>	<b>74.5</b>		0 - 100 where 100= best and 0=worst
1.1) Healthcare spending	46	36.9	6.6	% of GDP
1.2) Presence and effectiveness of government-led national palliative	=1	100.0	5	EIU rating
1.3) Availability of research-based policy evaluation	=1	100.0	5	EIU rating
1.4) Capacity to deliver palliative care	12	61.3	39.0	%
<b>2) HUMAN RESOURCES</b>	<b>10</b>	<b>69.4</b>		0 - 100 where 100= best and 0=worst
2.1) Availability of specialised palliative care workers	=4	75.0	4	EIU rating
2.2) General medical knowledge of palliative care	=7	75.0	4	EIU rating
2.3) Certification for palliative care workers	=1	100.0	1	EIU rating
2.4) Number of doctors per 1,000 PC-related deaths	24	49.2	588.8	Doctors per 1,000 non-accidental deaths
2.5) Number of nurses per 1,000 PC-related deaths	=11	47.7	1731.9	Nurses per 1,000 non-accidental deaths
<b>3) AFFORDABILITY OF CARE</b>	<b>=6</b>	<b>91.7</b>		0 - 100 where 100= best and 0=worst
3.1) Availability of public funding for palliative care	=7	75.0	4	EIU rating
3.2) Financial burden to patients for available palliative care	=1	100.0	5	EIU rating
3.3) National pension scheme coverage of palliative care services	=1	100.0	3	EIU rating
<b>4) QUALITY OF CARE</b>	<b>=7</b>	<b>87.5</b>		0 - 100 where 100= best and 0=worst
4.1) Presence of monitoring standards for organisations	=1	100.0	1	EIU rating
4.2) Availability of painkillers	=1	100.0	5	EIU rating
4.3) Availability of psycho-socio support for patient and families	=1	100.0	3	EIU rating
4.4) Presence of Do not resuscitate (DNR) policy	=1	100.0	1	EIU rating
4.5) Shared decisionmaking	=5	50.0	3	EIU rating
4.6) Use of patient satisfaction surveys	=4	75.0	4	EIU rating
<b>5) COMMUNITY ENGAGEMENT</b>	<b>=3</b>	<b>87.5</b>		0 - 100 where 100= best and 0=worst
5.1) Public awareness of palliative care	=5	75.0	4	EIU rating
5.2) Availability of volunteer workers for palliative care	=1	100.0	5	EIU rating

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### Case study: Taiwan—Leading the way

	Rank/80	Score/100
<b>Quality of Death overall score (supply)</b>	<b>6</b>	<b>83.1</b>
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



The quality of palliative care in Taiwan is high (it is tied for eighth place in this category), with a focus on improving the quality of a patient's last days. Major steps have been made in recent years: Dr Siew Tzuh Tang, a professor at Chang Gung University School of Nursing, reports substantial improvement in several end-of-life indicators between her team's national surveys in 2003/4 and 2011/12. For example, while less than half of terminally ill cancer patients were aware of their prognosis in the first survey, this number increased to 74% by 2012. Use of aggressive medical treatments for cancer patients in the last month of life, such as CPR and intubation, also declined over this period.

Community engagement, in particular to break down cultural taboos against discussing death, has also been a focus. Such taboos are still widespread, but proponents of palliative care are attempting to change that by introducing discussions of life and death into the education system from primary school through university, and by changing the mindset of patients.

"Family members feel that for the patient to die without CPR is not filial," says Dr Rongchi Chen, chairman of the Lotus Hospice Care Foundation. "But we are trying to teach people that filial duty and love should find its expression in being with the family member at the end of his or her life, and in encouraging acceptance of disease and peaceful passing."

### Social movement and advocacy for death education

財團法人  
佛教蓮花基金會

全國第一個以臨終關懷為宗旨，  
推動生死教育的佛教公益機構。

~活著，是最好的禮物；  
善終，是最美的祝福~







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送你一份  
的禮物  
Love Gift

預立醫療自主計畫  
Advance Care Planning

王英倩

送你一份  
的禮物  
Love Gift

預立醫療自主計畫(ACP)宣傳影片

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安寧照顧基金會  
AN寧照顧基金會

對於生死，你的態度是什麼？

The four seasons of life

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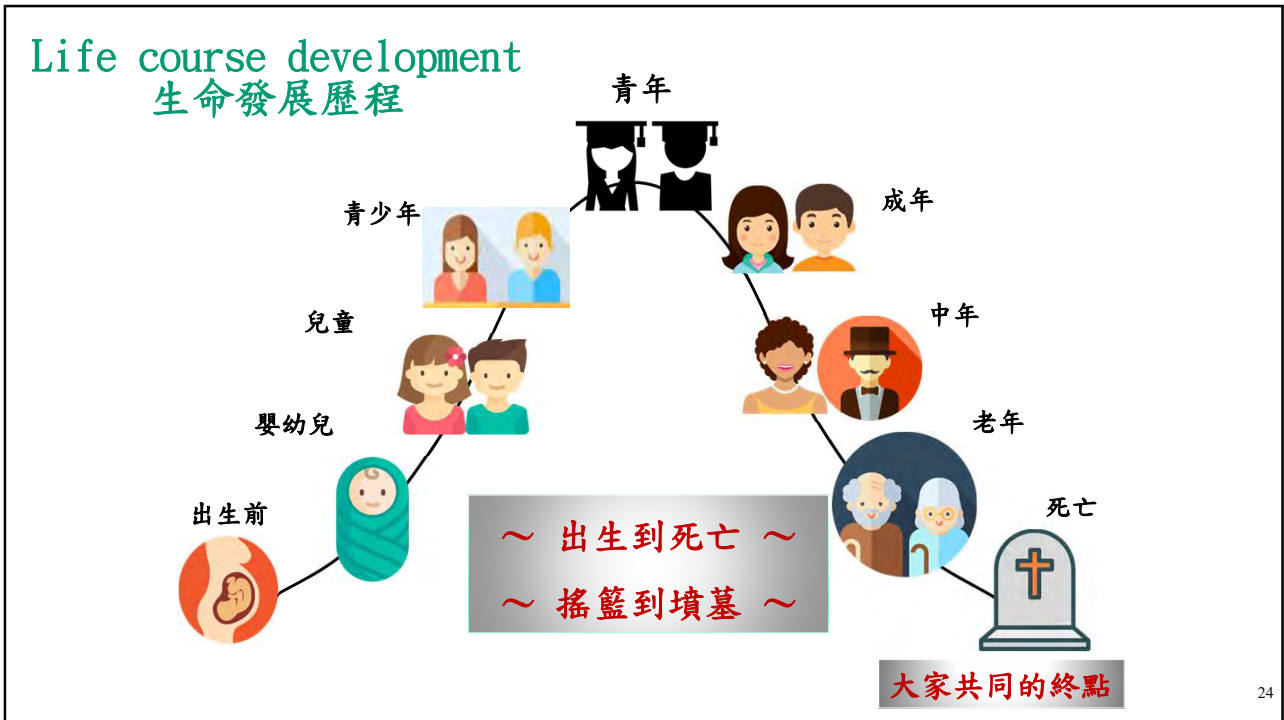
## 社區ACP 的推動

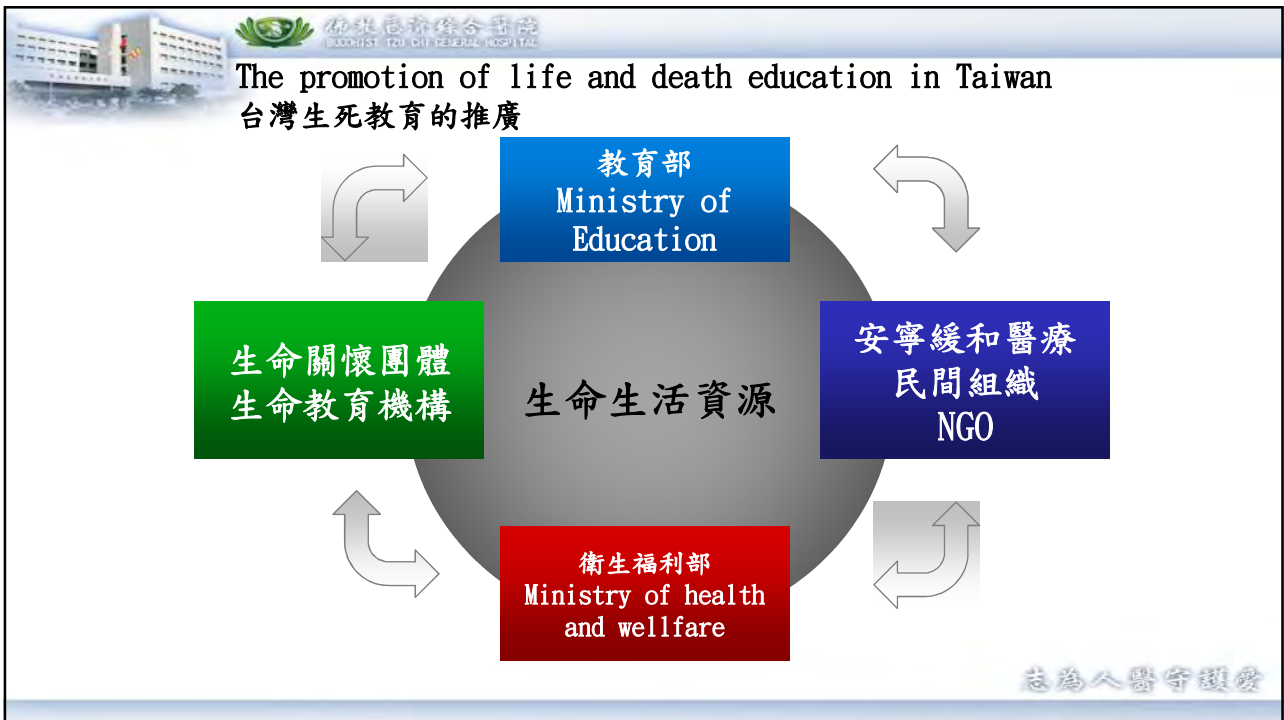
1200 午間新聞  
預立醫療意願 慈濟醫院下鄉宣導

花蓮 吉安  
尊重病患治療權 節省醫療資源

花蓮慈院家醫科醫師 程慧娟  
吞刀吞劍 先插好 從這邊下去

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NGO : life and death promotion organization  
台灣生命教育機構 (17個機構)

台灣佛教慈濟慈善事業基金會

慈濟 TZU CHI

《人文專欄》  
生命的禮物  
The Real Life Stories

LIFE 社團法人 台灣生命教育學會  
Taiwan Life Education Association

財團法人 生命教育基金會  
Life Education Foundation

生命教育學科中心  
Life Education Resource Center

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**生命關懷團體 (30個團體)**

- 財團法人台灣世界展望會
- 財團法人「張老師」基金會



**愛與分享的禮物型錄**  
一份禮物，讓施與受同得祝福！



•社團法人中華民國關懷生命協會



**沒有買賣 就沒有殺害**  
When the buying stops, the killing can too.

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**Hospice palliative related organization**  
 緩和醫療民間組織 (至少13個組織)



**台灣癌症安寧緩和醫學會**  
Taiwan Society of Cancer Palliative Medicine



**台灣安寧緩和醫學學會**  
Taiwan Academy of Hospice Palliative Medicine



**台灣心理腫瘤醫學學會 Taiwan Psycho-Oncology Society**



**蓮花基金會**



**大悲亭苑**



**原泰**  
財團法人天主教康樂醫療教育基金會



**財團法人亞太心理腫瘤學交流基金會**  
Asia Pacific Psycho-Oncology Exchange Foundation



**財團法人(台灣)安寧照顧基金會**  
中華民國 Hospice Foundation of Taiwan



**台灣安寧照顧協會**  
Taiwan Hospice Organization



**財團法人高雄市張啓華文化藝術基金會**

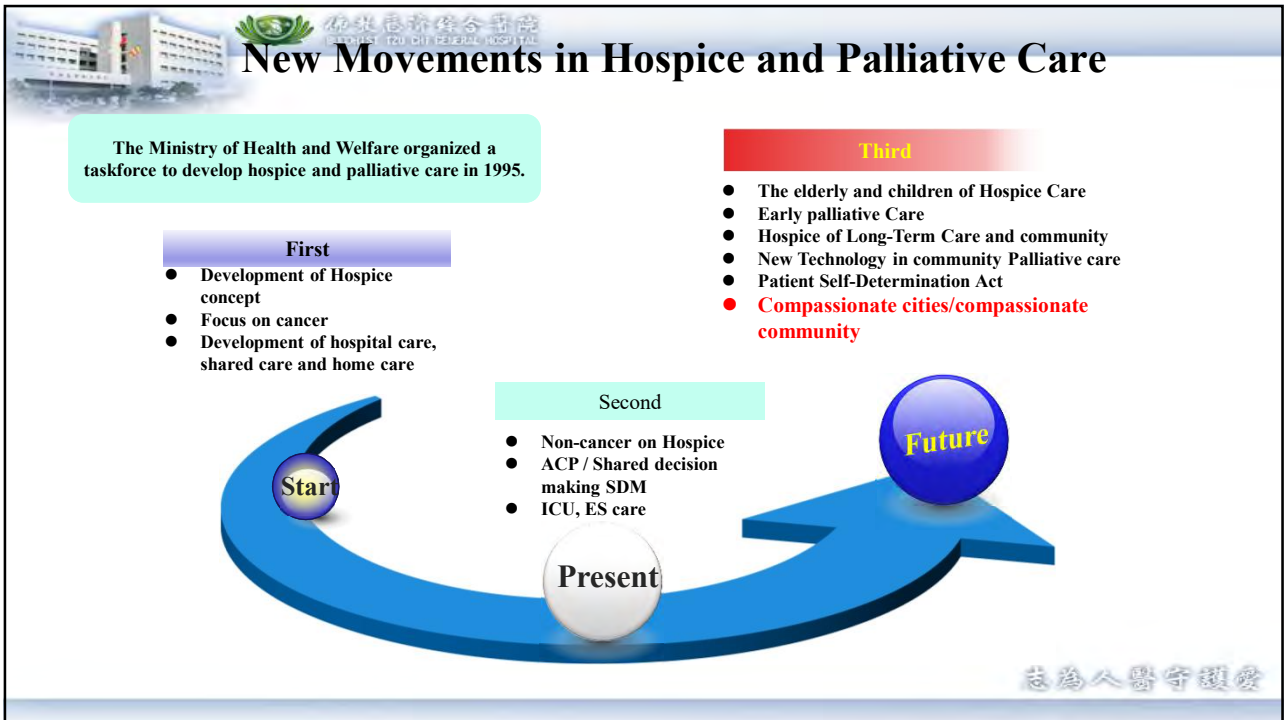



**中華民國醫務社會工作協會**  
MEDICAL SOCIAL WORK ASSOCIATION.R.O.C



**信望愛**  
財團法人基督教史懷哲宣道會

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## What is modern end-of-life (EoL) care

- **Modern end-of-life** care is **largely service-driven**.
- Palliative care is a major player in modern end-of-life care.
- Palliative care prioritizes terminal cancer care, serious neurological disorders, AIDS, other life-limiting conditions **in the last weeks and hours of life**.
- Community settings commonly escape formal EoL care service engagement.
- Social experiences associated with dying, caring and loss such as loneliness and social isolation, as well as, break down of relationships create psychological troubles.
- Palliative care is at best psychosocial, and it is **more ‘psycho’ than ‘social.’**
- Palliative care needs to revisit its early community oriented tradition.

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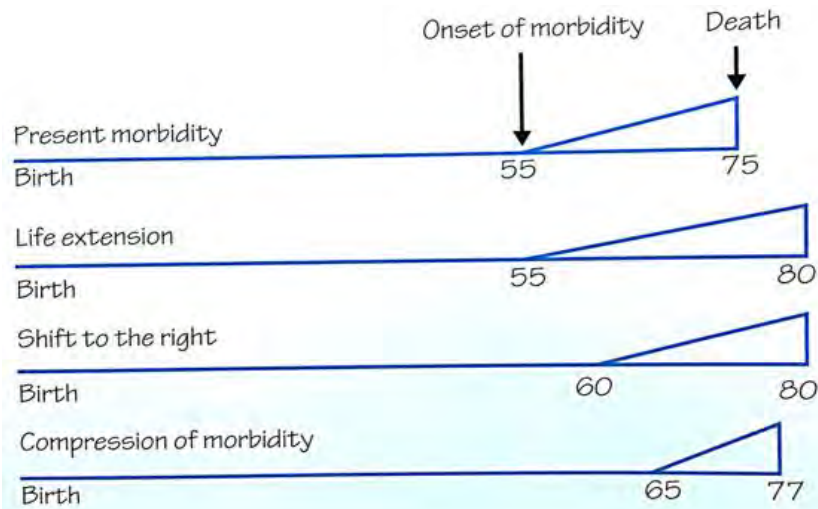
## Public health and end-of-life care: beyond a services approach

- Public health end-of-life care provides post-diagnosis and early care, care for experiences that **take place in community settings** (eg. sudden deaths), and wider support for loss and bereavement.
- Public health end-of-life care relies upon **relationships and partnerships between communities, governments and services**.
- Health and death education provide guidance in communities where dying and loss is not viewed as normal and routine.
- **Cultural organisations (museums, galleries, media, etc.), workplaces, schools, churches, local governments and a range of other community actors engage in collaborative partnerships.**

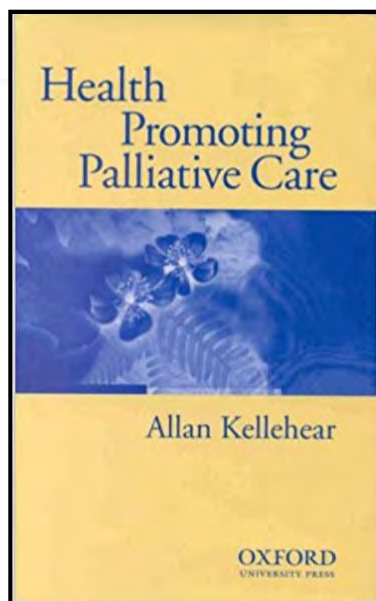
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## Compression of morbidity - Health Promotion + Advanced Care Planning




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Underdeveloped areas of palliative care:

- Social science and public health perspectives
- The **social side of care**
- Early-stage care (not just end-stage)
- Active treatment of disease
- Care for those with life-threatening illness (not simply terminal)

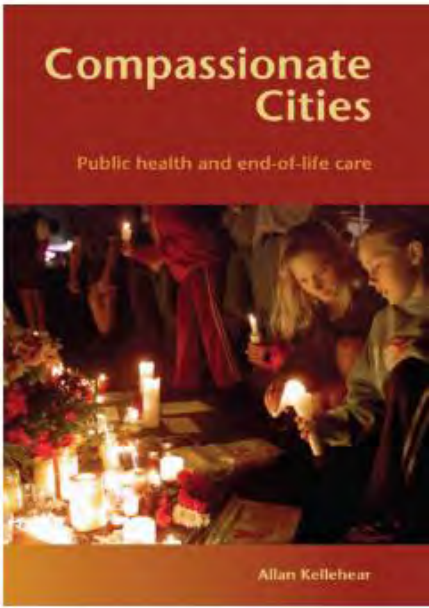
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## The public health approach to end-of-life care

- EoL experiences often take place within community contexts .
- **Social morbidities** associated with the end of life are **amenable to traditional public health methods - health promotion, public education, or community development.**
- Social supports that result from increase of social capital (trust, empathy, cooperation) counteract serious psychological and social morbidities, such as depression, anxiety, or loneliness, social isolation, neglect, or stigma...

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**THE COMPASSIONATE CITY**  
- A CHARTER OF ACTIONS -

Compassionate Cities are communities that recognize that all natural cycles of sickness and health, birth and death, and love and loss occur everyday within the orbits of its institutions and regular activities. A compassionate city is a community that recognizes that care for one another at times of crisis and loss is not simply a task solely for health and social services but is everyone's responsibility.

Compassionate Cities are communities that publicly recognize, facilitate, supports and celebrates care for one another during life's most taxing moments and experiences, especially those pertaining to life-threatening and life-limiting illness, chronic disability, frail aging and dementia, grief and bereavement, and the trials and burdens of long term care. Though local governments strive to maintain and strengthen quality services for the most fragile and vulnerable in our midst, those persons are not the focus of our experience of fragility and vulnerability. Serious personal crises of illness, dying, death and loss may visit any us, at any time during the normal course of lives. A compassionate city is a community that squarely recognizes and addresses this social fact.

Through support of the Mayor's office a compassionate city will : by public marketing and addressing, by use of the cities network and influence, by direct collaboration and co-operation, in partnership with social media and its own offices - develop and support the following 12 social changes to the cities key institutions and activities.


- Our schools will have annually reviewed policies or guidance documents for dying, death, loss and care
- Our universities will have annually reviewed policies or guidance documents for dying, death, loss and care
- Our trade unions will have annually reviewed policies or guidance documents for dying, death, loss and care
- Our churches and temples will have at least one dedicated group for end of life care support.
- Our city's hospitals and nursing homes will have a community development program involving local area citizens in end of life care activities and programs.
- Our city's major museums and art galleries will hold annual exhibitions on the experiences of aging, dying, death, loss or care



**Dr. Allan Kellehear**

- Medical and Public Health Sociologist
- Professor of Palliative Care

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- *"A city is not merely a place to work and access services but equally a place to **enjoy support in the safety and protection of each other's** company, in schools, workplaces, places of worship and recreation, in cultural forums and social networks anywhere within the city's influence, even to the end of our days".*

*Compassionate city charter, A Kellehear*

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## Whole Person Care 2

- Palliative and hospice care and literature emphasise the family as a basic unit of care. But the **public health approach requires us to include communities** and the state as important partners in all end-of-life care.
- End-of-life care, like all health care, must go beyond mere services in order to create sustainable for health environments and relationships. In this way, **end-of-life care is everyone's business.**

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## 「Compassionate Cities Workshop」

### November 8-9, 2017




  
 Unity is strength

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Figure 1 Circles of care.

## Inner network

- Comprise people provide intimate and direct hands-on care, companionship and support.
- Discovering by the person and their main carer.
- A rich resource providing meaning, value and support that enhances the capacity of the community to care for their dying.

Abel J, Walter T, Carey LB, et al. Circles of care: should community development redefine the practice of palliative care? *BMJ Supportive & Palliative Care* 2013;3:383–388.



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## Outer network:

- Includes less close family members, friends and neighbors who may respond to requests for help.
- The type of tasks may relate to practicalities of living :**activities outside the home (eg, bringing meals, shopping, mowing the lawn, walking the dog....**
- Providing support for **the carer for what can be a marathon rather than a sprint**, creating capacity and space for the carer to attend to what is most needed.
- This can save carer exhaustion.


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## The Compassionate Cities (CC) model

- Is an end of life care community application of **WHO Healthy Cities model**
- is a theory of practice for HPPC (**health promotion palliative care**)
- the principle of **healthy communities – health is everyone’s responsibility**
- the principle of compassionate communities – palliative and end of life care is everyone’s responsibility
- IN BOTH – **communities and services** create partnerships where *both* lead in areas where they have authority and responsibility


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## The Compassionate City Charter

- Our schools, trade unions, and workplaces will have policies in EoL Care
- Our churches and temples will provide appropriate supports for EoL Care
- Our hospices and nursing homes will engage in community development
- Our Cultural Centres will raise awareness of EoL Care issues
- There will be a peacetime memorial parade/festival
- There will be an incentives scheme for compassionate leaders - both individuals and organisations

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## The Compassionate City Charter(2/2)

- The Town council will showcase its achievements and ambitions in the area.
- There will be annual local short-story or art competitions within the city to raise awareness of EoL Care.
- We will incorporate diversity in all we do.
- We will address EoL Care issues in the margins of our city – homeless, prisons, refugees, travelers, etc.
- We will expand our influence annually into another social sector – emergency services, universities, creches, etc.

Compassionate Communities: Case Studies from Britain and Europe, Routledge, 2016, pp 80-82

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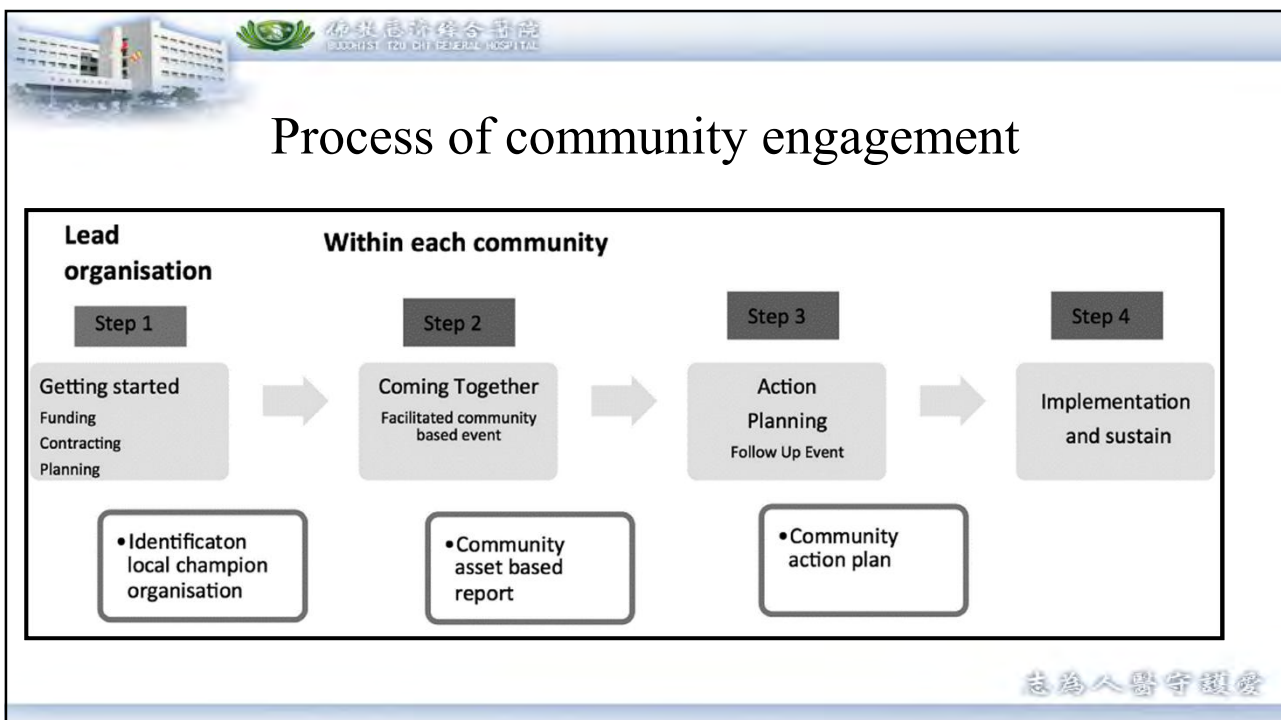
## Compassionate community networks: supporting home dying

Julian Abel,<sup>1</sup> Jon Bowra,<sup>2</sup> Tony Walter,<sup>3</sup> Glennys Howarth<sup>4</sup>

- Performing practical tasks** may be more acceptable to some family, friends and neighbors than having to engage in a conversation about dying, and provides a familiarity with dying that is often lacking in modern societies, so in this model, **behavioural change precedes attitudinal change**. The scheme rejects a service delivery model of care in favor of a community development model, but differs from community development schemes in which the mentor is a volunteer rather than a health professional, and also from those approaches that strive to build community capacity before any one individual dying person is helped.

*BMJ Supportive & Palliative Care* 2011;1 :129–133

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## 20 Pilot spots for compassionate communities since March 2018

Dabei Buddhist Center - Spiritual Café



### Compassionate Community 臺南市天主教守護生命關懷協會



### Knowledge and Skills to initiate Compassionate communities


**Something needs to know**

Something is nice to know

“what do I hope to achieve with this lecture?”

Practice points for community engagement in EoL






## Health promotion (WHO)

- Health promotion is the process of **enabling people to increase control over**, and to improve, their health. It moves beyond a focus on individual behavior towards a wide range of **social and environmental interventions**.

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## Health Promotion Definition

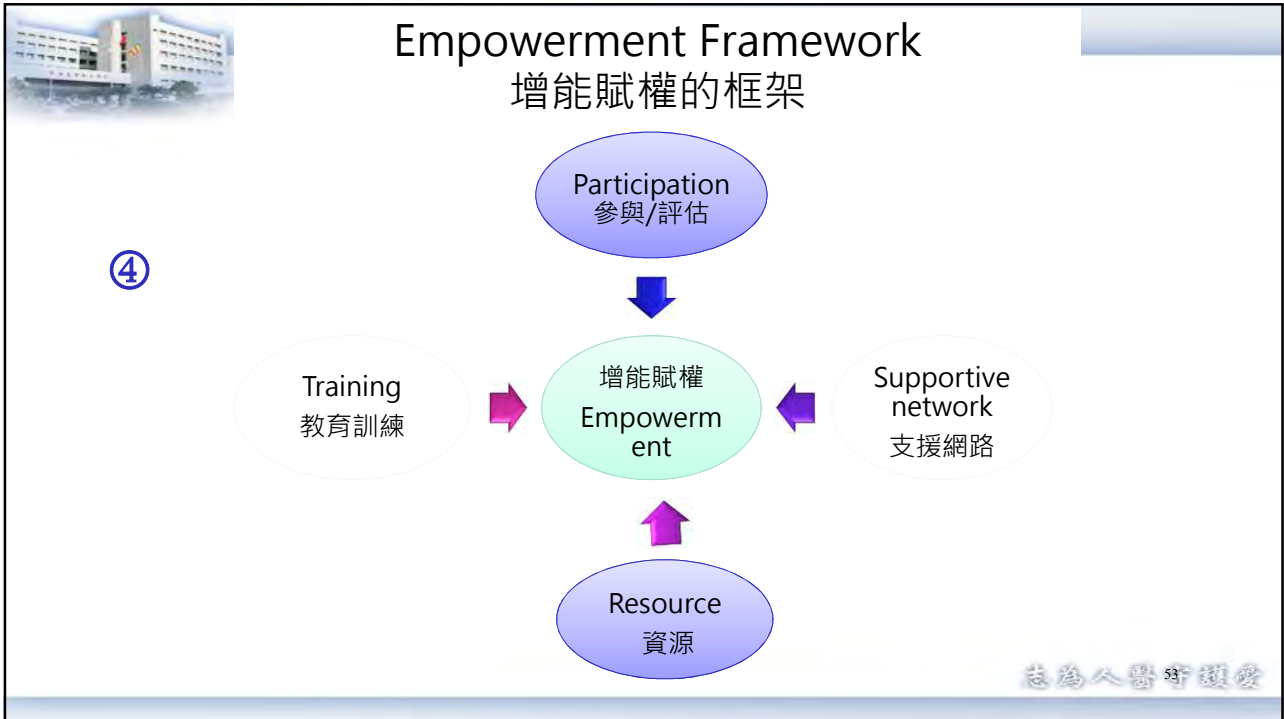
The process of enabling people to increase control over, and to improve their health.

① **Empowerment**

(WHO,1984)

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**2016 上海宣言**  
9th Global Conference on Health Promotion

- **Health Literacy** is an important factor in improving health outcomes
- Increase knowledge to help people to make healthiest choice and decision for themselves or theirs family to achieve the goal:
  - **Empowering citizens**
  - **Reducing health inequities**



World Health Organization | 39th Global Conference on Health Promotion | SHANGHAI, 2016

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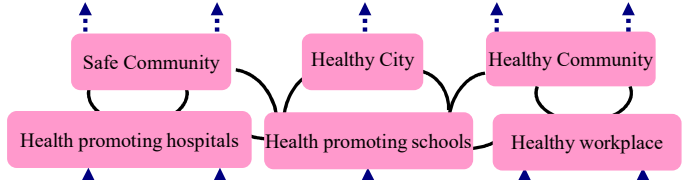


**Development of Health Promotion**

Shanghai Charter Health Promotion (2016) Healthy cities and Health Literacy

Helsinki Statement (2013), health in all policies, universal health coverage

The Bangkok Charter for Health Promotion in a Globalized World (2005)



- Combined use of the Ottawa Charter strategies are far more effective than single strategy
- Combination can be adapted for use in different settings
- The population should be involved in the action and decision making process
- Learning and communication, granting autonomy to the communities and population.

**Jakarta Declaration** on Leading Health Promotion into the 21<sup>st</sup> Century (1997)

Building Healthy  
Public Policy

Creating Supportive  
Environment

Strengthening  
Community Action

Developing Personal  
Skills

Reorient Health  
Services

**Ottawa Charter** for Health Promotion (1986)

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# End-of-life conversations and care: an asset-based model for community engagement


Mary Matthiesen,<sup>1</sup> Katherine Froggatt,<sup>2</sup> Elaine Owen,<sup>3</sup> John R Ashton<sup>4,5</sup>

Matthiesen M, et al. *BMJ Supportive & Palliative Care* 2014; 4:306–312. doi:10.1136/bmjspcare-2013-000516

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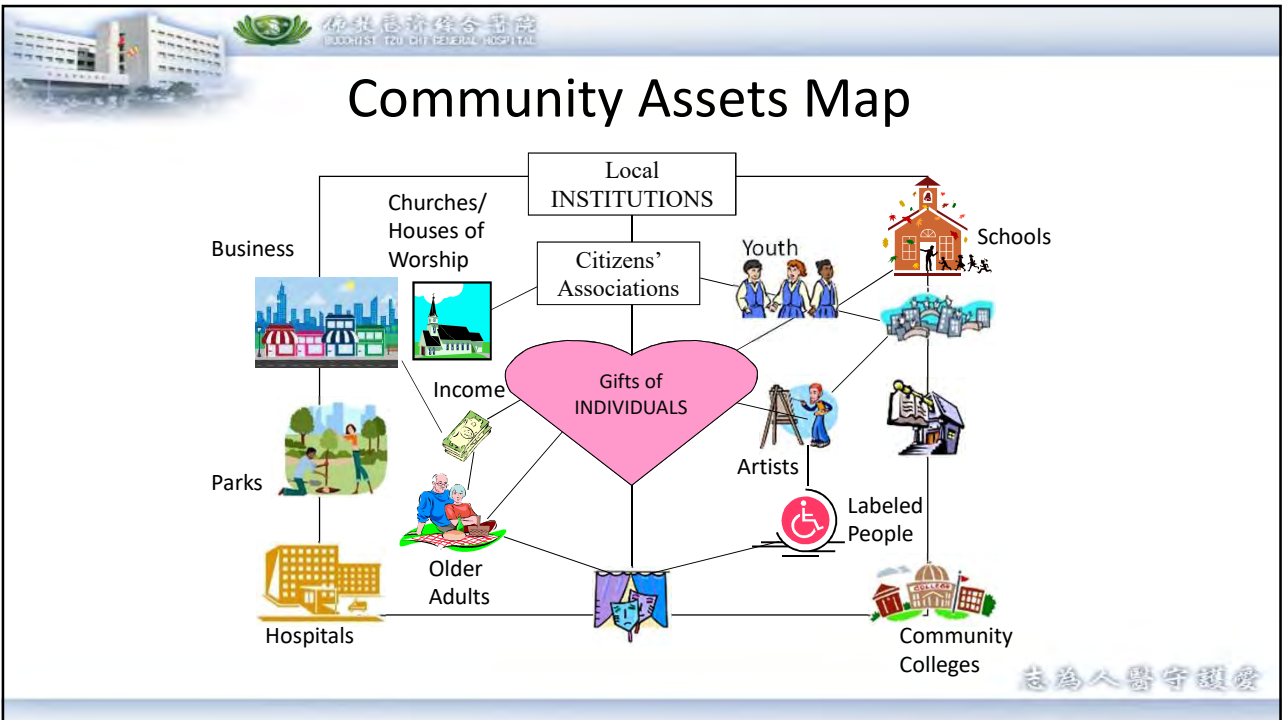
Tool 1

## Asset-Based Community Development



- } People and Communities have *deficiencies & needs*
- } Individuals and Communities have *assets and capacities*

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## Six Community Assets

1. Individuals
2. Associations
3. Institutions
4. Physical Space
5. Exchange
6. Culture/Stories/History

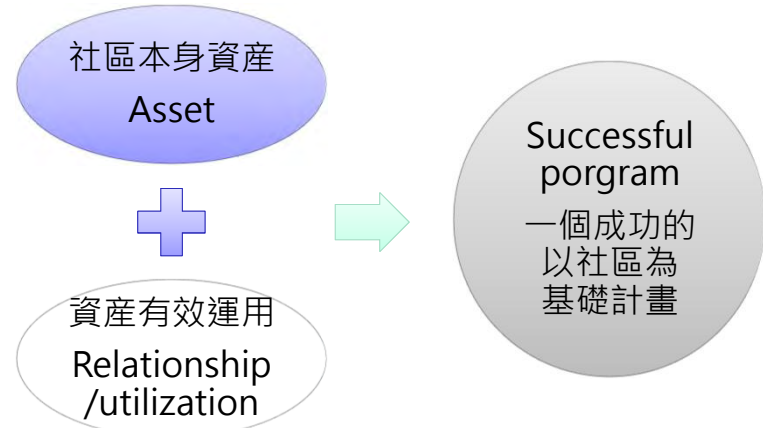
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## The concept of ABCD

資產為導向之社區發展(ABCD)理念




社區本身資產  
Asset

+

資產有效運用  
Relationship  
/utilization

Successful program  
一個成功的  
以社區為  
基礎計畫

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## Principle of ABCD

以有用資產為導向 Asset based


- 強調社區已有的資產，而不是什麼都沒有
- 有效運用社區的資產

內部為出發點 Internally focused


- 社區民眾設定議題
- 建立內部的能力，再尋求外界的協助

推動關係的建立 Relationship driven

- 加強人際的互信
- 加強個人與團體的互動與關連




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## Personal Capacity Inventory

### Individuals



### Gifts I Can Give To My Community

**Gifts of the Head** (Things I know something about and would enjoy talking about with others, e.g., art, history, movies, birds).

**Gifts of the Hands** (Things or skills I know how to do and would like to share with others, e.g., carpentry, sports, gardening, cooking).

**Gifts of the Heart** (Things I care deeply about, e.g., protection of the environment, civic life, children).

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**Tool 2**

## Media advocacy

影響個人→社會的改變 social change  
 提供健康的資訊→促使政策的改變 policy change  
 提供個人健康→社區對公共衛生政策的關懷 Public health approach

運用大眾媒體的策略，使有影響力的人士重視公共衛生政策 – Target : leader, decision maker

不是針對所有的民眾，主要是針對有影響力的領導者，形成一種連鎖反應，最後達到足夠能影響的力量

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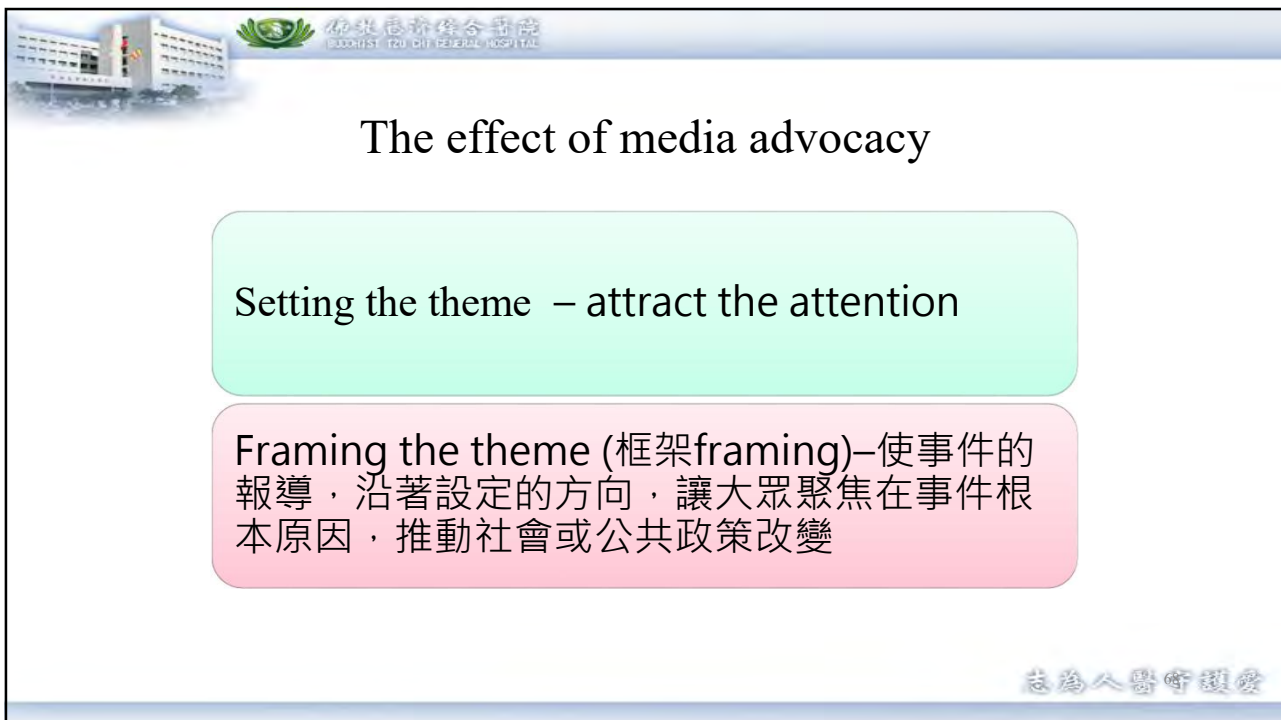
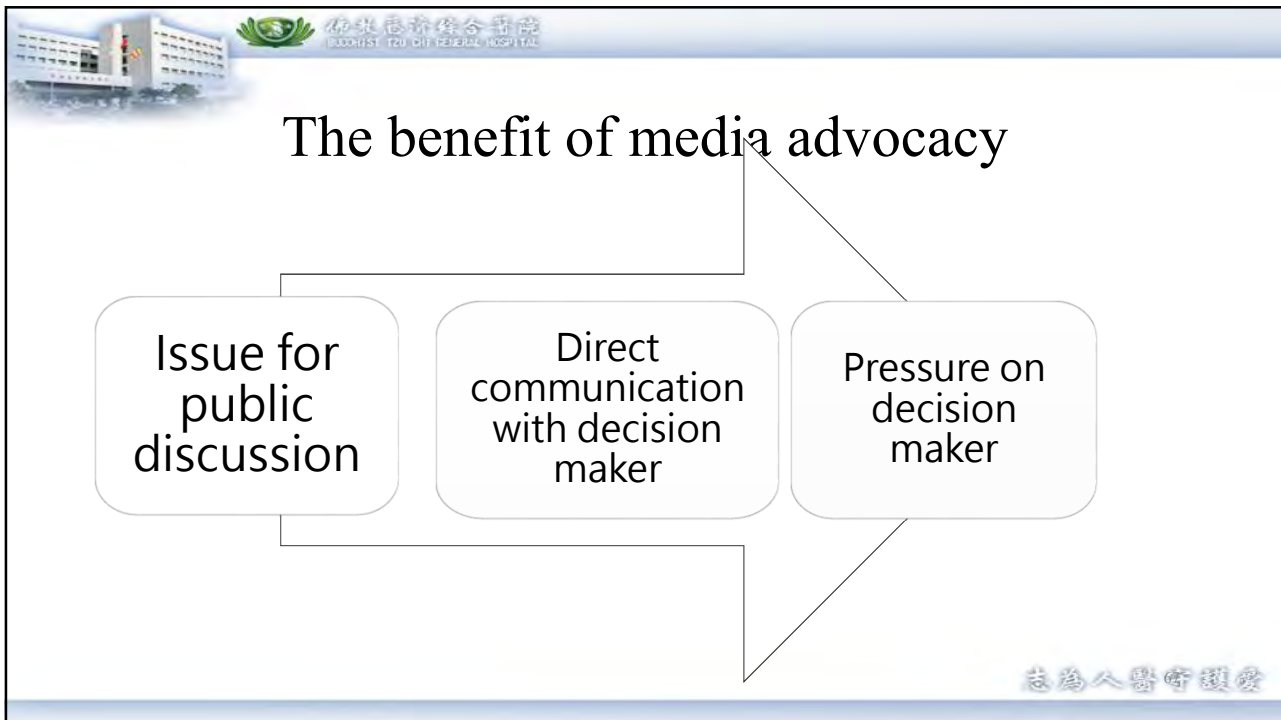


## Aim of Media Advocacy

媒體倡議的目標不單是媒體的涵蓋率或個人的改變，其目標為：**政策改變 change of policy**


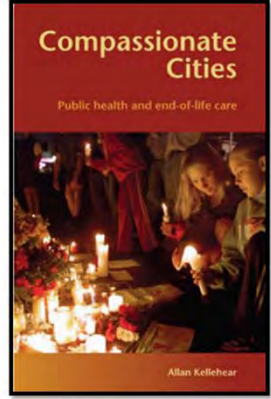
圖片來源<http://www.gettyimages.com/>

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**In the future :**

**Age-friendly city + Dementia friendly city + Compassionate city**

Health Promotion Administration,  
Ministry of Health and Welfare

**Balancing risks & benefits**

Lifestyle > Health & Families > Health News

## Home is not always the best place to die, says end-of-life care expert


Dr Kristian Pollock says more 'attention and resources' should be spent on end-of-life care in other locations

Chris Green | @cghgreen | Thursday 8 October 2015 | 2 comments


“The person may have been **alone, inadequately supported** (...) **Idealized** accounts of ‘the good death at home’ often do not recognize the **‘intractable pain and discomfort’** experienced by some dying patients”

Palliative Social Work Symposium  
2015 10Nov2015

Source: <http://www.independent.co.uk/life-style/health-and-families/health-news/home-is-not-always-the-best-place-to-die-says-end-of-life-care-expert-a6685386.html>


Take home message :

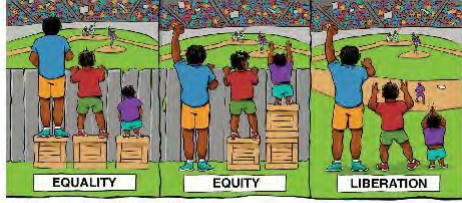
1.



Carrot and stick → Carrot and baton

3.




**EQUALITY**      **EQUITY**      **LIBERATION**

the4mbox.com

FIGURE 1 | Equality, Equity, and Liberation  
 AKA, RC = Image by Angus Vagstad, illustrations available for public change, adapted from Craig-robie.co.

2.




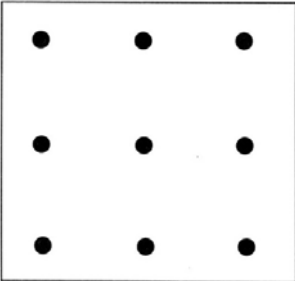
Top down and bottom up  
 Partnership between  
 government and health  
 service organization


Remove barrier for  
 communication

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Take home message :

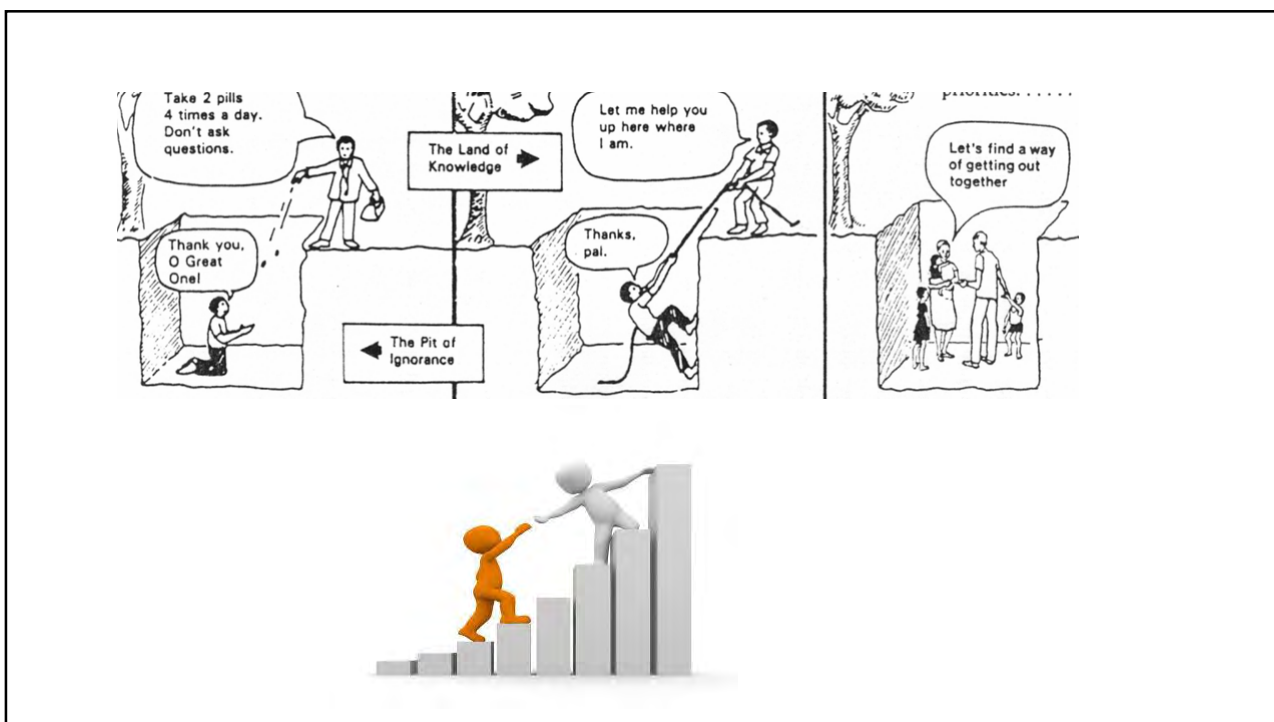


Use 4 lines to connect all 9 dots  
 without lifting your pen  
 - Try to draw outside the square



Start from the half full

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Patient centered care  
Holistic care



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佛光山佛陀紀念館  
BUDDHIST TZU CHI GENERAL HOSPITAL

*Coming together is a beginning,  
Staying together is progress,  
Working together is success,  
Laughing together makes it all worthwhile*  
*Green*

志為人醫 守護愛