Compassionate Communities: A Taiwan Experience

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Contents

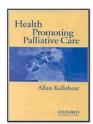
- My own story
- · What is a compassionate community, and why is it essential?
- Basis concepts of health promotion and community development
- The development of compassionate communities, example from the world
- Our own experiences...

My own story:

- I began my journey as a family medicine physician after graduating from medical school.
- I earned my doctoral degree in public health in the United States 23 years ago.
- Approximately 27 years ago, I had the privilege of establishing the first Buddhist Hospice, known as the Heart Lotus Hospice, in East Taiwan.
- "15 years ago, I was seconded from the university to the Bureau of Health Promotion, where I served as Deputy Director General for a period of two years."

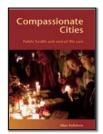
My own story cont....

- When I started my new job, a colleague approached me and said, "We are
 considering withdrawing the palliative care program from the Bureau of Health
 Promotion. After all, our department focuses on health promotion, not end-oflife care."
- How can I response?
- I was fortunate to come across the book "Health Promoting Palliative Care" authored by Professor Allan Kellehear. This book delineates the application of health promotion principles, as outlined in the Ottawa Charter, to communitybased palliative care. Armed with these principles, I am confident that I can persuade my colleague to retain the palliative care program as an integral component of our health promotion initiatives.

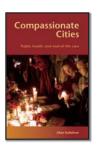


My own story cont....

- Seven years ago, I was once again seconded, this time from the university to the Health Promotion Administration, where I assumed the position of Director General.
- I initiated community intervention programs grounded in the principles of health promotion, including initiatives like healthy cities and age-friendly cities. It was during this time that I encountered another impactful book, "Compassionate Cities," also authored by Professor Allan Kellehear.



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

I searched Youtube -Bill's Story by Milford Care Centre

Bill's Story

World Hospice & Palliative Care Day





WHAT IS A COMPASSIONATE COMMUNITY?

A Compassionate Community is a community of people who are passionate and committed to improving the experiences of those who are living with a serious illness, caregiving, dying and grieving. A Compassionate Community takes an active role in caring for people affected by these experiences, connects people to supports, raises awareness about end-of-life issues, and builds supportive networks

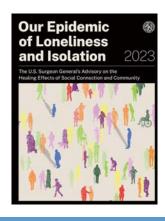
What is community?

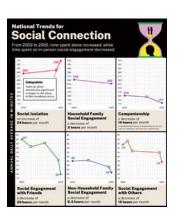
 A community can be a geographical location (e.g. city, town or neighborhood), a social group (e.g. book club or running group), a group of people united by a common purpose (e.g. members of a faith community, co-workers or neighbors), and even an online community.

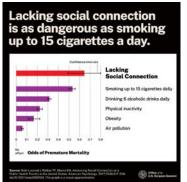
What is a new public health approach to end of life care?

Goes by many names...

- · Community engagement, participation, development
- Health promotion
- · Community capacity building
- Social network approaches
- Compassionate Communities

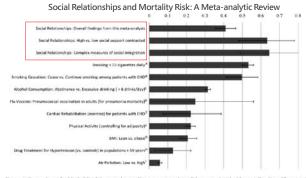






American Heart Association 2022

- "social isolation and loneliness are common, yet underrecognized, determinants of cardiovascular health and brain health
- Heart failure with high levels of loneliness :
 - 68% increased risk of hospitalization,
 - 57% higher risk of emergency department visits,
 - 26% increased risk of outpatient visits,
- Chronic loneliness and social isolation can increase the risk of developing $\ensuremath{\mbox{dementia}}$ by approximately 50% in older adults.
- "Social isolation is arguably the strongest and most reliable predictor of suicidal ideation, attempts, and lethal suicidal behavior among samples varying in age, nationality, and clinical severity."



PLoS Med 7(7): e1000316. 2010

Factors That Can Shape Social Connection

Individual

- Physical health
 Personality
- Race Gender
- Socioeconomic status
 Life stage

Relationships

- Structure, function, and quality Household size
- Characteristics and behaviors of others · Empathy

Society

Health care · Transportation

Community Housing Schools
Workplace
Local government
Local business

Community organizations

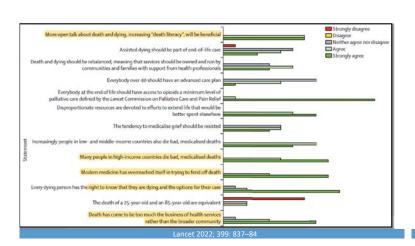
- Norms and values
 Public policies
 Tech environment and use
 Civic engagement
 Democratic norms
 Historical inequities

The Lancet Commissions

Report of the Lancet Commission on the Value of Death: bringing death back into life



Lancet 2022; 399: 837-84



The changing nature of death and dying

	Before 1950	1950	2019
Level of medical technology	Low	Increasing	High and increasing
Detection of terminal disease	Poor	Improving	High
Definition of death	Simple	Still simple	Complex
Deaths from acute disease (mostly rapid)	High	Still high	Low
Deaths from injuries (mostly rapid)	High	Still high	Lower
Deaths from chronic disease (mostly slow)	Low	Increasing	The majority
Length of dying	Short	Still mostly short	Long
Passivity in response to a person dying	Common	Decreasing	Gone in western medicine
Involvement of doctors in dying	Low	Increasing	High
Number of doctors in UK per 100 000 people	Fewer than 26	26	280
Familiarity with death among the population	High	Still high	Low
Activities to manage death (death awareness campaigns, advance care planning, assisted dying, etc)	Low	Low	High
Community involvement in death and dying	High	Falling	Low
Meaning in death and dying	Mostly supplied	Faith and faith	Inadequately supplied by

Lancet 2022; 399: 837-84

Death is a social event with a medical component, not a medical event with a social component. Professor Allan Kellehear

Why is the presence of compassionate communities important?

"For patients in the last year of life, only 5% of their day is provided by formal care, while the remaining 95% is delivered through informal care."

Informal Care **Formal Care** 95% of the Day <5% of the Day √ Spouse √ Caregiver √ Nurse √ Family & Friends √ Nurse Practitioner √ Neighbours Personal Support √ Workplaces & Schools Worker √ Community Agencies √ Municipalities √ Social Worker √ Faith Communities √ Pharmacist √ Hospices & Volunteers

Preferred Place of Death in Adult **Cancer Patients: A Systematic Review and Meta-Analysis**

Armin Fereidouni¹, Maryam Rassouli², Mahmood Salesi², Hadis Ashrafiz Amir Vahedian-Azimi⁵ and Salman Barasteh⁴⁴

Results: A total of 14,920 participants of 27 studies were included into the meta-analysis. Based on the results, 55% of cancer patients with a confidence interval [95% CI (41-49)] preferred home, 17% of patients with a confidence interval [95% Cl (-12%) 23)] preferred hospital and 10% of patients with confidence interval [95% Cl (13-18)] preferred hospices as their favored place to die. Effective factors were also reported in the form of demographic characteristics, disease-related factors and

Conclusions: This study showed that more than half of cancer patients chose home as their preferred place of death. Therefore, guided policies need to ensure that the death of the patients in the preferred place should be considered with priority.

Front. Psychol 2021. 12:704590.

Congruence between Preferred and Actual Place of Death for Those in Receipt of Home-Based Palliative Care

Jiaoli Cai, PhD.1 Li Zhang, PhD.1 Denise Guerriere, PhD.2 and Peter C. Coyte, PhD2

Table 2. Congruence between the Preferred and Actual Place of Death among All the Decedent (n= 290)

	Actual place of death [n (%)]				
Preferred place of death [n (%)]	Home	Hospice	Hospital	LTC	Total
Home	130 (68.42)	14 (7.37)	46 (24.21)	0 (0.00)	190
Hospice	2 (4.27)	40 (85.11)	4 (8.51)	1 (2.13)	47
Hospital	9 (18.37)	5 (10.20)	35 (71.43)	0 (0.00)	49
LTC	0 (0.00)	1 (25.00)	0 (0.00)	3 (75.00)	4
Total	141	60	85	4	290

The overall congruence was 71.72% with an overall kappa statistic of 0.527.

Values in bold and italic illustrate number and proportion of decedents who achieved congruence.

LTC, long-term care.

My own story cont....

The development of compassionate communities in Taiwan



Invitation to

2017.11.8-9 Workshop on compassionate and dementia friendly communities

Professor Allan Kellehear

- March 2017 in Hong Kong
- July 2017 in Singapore

2017.10.14 WHPD **Initiative Compassionate Community Program**

JOURNAL OF PALLIATIVE MEDICINE Volume XX, Number XX, 2020

2017 Compassionate communities workshop

- Aged friendly, dementia friendly, compassionate communities -



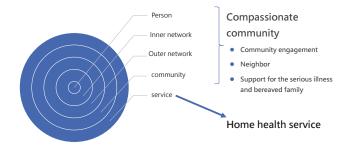








Community responses to EOL (Kumar, 2005)



The public health vision for end of life care



Service-orientated approach

- Palliative/hospice services extended into the community
 - Dependent on provider
 - Focus on professionals



Public health approach

- Engaged and developed communities able to provide community led care
- · Utilisation of community networks and assets



2019 Compassionate communities workshop -



Workshops organized by Bonnie Tompkins, Companionate Communities National Lead Pallium Canada:

-In North, Central, South and East Taiwan -

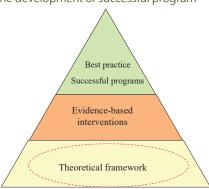
NGO from different communities participated in the workshop



2020 Compassionate communities campaign



The development of successful program



Access to palliative care: the primacy of public health partnerships and community participation

- Older people (aged ≥85 years), ethnic minorities, people with non-cancer illnesses, and people living in rural locations or areas of social deprivation had unequal access to palliative care.
- Palliative-care providers adopting new public health approaches will be best-equipped to tackle the challenges of equity and access for diverse populations
- By community, we mean not merely community services or volunteers but members of neighborhoods, faith groups, workplaces, schools, local government agencies, as well as sporting clubs, and cultural organisations such as galleries and museums.
- WHO through recognition of community assets and respect for community-defined priorities, community development empowers and enables social networks to identify shared concerns and engage in participatory
- Central to the development: strengthen community action and create supportive environments - Ottawa Charter

www.thelancet.com/public-health Vol 6 November 2021

What is health promotion?

Health promotion enables people to increase control over their own health. It covers a wide range of social and environmental interventions that are designed to benefit and protect individual people's health and quality of life by addressing and preventing the root causes of ill health, not just focusing on treatment and cure.



Empowerment

1986 World Health Organization (WHO) Ottawa Charter for Health Promotion

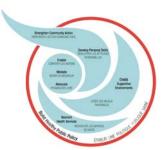
Key concept of Health Promotion

3 Strategies

- Enable
- Mediate
- Advocate

5 Domains

- · Building healthy public policy
- Create supportive environmer
- Strength community action
- Development personal skills
- Reorient health services



1986 World Health Organization (WHO) Ottawa Charter for Health Promotion

Compassionate community strategies

Strategies to Move Forward

Enable

- · Promote education
- Association and agency leadership

Mediate

- Support local adoption
- Engage local, regional and provincial leaders

<u>Advocate</u>

- Advocacy common messages
- Incorporating common messages into association/organizational policy

HPCO

The underpinning principles guiding change

Ottawa Charter for Health Promotion

- $1 \circ$ Integrate community provision of palliative and end of life care into public health practice and policy
- Formalize and share organizational commitment to community development (e.g. publish on website)
- Adopt a Compassionate City Charter to drive civic change at a population level
- Develop policies and processes to promote and support people at the end of life, their families and carers, such as compassionate workplaces
- Respect differences and diversity in the community as individuals' experiences, needs and preferences across the spectrum of death and dying can vary significantly.

Compassionate communities implementation guide 2018

- $2. \ Draw \ on community \ strengths \ to \ create \ supportive \ environments \ and \ generate \ advocacy$
- Identify and build on existing community strengths, activities and organisations
- Aim to foster supportive communities that care for each other, reduce stigma and promote respect
- Engage community champions (individuals and organisations) to provide credibility, increase profile and awareness
- Be flexible and embrace a variety of solutions compassionate communities and public health approaches can only operate on the available capacity within each specific community.

3. Strengthen community development and action

- Support the community to define their own compassionate community, what it stands for and what it does
- Support community-led and driven activities and initiatives to align as closely as possible to community needs
- Emphasize the development of networks to increase social connectedness
- Provide training and support to citizens to mobilise compassionate communities and ensure that actions are sustainable.

4. Develop individual knowledge and skills about end of life

- Facilitate and normalize conversations about dying and end of life, including advance care planning
- Increase knowledge of palliative care, available services and other supports and how to access them
- Invest time in building the knowledge and skills of community members and volunteers, especially in finding, training and retaining volunteers with suitable skills.

Compassionate communities implementation guide 2018

- 5. Re-orient health services to work in partnership with community
- Develop a system where individuals, families, carers, communities, social, health and aged care services can collaborate to deliver integrated support
- Focus on what matters to people at end of life and their families, including what is important to their quality of life and their preferred place of care
- Build a culture where the roles of all those involved in delivering palliative and end of life care – including health professionals and communities – are recognised, respected and supported
- Provide education and support for health services to broaden awareness of non-health services available to support end of life, and encourage power-sharing.

Compassionate communities implementation guide 2018

9th Global Conference on Health Promotion, Shanghai 2016

- 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



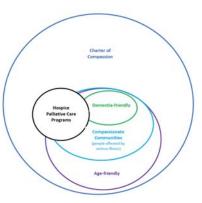
WORLD REPORT AGEING AND HEALTH

Public Health Framework for Healthy Ageing High and stable capacity Declining capacity Significant loss of capacity Functional ability Intrinsic capacity Reverse or slow declines in capacity Long-term care: Long-term care: Environments: Remove barriers to

14 OCTOBER 2023

Compassion is care:

- Caring for others is an act of kindness.
 Compassion entails empathy. Sharing in other people's feelings helps in gaining an understanding and compassion of how they feel.
- Compassionate caregivers are empathetic to the pain and suffering of their patients which is vital to their well-being. Compassionate care makes people living with palliative care needs more comfortable when they are in pain, feeling ill or suffering from emotional, or psychological stress.



Towards an age-friendly society



Global Age-friendly City: A Guide, 2007





WHO 2023 April

Building Dementia-Friendly Society in Japan

Since 2005 indicate that the Japanese society places great emphasis on prevention, awareness/ promotion population needs, community development and partnerships, supportive systems and environments, and capacity of health care providers.

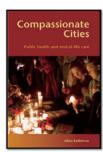
- 1. Nationwide caravan to train one million dementia supporters
- 2. Building dementia-friendly communities
 - Regional Comprehensive Support networks
 - Happy cafes
 - Wandering-watch program
 - "Community support centres"



Japan: Dementia Supporter Caravan Model









The Compassionate City Charter

• ALLAN KELLEHEAR

People who live with life-threatening or life limiting illness, their caregivers, and the bereaved are segmented social groups, forced to experience lifestyles that are commonly socially hidden and disenfranchised from the wider society. Outside of the health services that deal specifically with their immediate problems, these populations suffer from a range of other troubles that are separate but linked to their health conditions or social circumstances – loneliness, isolation, job loss, stigma, depression, anxiety and fear, or even suicide. These populations also suffer from a range of other debilitating health problems often caused by their social and psychological troubles - insomnia, cardiac $arrhythmias, chronic fatigue \ and \ headaches, \ hypertension, \ and \ gastric-intestinal \ disorders.$

Compassionate Cities are communities that publicly encourage, facilitate, supports and celebrates care for one another during life's most testing moments and experiences, especially those pertaining to life-threatening and life-limiting illness, chronic disability, frail ageing and dementia, grief and bereavement, and the trials and burdens of long term care. T

The Compassionate Cities Charter

1	Schools	Annually review policies or guidance documents for dying, death, loss and care
2	Workplaces	Annually review policies or guidance documents for dying, death, loss and care
3	Trade unions	Annually review policies or guidance documents for dying, death, loss and care
1	Worship places	Have at least one dedicated group for erd-of-life care support
5	Hospices & Nursing homes	Have a community development program involving local area citizens in end-of life care activities and programs
6	Museums & Art	Hold annual exhibitions on the experiences of ageing, dying, death, loss or care

The Compassionate Cities Charter

7	City	Host an annual peacetime memorial parade representing the major sectors of human loss outside military campaigns
8	City	Create an incentives scheme to celebrate the most creative compassionate organization, event, and individual/s.
9	City	Publicly showcase, in print and in social media, the local government policies, services, funding opportunities, partnerships, and public events that address 'the community's compassionate concerns' with living with ageing, life-threatening and life-limiting illness, loss and bereavement, and long term caring.
10	City	Work with local social or print media to encourage an annual city-wide short story or art competition that helps raise awareness of ageing, dying, death, loss, or caring.

The Compassionate Cities Charter

11	All compassionate policies and services	Demonstrate an understanding of how diversity shapes the experience of ageing, dying, death, loss and care – through ethnic, religious, gendered, and sexual identity and through the social experiences of poverty, inequality, and disenfranchisement.
12	People	Seek to encourage and to invite evidence that institutions for the homeless and the imprisoned have support plans in place for end-of-lifecare and loss and bereavement.
13	City	Establish and review these targets and goals in the first two years and thereafter will add one more sector annually to our action plans for a compassionate city – e.g. hospitals, further & higher education, charities, community & voluntary organizations, police & emergency services, and so on.

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

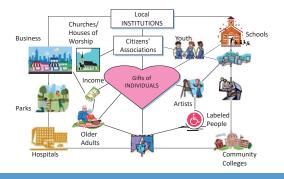
Mary Matthiesen, 1 Katherine Froggatt, 2 Elaine Owen, 3 John R Ashton 4,5

Matthiesen M, et al. BMJ Supportive & Palliative Care 2014; 4:306-312.

The Dilemma . . .



Community Assets Map



The principle of Asset based community development ABCD

- Asset based
- Internally focused
- Relationship driven

Six Community Assets

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

The development of compassionate communities, with examples from around the world..



"The public health approach has the most potential to enhance the quality of life and sense of well-being to the widest number of people in sickness, in dying and in loss, as well as in health toward one another."

https://www.phpci.org/

Canada



The Compassionate Community Movement in Canada

- · Pallium Canada
- · BC Centre of Palliative
- · Hospice Palliative Care Ontario
- · Building Compassion in Children, Schools & Communities in Peel
- Hospice Northwest
- Community Connection and Outreach; supporting Education and Service Delivery in Toronto
- compassionate communities

Pallium Canada – Mobilizing Compassionate Communities at a National Level

How can you launch a Compassionate Community?

Pallium is a national, non-profit organization

Vision: Palliative care is everyone's business

What we do: Provide practical and evidence-based solutions

Who we help:

- Health care organizations
- Health care professionalsCommunity champions



https://www.pallium.ca/compassionate-communities/

Supportive Approaches – Resources for Leaders

Develop resources to support those leading Compassionate Community (CC) initiatives

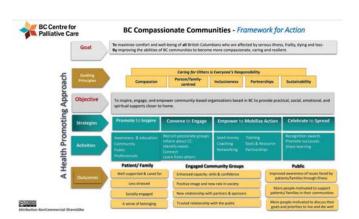
Compassionate Communities Startup Toolkit

Designed to support a community champion who wants to launch a CC initiative

Compassionate Communities Sustainability Guide

 Designed to build off the Startup Toolkit by supporting the stages of development through the life of the initiative

compassionate communities

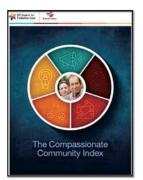




Principles

- Communities know best.
- Perceptions are powerful. Measuring and communicating them is a key to jump-starting a community to action.
- Communities have untapped human resources and energy that the Compassionate Community Index can tan into
- The process is better when it's inclusive and engages potential partners and allies.
- The **Compassionate Community Index** can assist in community planning.
- $\bullet \;$ Small steps/actions to build capacity are recommended

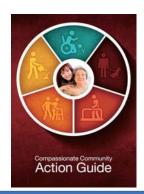
Handbook for the Compassionate Community Index - June 2020



- Compassionate Community Index is a survey that assesses communities with respect to their level of readiness, commitment and efforts to become a more Compassionate Community.
- Before administering the survey, the meeting facilitator should make sure that **participants**:
- have been introduced to the concept of Compassionate Communities
- are made aware of the gaps in supports and unmet needs of people with serious illness and their families, and
- are informed about examples of Compassionate Community initiatives in other communities

https://bc-cpc.ca/wp-content/uploads/2019/10/CC-Index_PRESS-1-1.pdf





- Action Guide is recommended after the completion of a Compassionate Community
 Index (CC Index) survey
- level of difficulty in implementing

EASY MODERATE ADVANCED

Resources: Australia





 $\underline{end\text{-}of\text{-}life\text{-}care/}{https://ncq.org.au/wp\text{-}content/uploads/2020_GroundswellProject_Building\text{-}Compassionate\text{-}Communities\text{-}instance of the project of the$

Australia.pd







Compassionate Community Connector
Partnership between the community and health service
in Western Australia



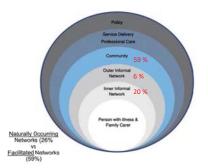


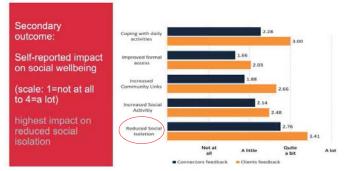
Figure 1. Social network mapping before and after the intervention

Palliative Care & Social Practice 2022, Vol. 16: 1–11

Role of connector: Enhance networks within circles of care

Connectors provide assistance to the person affected by advanced illness and their family by identifying the additional social and practical support they may require from within their local community and tap into formal and informal sources.





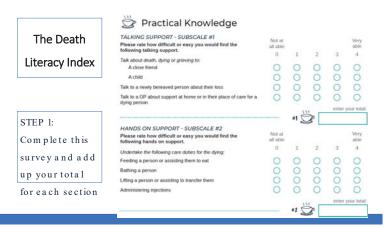
Key Outcomes-Effectiveness Analysis (Cook & Aou

- Significant decline in frequency of hospitalisations per month: (-0.509 events/month; 95%CI: -0.752,-0.266)
- · Significant decline in number of hospital days per month

(-0.475; 95%CI: -0.615,-0.335)

. Increased use of outpatient services (+1.180; 95%CI: 0.957, 1.402)

Net savings of the Connector program was on average \$AUD 561,256 over a six-month period.



National Palliative and End of Life Care Partnership

Six ambitions to bring that vision about



"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]."



Each community is prepared to help

The building blocks for achieving our ambition

Public health approaches to palliative and end of the care need to be accelerated and support given to people and communities who can provide practical help and compassion.

Practical support

Local health, care and voluntary organisations should find new ways to give the practical support, information and training that enables farmlies, neighbours and community organisations to help.





The Charter and Toolkit

- · The Dying Well Community Charter
 - NCPC
 - Engagement with NHS England, hospices, charities and Royal Colleges
- Public Health Approaches to End of Life: A Toolkit
 - · Allan Kellehear

http://www.ncpc.org.uk/communitycharter



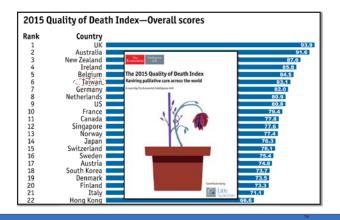
MAKING CONNECTIONS, MAKING A DIFFERENCE

Nav-CARE is a free volunteer navigation program that supports people with declining health to live as well and independently at home for as long as possible. Specially trained volunteer navigators help clients access resources and services in their community, while providing companionship and emotional support.



https://nav-care.ca/

The development of Compassionate communities in Taiwan



New Movements in Hospice and Palliative Care



Compassionate Community Volunteer training



Compassionate Community-Series Activities for Spreading the Word

- competition activities to collect stories from the communities



Training / advocacy

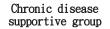


早期安寧緩和照護與社區關懷 (花蓮慈濟醫院-病房區)





宗教師/志工訓練





往生病人家屬- 節日的支持





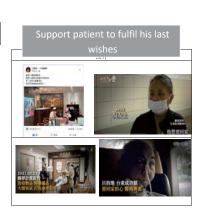
College students community service (What matters)

社

區關懷活動







Provide internal training for health professional - social prescribing











Primary school 校內辦理學生/社團宣導

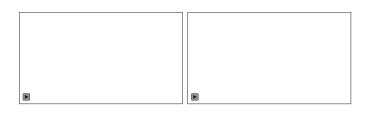
分享「癌症與重症病人慈悲關懷友善社區推動計畫」

觀看孫越《生命的樂章-人生四季之歌》、





Community creative activity – board game about death literacy

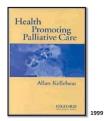


Help Aunt Chen in the community in her final year of life!



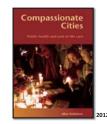
Extensions and shifts through public health end-of-life care





Ottawa Charta(1986)

- Healthy public policy
- · Community action
- Improve personal skill
 Reorienting health services



- WHO Healthy city/community Community volunteer
- Death, Dying, Loss and Care ; (DDLC



New public health

Palliative care—the new essentials model

Palliative care - the new essentials



Ann Palliat Med 2018;7(Suppl 2):S3-S14

大道之行也·天下 為公 When the great way prevails, the world communi equally shared by all.	ty is
進賢與能 The worthy and able are chosen as office holders	
第信修睦 Mutual confidence is fostered and good neighborliness cultivated.	
故人不獨親其親・ 不獨子其子 所述の。 連件できる 不獨子其子 所不る。 本性表 所不可見する。 有点 所不可見する。 有点 所有している。 有点 可能可能可能可能可能可能可能可能可能可能可能可能可能可能可能可能可能可能可能	vn
使老有所終・壯有 provision is made for the aged till their death, the material services of the servic	ie
鰈、寡、孤、獨、 廢疾者皆有所養 didless as well as the sick and disabled are all w taken care of.	ell

Chinese Confucius Culture -





Dr. Sidney Burwell, the dean of Harvard Medical School from 1935-1949,

" Half of what we are going to teach you is wrong, and half of it is right. Our problem is that we don't know which half is which."

God grant me the serenity

To accept the things I cannot change,
The courage to change the things I can,
And the wisdom to know the difference.
Reinhold Niebuhr