



# Social Care System and Delivery for Families of Patients with Advanced Illness

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We are here. Riding high together.

合作夥伴 Project Partner:



Faculty of  
Social Sciences  
The University of Hong Kong  
香港大學社會科學學院

Questions we all have to think about at the end ...



Where do you want to die?

What is the most  
important to you in  
your final days?

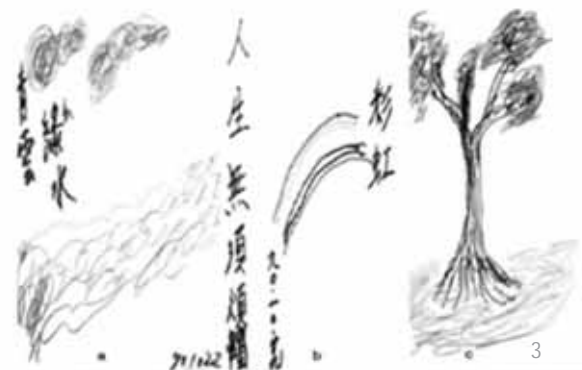
How do you want to die?

What taste of food will you  
miss the most in your final  
days?

At the final moment, who  
do you want to meet?

## Art pursuits

賽馬會安寧頤  
JCECC  
Jockey Club End-of-Life Community Care Project



Source: <http://www.channelnewsasia.com/news/singapore/young-cancer-patients/2506308.html>; Lin et al., 2012, *Palliative Supportive Care*

## Painting on silk

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JCECC  
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Jockey Club End-of-Life Community Care Project



VS.



10 months

6 months to 1 year

**Pamper persons in their end-of-life as someone who is pregnant?**

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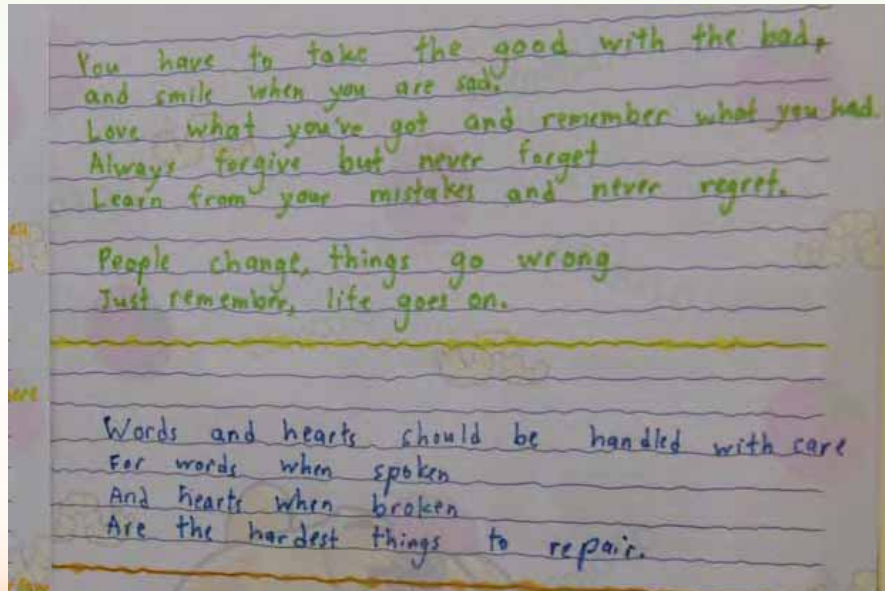
## The joy of artistic fulfillment: painting




Source: <http://www.newsherald.com/article/HR/20130726/NEWS/307269884>;  
<http://www.news-herald.com/article/HR/20120320/NEWS/303209988>

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## Beauty of Expression: Writing poetry



Source: <http://www.channelnewsasia.com/news/singapore/young-cancer-patients/2506308.html>

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## Somatic Expression: Dance together



Source: <http://www.istd.org/news/news-archive/careers-corner-dance-movement-psychotherapy/> &  
[http://www.octaband.com/dementia\\_therapy.htm](http://www.octaband.com/dementia_therapy.htm)

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## Vibration, Percussion, Music, Songs

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Source: VNA of Middlesex-East, Sawtelle Family Hospice House



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## Enjoyment and indulgences

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### French hospital to open wine bar for terminally ill patients

Aim is to 'improve quality of patients' day-to-day existence', says head of palliative care centre in Clermont-Ferrand

Source:  
<http://www.theguardian.com/world/2014/aug/01/french-hospital-open-wine-bar-terminally-ill-patients-clermont-ferrand>



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## Pet therapy: Love

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Photo: The Good Dog Foundation  
Source: Fleishman et al., 2015; *J Community Supportive Oncol*

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## Human touch

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JC Eccc  
Jockey Club End-of-Life Community Care Project

### *Comfort Touch<sup>®</sup>*

*can enhance the quality of life for anyone  
in need of a caring touch.*



Source: <http://www.comforttouch.com/>

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## Fun and empowerment

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### A true Wonder Woman! Woman battling breast cancer dresses up as her favourite superhero for her final day of chemo

- Danielle Javernig, 43, was diagnosed with breast cancer in May this year

Source: <http://www.dailymail.co.uk/femail/article-3332943/Danielle-Javernig-dresses-Wonder-Woman-day-chemotherapy-treat-breast-cancer.html>

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## Living instead of dying

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Source: <http://www.ambulancewens.nl/>

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## Family reunion



### Dream Foundation brings joy to family reunion : As end of life *nears*, veteran goes camping with ones he loves

JUNE 11, 2012 BY ADMIN



Source: <http://www.dreamfoundation.org/>

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## Having your loved ones at your bedside when you pass away



Source: <http://www.independent.co.uk/arts-entertainment/the-lessons-for-living-we-learn-from-the-dying-1167510.html>

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## Back to the reality



## Patients' psychological distress



About **40%** of EOL patients demonstrated significant level of **self-perceived burden**

Chochinov et al., 2007, *J Pain Symptom Manag*

**1 in 4** patients demonstrated **anxiety + depression symptoms**

O'Connor et al., 2010, *MJA*

**20.7%** prevalence for **depressive disorders (DSM-IV)** in palliative care patients

Wilson et al., 2007, *J Pain Symptom Manag*

**13.9%** prevalence for **anxiety disorders (DSM-IV)** in palliative care patients

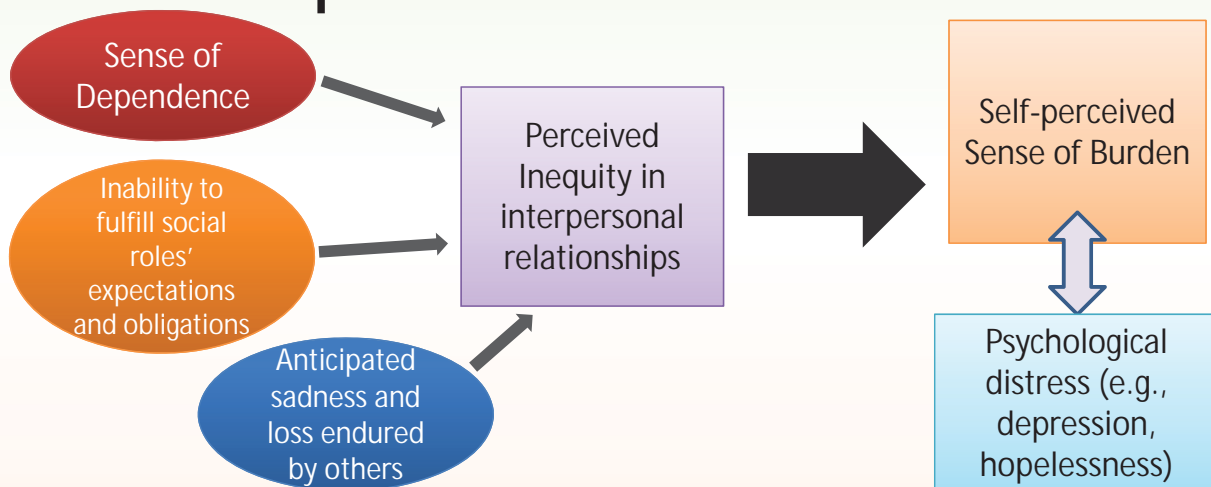
Wilson et al., 2007, *J Pain Symptom Manag*

**1 in 6 (17%)** terminally ill cancer patients **wished to hasten death or felt hopeless**

Breitbart et al. 2000, *JAMA*

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## Self-perceived burden & distress



Source: McPherson et al., 2007, *J Palliative Care*

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## Conflict among family members



## Self-perceived burden & distress

### Potential Sources of Sense of Burden

Provision of Physical Care	Caregiver witnessing the death	Substituted decision- making for life-sustaining treatment
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Source: Chochinov et al., 2007, *J Pain Symptom Manag*

## Caregivers psychological distress



**32% clinical level of anxiety**

Gough & Hudson, 2009, *J Pain Symptom Manag*

**30% caregivers felt anxiety, sadness, and frustration**

National Family Caregiver Association, 1998

**12% clinical level of depression**

Gough & Hudson, 2009, *J Pain Symptom Manag*

**40-60% high level of psychological distress (vs. 19% in general population)**

Dumont et al., 2006; *J Palliative Med*

Other distress:  
Helplessness,  
burden,  
loneliness, anger

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## How to empower patients and families?



### Community engagement in end-of-life care

- Engaging & empowering families, friends, volunteers, and community members as a part of the "*caring team*" together *with the professionals*
- Enhancing community's death literacy

Source: Sallnow et al., 2016, *Palliative Med*; Brown & Walter, 2014, *Brit J Soc Work*

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## Death is ...



Holistic care by  
professionals to families  
and patients

Engaging and  
empowering  
community



An issue that concerns  
all walks in the  
community

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## Quality co-ordination of care – chronic and complex medical conditions



Source of artwork: <http://www.nationalhme.com/img-care-img.png>

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## What can the community do to help patients and families?



From the experience of **8 local community groups** within an interest in end-of-life care and death in **Canberra, Australia**:

### Pragmatic support

- Financial assistance
- Food vouchers
- Housework
- Information navigate health system

### Respect & responsiveness

- Normalization activities to reduce stigma
- Offer respect and reassurance to encourage social engagement

### Connection & empowerment

- Peer support
- Social reconnection
- Social networks (art groups, exercise groups, social outings)

Source: Mills et al., 2014, *Critical Public Health*

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## Structure of community engagement



### Circles of care

- Needs of patients to be fulfilled by its nearest circles (i.e., close family members).
- Outer circles empower and support inner circles
- ***Dual-role for professionals:***
  1. Deliver professional service
  2. Empower community and informal caregivers



Source: Abel et al., 2013, *BMJ Supportive Palliative Care*

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## Outcomes of community engagement



**Burns, C. M., et al. (2011).** What is the role of friends when contributing care at the end of life? Findings from an Australian population study. *Psycho-oncology*, 20, 203-212.

Involving friends  
as caregivers



Home deaths &  
use of palliative  
care services

*N* = 2093, South Australia

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## Outcomes of community engagement



**Greene, A., et al. (2012).** Can assessing caregiver needs and activating community networks improve caregiver-defined outcomes? A single-blind, quasi-experimental pilot study: Community facilitator pilot. *Palliative Medicine*, 26, 917-923.

Community network  
facilitator to assess  
and help mobilize  
caregivers' own social  
network



Caregiver fatigue,  
role resentment



Support, confidence in  
seeking assistance

*N* = 66, South Australia

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## Outcomes of community engagement



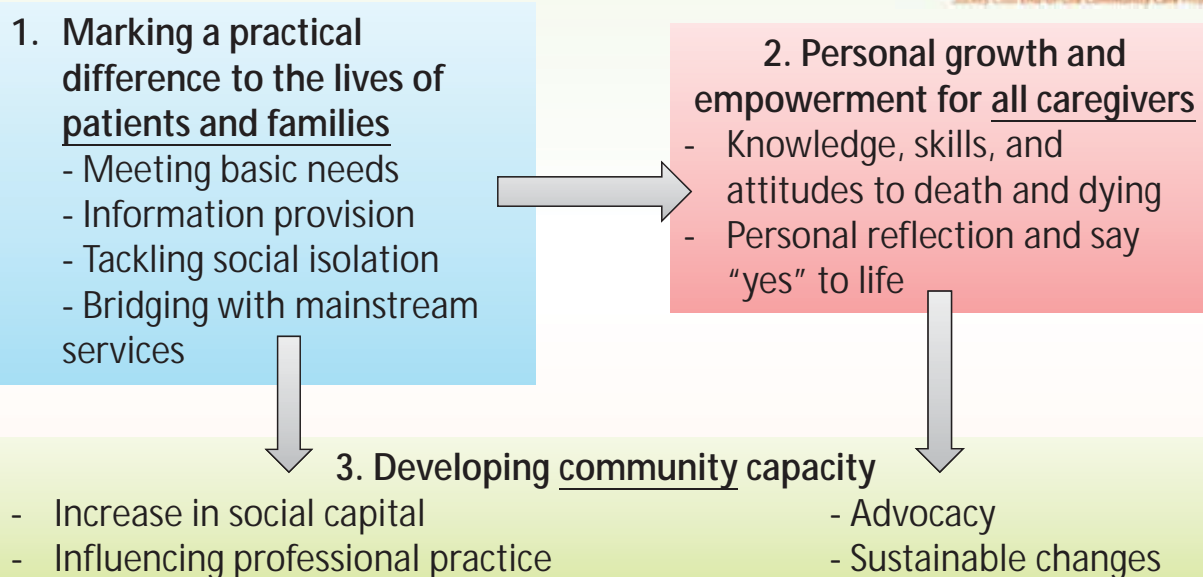
Jack, B. A., et al. (2011). "A bridge to the hospice": The impact of a community volunteer programme in Uganda. *Palliative Medicine*, 25, 706-715.

Theme 1: Impact on patients and families	Theme 2: Education & support	Theme 3: Bridge to the hospice
<ul style="list-style-type: none"> <li>- Physical care</li> <li>- Practical help</li> </ul>	<ul style="list-style-type: none"> <li>- Counseling</li> <li>- Education about medical procedures</li> </ul>	<ul style="list-style-type: none"> <li>- Linking up patients to the hospice services</li> </ul>

N = 64, Uganda

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## Outcomes of community engagement – Summary from a systematic review



Source: Sallnow et al., 2016, *Palliative Med*

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## Learning from the champions

Figure 6.1

### Community engagement (10% weighting)

Rank	Country	
1	Belgium	100.0
2	New Zealand	100.0
3	France	92.9
4	UK	92.9

*"In Belgium, for example, a strong network of volunteer workers exist. In New Zealand (...) public awareness of palliative care and advance care planning is increasing, while Hospice New Zealand, which leads the country's hospice movement, has a robust community engagement goal in its strategic plan."* (Extracted from Quality of Death Index 2015, p. 45)

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Living Every Moment  
**hospice**  
New Zealand



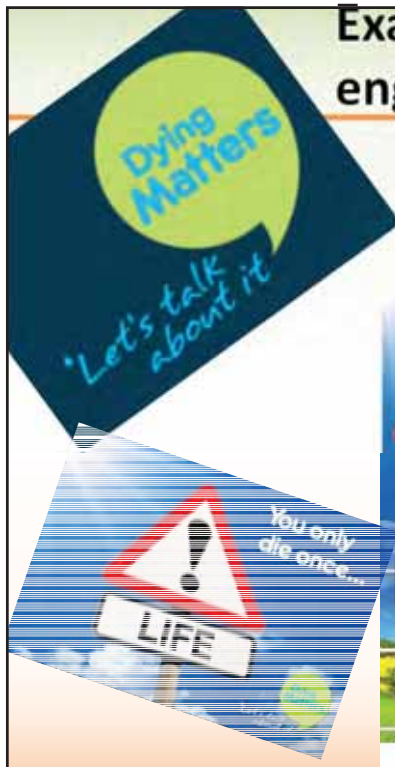
European Association for Palliative Care  
Non Governmental Organisation (NGO) recognised by the Council of Europe

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## Examples of community engagement

Dying Matters, set up in 2009, is a coalition of 30,000 members across England and Wales which aims to help people talk more openly about dying, death and bereavement, and to make plans for end of life.

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Source: Dying Matters – England & Wales

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## Examples of community engagement

it takes a village  
death awareness week scotland  
9-15 may 2016

*(...) If “it takes a village to raise a child”, it also takes a village to support someone who is dying and their family. This year’s Awareness Week celebrates everyone who has ever cared for someone who has died. (...)*

Source: <http://www.goodlifedeathgrief.org.uk/content/awareness-week-2016/>

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## Examples of community engagement

**Compassionate Communities**  
...because death and dying is everyone's business

*(...) The Good Neighbour Partnership can assist the person affected by advanced illness, and their family, to find the extra **social and practical support** that they may need **from within their community** by making links with those living close-by who would like to offer help. (...)*

Source: <http://www.compassionatecommunities.ie> & McLoughlin et al., 2015, *BMC Palliative Care*

## Examples of community engagement



*A collaboration between beauty professionals and community volunteers(befrienders)*



Source: <http://www.beautybus.org/>

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## Examples of community engagement



Symposium on **Hospice Palliative Care Volunteering** held at European Association for Palliative Care (EAPC) World Congress in Vienna, April 2015.

Source: <https://www.ehospice.com/Default/tabid/10686/ArticleId/16480/>

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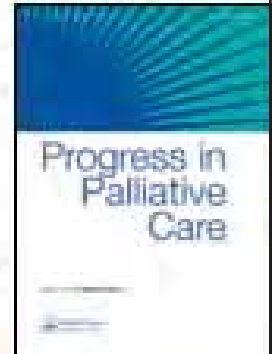
## Recently published special issue on public health in *Progress in Palliative Care* Feb 2016

Editorial

Putting the 'public' into public health:  
community engagement in palliative and end  
of life care

**John P. Rosenberg<sup>1</sup>, Jason Mills<sup>2</sup>, Bruce Rumbold<sup>3</sup>**

<sup>1</sup>Queensland University of Technology, Brisbane, Australia, <sup>2</sup>University of Sydney, Sydney, Australia, <sup>3</sup>La Trobe University, Melbourne, Australia



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### Key success factors of care co-ordination for persons with complex needs (The King's Fund, 2013)

Jockey Club End-of-Life Community Care Project

Personal	<ul style="list-style-type: none"> <li>• Holistic focus on patients &amp; carers</li> <li>• Supporting resilience, and living with the disease</li> </ul>
Clinical and services	<ul style="list-style-type: none"> <li>• Single point-of-entry, single point-of-contact</li> <li>• Flexible and multi-faceted care co-ordinators</li> </ul>
Community	<ul style="list-style-type: none"> <li>• Support from volunteers</li> <li>• Community awareness and trust</li> </ul>
Functional	<ul style="list-style-type: none"> <li>• Effective communication of client information</li> <li>• Electronic health records OR "high touch low tech"</li> </ul>
Organizational	<ul style="list-style-type: none"> <li>• Local leadership and commitment</li> <li>• Care suited to local needs</li> </ul>
System	<ul style="list-style-type: none"> <li>• Funding for health and social care</li> <li>• Social climate supportive of person-centered care</li> </ul>

# Ambitions for Palliative and End of Life Care:

A national framework for local action 2015-2020



Partnership of 27 national EOLC organizations

## National Palliative and End of Life Care Partnership


- Association for Palliative Medicine
- Association of Ambulance Chief Executives
- Association of Directors of Adult Social Services
- Association of Palliative Care Social Workers
- Care Quality Commission
- College of Health Care Chaplains
- General Medical Council
- Health Education England
- Hospice UK
- Macmillan Cancer Support
- Marie Curie
- Motor Neurone Disease Association
- National Bereavement Alliance
- National Care Forum
- National Council for Palliative Care
- National Palliative Care Nurse Consultants Group
- National Voices
- NHS England
- NHS Improving Quality
- Patients Association
- Public Health England
- Royal College of General Practitioners
- Royal College of Nursing
- Royal College of Physicians
- Social Care Institute for Excellence
- Sue Ryder
- Together for Short Lives

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

Source : National Palliative and End of Life Care Partnership, 2015

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# 6 ambitions for end-of-life care



See each person as an individual	Fair access to care	Comfort & well-being
Co-ordinated care	Competent staff	Supportive community

Source : National Palliative and End of Life Care Partnership, 2015

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## Foundations for the ambitions:



1. Personalized care planning
2. Shared records among care teams
3. Evidence-based measurement of outcomes
4. Involving families, friends, and caregivers
5. Competence building for staff
6. Round-the-clock access to services
7. Co-design with beneficiaries and experts
8. Local and clinical leadership

Source : National Palliative and End of Life Care Partnership, 2015

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## Hong Kong Jockey Club Charities Trust End-of-Life Community Care Project (HKJCECC)

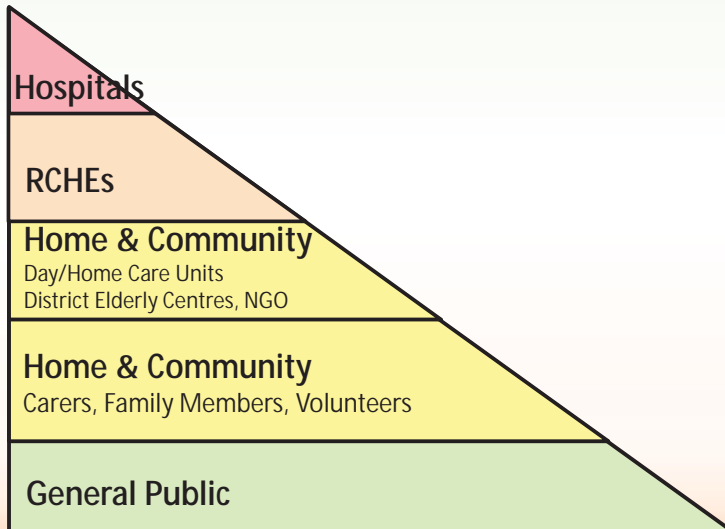


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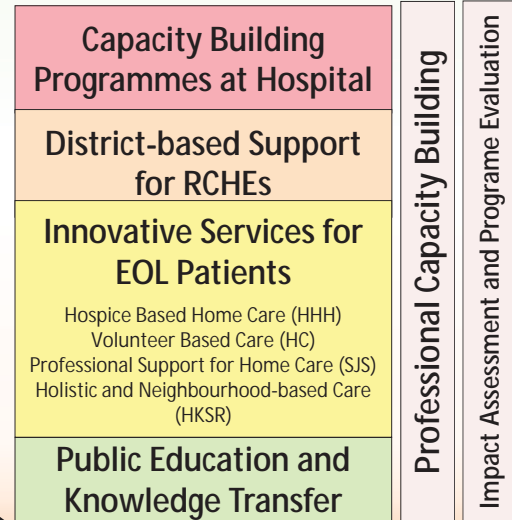
# Initiative in Hong Kong – JCECC



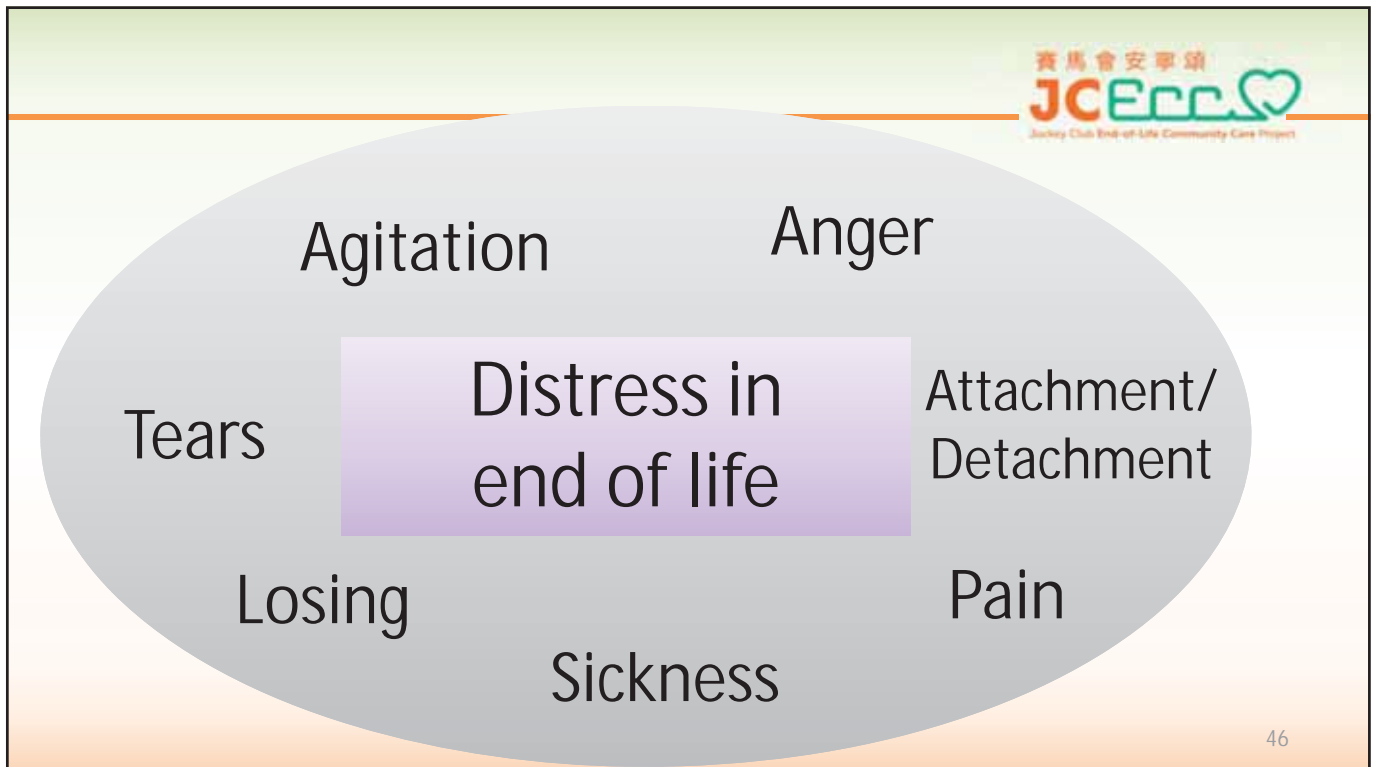
## EoLC Systems



## Project Components



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## Compassionate care

Source: <http://articles.latimes.com/2013/jul/03/local/la-me-ln-singing-nurse-20130703>



Jared Axen  
The "singing" nurse

'The Singing Nurse' at Valencia hospital soothes the suffering

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*Thank You!*

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