“Nursing Perspectives in End of Life Care”
(臨終照顧之護理角度)

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Timeframes of the End-of-Life process

THE END OF LIFE			THE DYING PHASE	
At risk of dying in 6-12 months, but may live for years	**MONTHS 2 – 9 months**	**SHORT WEEKS 1-8 weeks**	**LAST DAYS 2 – 14 days**	**LAST HOURS 0 – 48 hours**
DISEASE(S) RELENTLESS Progression is less reversible. Treatment benefits are waning.	**CHANGE UNDERWAY** Benefit of treatment less evident. Harms of treatment less tolerable.	**RECOVERY LESS LIKELY** The risk of death is rising.	**DYING BEGINS** Deterioration is weekly / daily.	**ACTIVELY DYING** The body is shutting down. The person is letting go.

End-of-Life (EoL) care is a

philosophy of care that provides a combination of **active** and **compassionate therapies** for patients who are living with a

chronic & progressive disease.

The focus of care is to

maximize **patient's quality of life** &

to **support families**.

Annals of Internal Medicine

Clinical Guidelines Ann Intern Med. 2008;148:147-159. www.annals.org

Evidence for Improving Palliative Care at the End of Life:

A Systematic Review

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What Are the Critical Issues for Clinicians to Address when Caring for Persons Nearing the End of Life?

Studies addressed **various illnesses and settings**, showing that dying patients & their families generally share these **concerns** include:

- Preventing and treating **pain and other symptoms**
- **Supporting families** and caregivers
- Ensuring **continuity**
- Making **informed decisions**
- Attending to **emotional well-being** (including spiritual concerns)
- Sustaining **function**
- **Surviving longer**

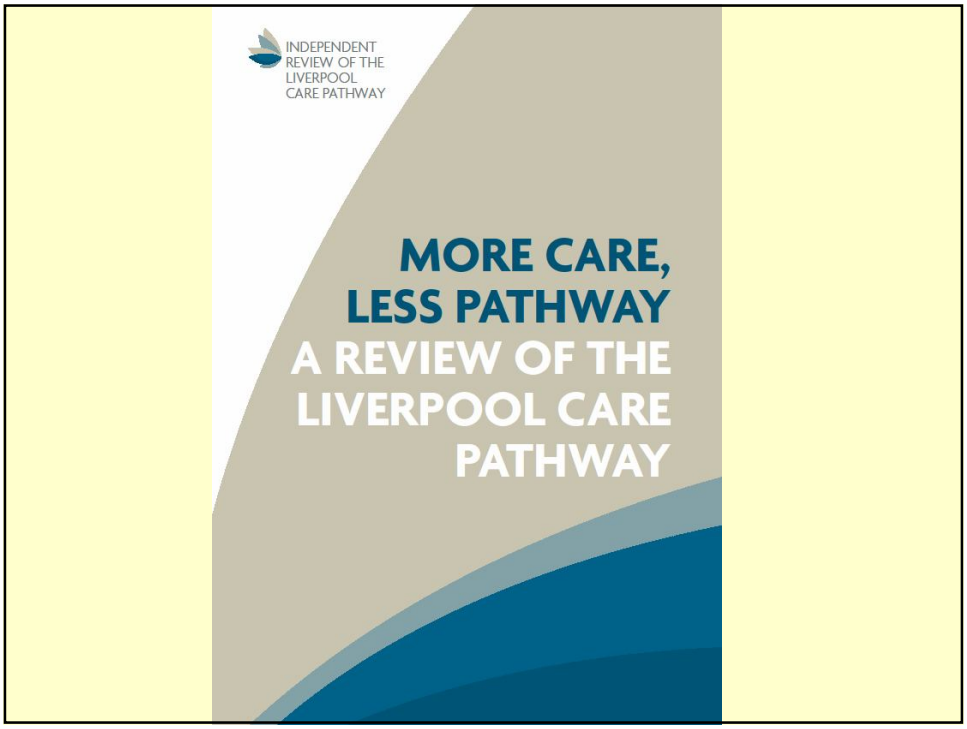
Good Death

To **know when death is coming** & to understand **what can be expected**
To be able to **retain control** of what happens
Dignity & Privacy
Pain Relief & Symptom Control
Choice & Control over Where Death occurs
To have **access to information & expertise** as required

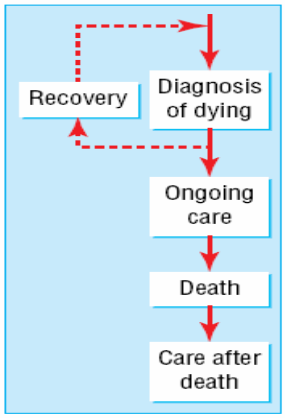
Age Health and Care Study Group (1999). *The Future of health and Care of Older People: The Vest is Yet to Come. Age Concern*. London.

Common Themes of good EoL

- Comfort
- Peace
- Dignity



Liverpool Care Pathway



Clinical trajectory of care of dying patients

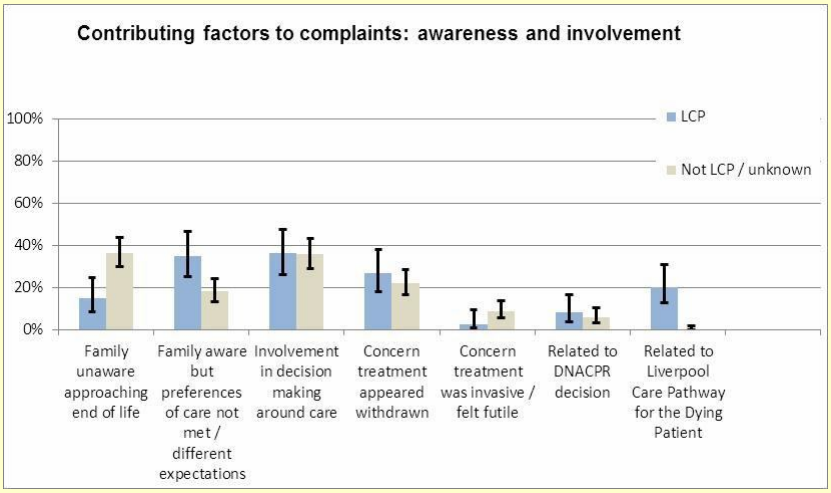
BMJ 2003;326(7379):30-4.

- Developed in 1990s
- Used in **a variety of care settings**
- Multi-disciplinary approach
- Focuses on physical, psychological and spiritual comfort of patients and their family
- As an audit tool for quality of EOL care

Snapshot Review of Complaints in End of Life Care Key findings

Themes of complaints in end of life care

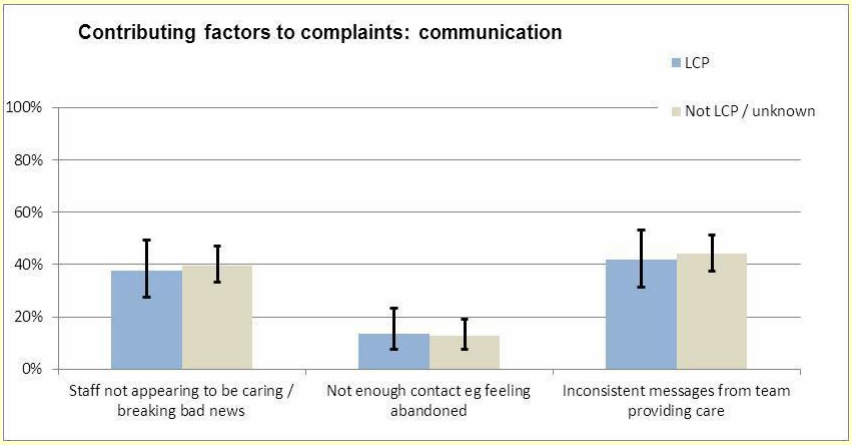
- **Awareness** of approaching end of life
- **Communication** & **being caring**
- **Concerns** around **clinical care**, including withdrawal of treatment
- Symptom management (including pain)
- Environment (privacy)
- **Fundamental** medical and nursing **care**



Contributing factors to complaints:

Awareness & Involvement

- **Involvement** of **decision making** around care
- Family aware **BUT** preferences of care not met
- **Concern treatment** appeared withdraw
- Family **unaware approaching EoL**
- Concern treatment was invasive /felt futile
- Related to **DNACPR decision**
- Related to Liverpool care Pathway for the dying patient



Contributing factors to complaints:

Communication

- **Inconsistent messages from team providing care**
- **Staff not appearing to be caring**
- **Not enough contacts, e.g., feeling abandoned**

The Review of the Liverpool Care Pathway (2013) uncovered issues of the complaints:
"What we have also exposed in this Review is a
fundamental problems with care for the dying

- A lack of **care , openness & compassion**
- Unavailability of suitably **trained st**aff
- **No access to** proper **palliative care advice outside** of 9-5 Monday to Friday

Reflection of EoL in HK

- End-of-Life care
- Education & Training (what kind of)
  Hospitals & Staff of OAH
- Promotion of Advance care planning

The impact of palliative care on cancer deaths in Hong Kong: a retrospective study of 494 cancer deaths

DMW Tse Department of Medicine and Geriatrics, Caritas Medical Centre, HKSAR, **KS Chan, WM Lam** Pulmonary and Palliative Care Unit, Haven of Hope Hospital, HKSAR, **KS Lau** Department of Respiratory Medicine, Ruttonjee and Tang Shiu Kin Hospital, HKSAR and **PT Lam** Department of Medicine and Geriatrics, United Christian Hospital, HKSAR

Objectives: To study the utilization of public health care by advanced cancer patients in
their last 6 months of life and their end-of-life process within the last 2 weeks of life.

Methods: This was a retrospective study on **494 cancer deaths** from four public hospitals in 2005. This sample was selected from all in-patient cancer deaths by the ratio of one in four. Data were collected by review of charts and an electronic data base.

Conclusion:

Our results suggest that palliative care service has **played a role in improving End-of-Life** cancer care in Hong Kong.

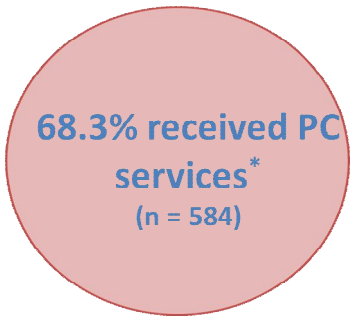
Palliative Medicine 2007; **21**: 425–433

PC Consultative Service

- PC Consultative Team: led by PC specialists (mainly doctors & nurses)
- Service scope:
  - Advice on **symptom control**
  - Advice on **psychosocial support** and **Advance Care Planning** (ACP)
  - **Coordination of care**, including post-discharge care needs (e.g. Day care service, Home care service, NGO support)
  - **Skill transfer** to staff in non-PC setting as appropriate
  - Consultative service **will enhance patients' access to PC services**, particularly for hospitals without PC units

% of Patients Received PC Services

- In-patient
- Consultation
- Home Care
- Out-patient
- Day care



* patients received any PC service under the scope of review (2012-13 - within 180 days)

In HK, less than 35% of cancer patients died in palliative care (PC) units.

Most of the **patients** with chronic illness died in acute / convalescent hospitals

may or **may not** have

support of palliative care.

Reflection of EoL in HK

- End-of-Life care
- **Education & Training, esp. nurses working in non-PC settings**
- Promotion of Advance care planning

Barriers to Communication About End-of-Life Care in AIDS Patients

J. Randall Curtis, MD, MPH, Donald L. Patrick, PhD, MSPH

Barriers identified by patient and physician

Discomfort in discussing death

Patient is **not sick enough to talk** about EoL care

Discussing death can **cause harm** or death

Patients avoid EoL discussion to protect physicians

Each person **waiting until** the other brings up EoL care

Commissioned Palliative Care Training for Nurses Working in Non-palliative Care Settings 2013

Target Participants:

Experienced clinical nurses

Recruited nurses' working experiences

Average-19.22 years

Median- 18.35 years

Commissioned Palliative Care Training for Nurses Working in Non-palliative Care Settings

Pre-Questionnaire

The nurses are overwhelmed with caring for the PC patients and their family members

The nurses are overwhelmed with caring for the dying patients and their family members

Commissioned Palliative Care Training for Nurses Working in Non-palliative Care Settings

Pre-Questionnaire

Taking care the patients with terminal disease, the nurses

- Irritable and distressed
- Powerless
- Helpless
- Very stressful in work
- Cope with detached attitude

- * “I know the needs of the patients but do not know how to help”

The EoL Care Strategy for England (DH, 2008) highlight the major deficiencies in

- **Knowledge**
- **Skills**
- **Attitudes**

} **Behaviours**

of staff groups who are in **frequent contact with people at the end of their lives**

Education & Training

Teaching Modes:

Classroom teaching and …..

Education & Training

Commissioned Palliative Care Training for Nurses Working in Non-palliative Care Settings

Aim of the Project:

To enhance the competence of nurses working in Non-PC settings to provide quality care for patients requiring palliative care and their family

Target Participants:

Experienced nurses

Day	Teaching Mode	Aims	Venue
1	**Workshop (Heart-Attitude)**	Rejuvenate the compassion towards those who are terminally ill and in suffering	**In a retreat centre** (20 x 2)
2	Lecture **(Head-Knowledge)**	Build knowledge on Palliative Care	Classroom (40 x1)
3	**Workshop (Hand-Skill)**	Drill skill on communication and crisis management	**Simulation & Skills Centre** (10 x4)

Overall result:

- The program helps in personal and professional growth.
- The nurses are more confident, willing, active to take care the terminal patients and patients approaching dying.
- The program is practical that it can apply directly for the care to the patient.

Result of **Day 1** workshop, some items are found significant improvement ($p<0.01$) by One-Sample T test

- **I feel powerless** 我感到無能爲力

- * **I know the needs of the patients but do not know how to help** 我知道他們的需要，但不知道如何幫助

- **I'm sensitive to identify the needs of terminal patients and their family members**
  我擁有敏銳的洞察力，知道晚期病人和家人的需要。

- **I'll explore the coping method of patients & their family members when the patient is facing impending death**
  我會瞭解病人/家人面對病人將要死亡的應對方法

Result of Day 3:

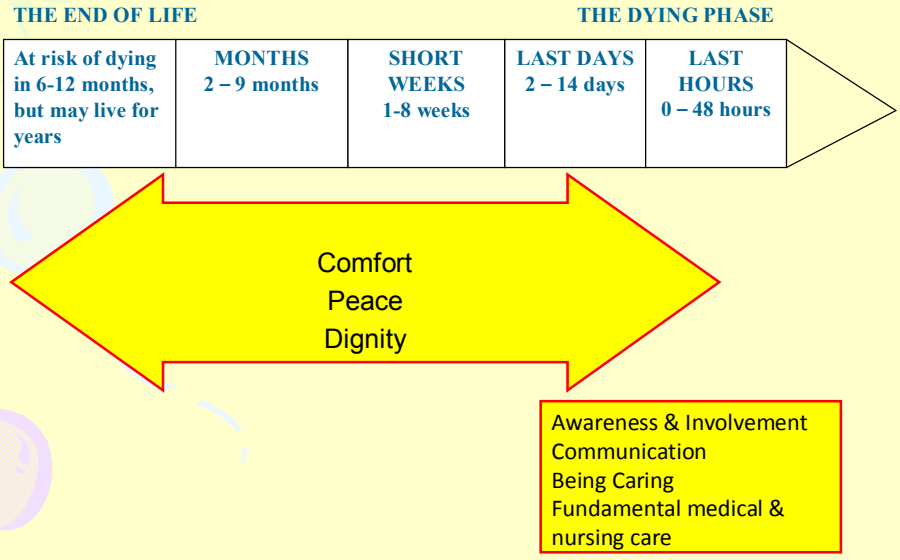
The experience of simulation-based practice can help the nurses to understand their strength and weakness of communication skill in clinical scenes.

They treasured the debriefing session because exchanging of ideas, suggestions & feelings are very useful in practice of clinical care.

"I like simulation the most. I faced the same situation as in the simulation training that I applied what I had learnt. It's so good and I am satisfied of what I have done".

"It helps me to identify the needs of a dying patient and his/her relatives' expectation. It would help us in delivering & constructing our care while facing various expectations of them".

Timeframes in the End-of-Life process



Considered teaching modes:

- Experiential workshop
- Simulation-based communication skill

Considered the contents of

- Family conference

(studies emphasize that acknowledging death risk is important for decision making)

- Facilitating decision making
- Case study

Reflection of EoL in HK

- End-of-Life care
- Education & Training, esp. nurses working in non-PC settings
- **Promotion of Advance care planning**

eLearning Courseware of HAHO written of Specialty Advisory Group (SAG) of PC, Nursing Section of HAHO in 2013-14

Title : Improving End-of-Life Care

Module I:

Facilitating Advance Care Planning in Life Limiting Illness

Module II:

Palliative Care in End-stage Organ Failure

Module III:

Using of Multidisciplinary Team Approach End-Of-Life Care

Pathways for the last hours or days of life

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What Issues are Important in Advance Care Planning for Patients Approaching the End of Life?

- Systematic reviews addressed **establishing goals of care** & **advance care planning** (ACP) are important in EoL care

- Studies evaluated effective outcomes of ACP are **positive** and none found harm (Song, 2004)

Recent research suggests that

- Engaging values

- Involving skilled facilitators

  and

- Including patients, caregivers, & providers

  can increase the rates and effectiveness of **communication about late-life goals** & **advance care planning**.

Good end of life care is important because

'How people die remains in the memory of those who live on'.

Dame Cicely Saunders. Quote from the front of the National End of Life Care Strategy July 2008.

Thank you

References:

Blues, A. G., & Zerwekh, J. V. (1984). Hospice and palliative nursing care. London: Grune & Stratton, Inc.

Canadian Hospice Palliative Care Association. (2002). Hospice Palliative Care Nursing Standards of Practice. Ottawa: Canadian Hospice Palliative Care Association.

Walsh RA, Girgis A, Sanson-Fisher RW. Breaking bad news. 2: What evidence is available to guide clinicians? Behav Med. 1998;24:61-72.

Song MK. Effects of end-of-life discussions on patients' affective outcomes. Nurs Outlook. 2004;52:118-25.

Shalowitz DI, Garrett-Mayer E, Wendler D. The accuracy of surrogate decision makers: a systematic review. Arch Intern Med. 2006;166:493-7.

Baggs JG. End-of-life care for older adults in ICUs. Annu Rev Nurs Res.2002;20:181-229.

http://www.england.nhs.uk/everyonecounts/