## Seminar on Living with a Dying Loved One: Tips from the East and the West

Conflict Resolution in Dementia Care

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# Dementia: A great Family Divider

# Dementia: a great family divider

- Cracks in family solidarity
- Intra-family dynamics
- 40% of adult child caregivers have relationship conflicts with another member
  - (Strawbridge and Wallhagen, 1991)

### Family Conflict in dementia (Int J Geri Psy 2006; 21:485-492)

- Mild to Moderate dementia
- (End of Life care)
- Between siblings
- *Service providers* in 25%
- Pwd with paranoid ideation fueled by family members: neglect, exploitation, lack of communication
- Conciliation successful in 30%

	Frequency <sup>#</sup>
Who is in conflict?	
Sibling vs sibling	27
Other intra-familial	9
Family vs agency	6
Person with dementia versus family	5
Family vs friend/'bystander'	3
Themes of conflict*	
Inadequate care	23
Money/financial exploitation	23
Lack of communication or sequestration	21
Placement/Where the person with dementia	15
should live	
Underestimation of the diagnosis	9
Paranoid ideation of the person with dementia	13
Risk	5
Position of person with dementia with respect	
to the conflict*	
Involved or allied	37
Inconsistent	13
Distressed 'trying to keep the peace'	7
Neutral, uninvolved	9

Table 2. Nature of family and systems conflict in dementia

\*Not mutually exclusive categories. Int J Geriatr Psy 2006;21:48 $\frac{1}{9}$ -492

Table 1. Common Examples of Conflict		
Family vs Clinician		
Son prefers life-sustaining treatment for patient	Physician thinks life-sustaining treatment would increase patient suffering	
Husband is uncertain about patient's wishes	Physician finds the husband is inconsistent when discussing patient's wishes	
Husband does not trust that clinician is acting in patient's best interests	Nurse thinks family is not acting in patient's best interests	
Wife does not believe prognosis given by clinicians	Physician believes wife is in denial	
Clinician vs Clinician		
Specialist physician wishes to continue interventions targeted at disease	Palliative physician wishes to focus on quality of life and patient goals	
Physician wants to continue life-sustaining treatment based on small chance of cure	Nurse wants to focus on quality of life based on large chance of treatment failure	
Physician thinks that medical decisions are his/her responsibility	Nurse thinks his/her input is excluded from decision making	
Attending physician gives resident increasing responsibility	Nurse thinks that resident decisions are inadequately supervised	
Family vs Family		
Daughter thinks she knows patient wishes best	Son thinks medical options have not been exhausted	
Wife has come to accept her husband's imminent death	Daughter has just arrived from out of town, insists on not giving up	
Patient vs	Clinician	
Patient wants to try another chemotherapy regimen	Physician thinks that more chemotherapy is futile	
Patient wants to live independently	Physician thinks patient's debility requires assisted living	
	IAMA 2005-202(11)-1274 1291	

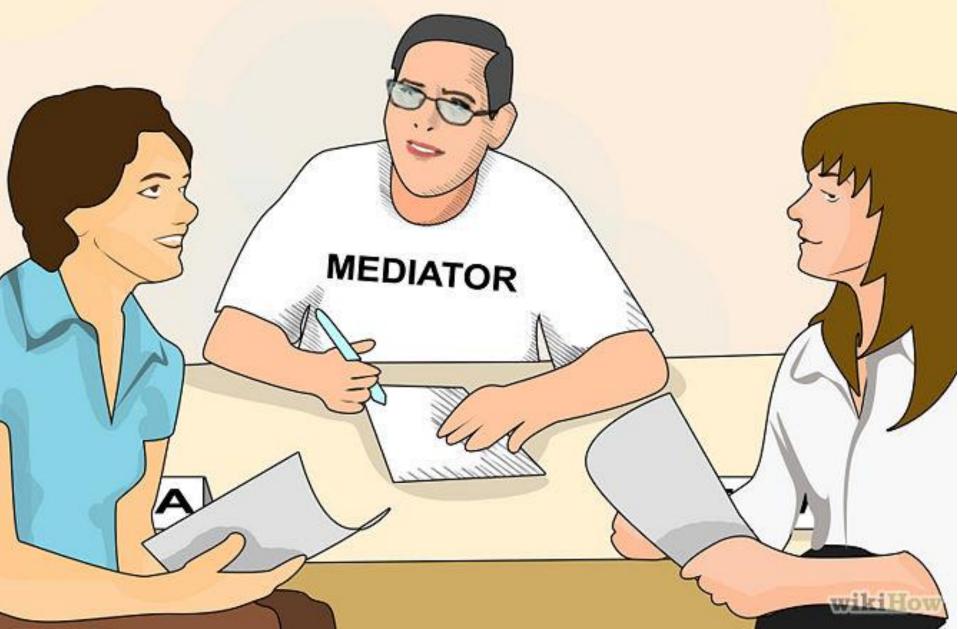
# Effects

- Dysfunctional alliances between disgruntled family members
- Caregiver burden and depression and anger
- Post placement depression among wives
- Legal disputes about wills, power of attorney, financial management

### Guardianship and financial management:

end point of family breakdown

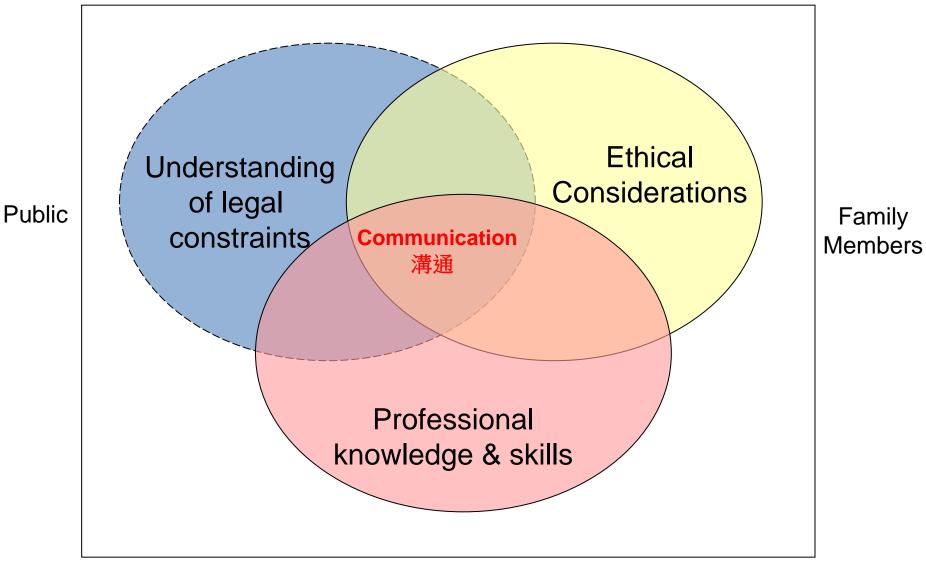
## The Healthcare Provider



### **Mediation:** At the Heart of Communication



#### The Modern Practitioner Patient



Colleagues

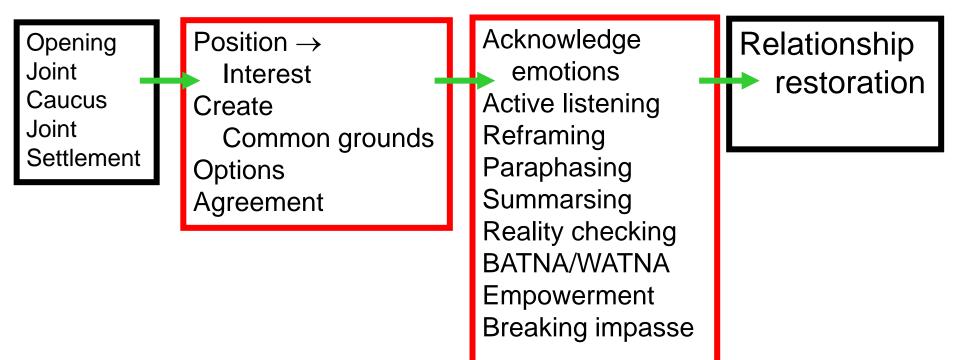
## Definition of Mediation 調解 (Folberg and Taylor, 1984)

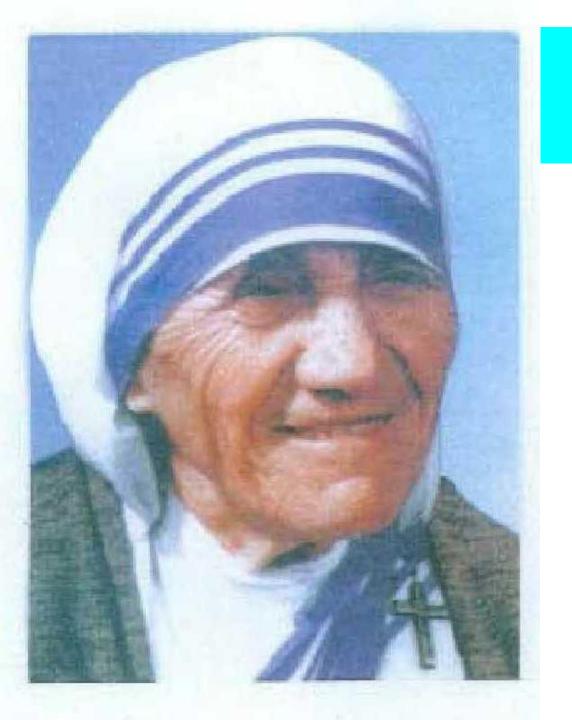


" (Mediation) can be defined as the process by which the participants, together with the assistance of a neutral third person or persons, systematically isolate disputed issues in order to develop options, consider alternatives, and reach a consensual settlement that will accommodate their needs."



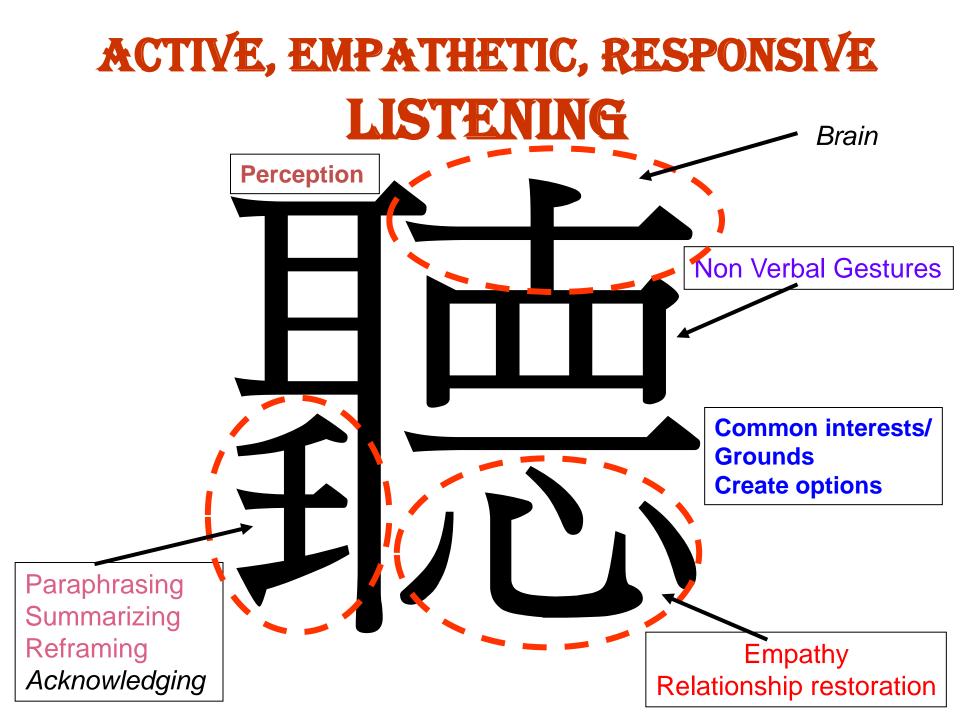






# Active Listening

"Remember before you speak, it is necessary to listen, and only then, from the fullness of your heart you speak..." (Mother Teresa)



Applied Mediation Skills in Dementia Care: From Diagnosis to EOL

## **Disclosure and breaking news:**

- preparation of clinical information
- active listening
- acknowledging emotions
- separate sessions with patient and family members
- identification of needs

Impact of disclosure ( Aging & MH, 2006; 10(5): 525-531)

- Disclosure without introducing stress
- Regular practice of careful planning and performance of diagnostic disclosure
- Emphasize hope in the face of a difficult diagnosis, progressive disclosure to allow preparation (Alz Dis & Assoc Dis, 2007; 21(2): 107-114)

### Changing needs ( Alz & Dis 2007;3: 404-410)

### **Evolution of disease**

- Individual, family, future care provider
- Progressive process:

Diagnostic uncertainty, treatment options, future plans,

Respite, Institutionalisation, Hospitalisation

Financial planning, EPOA, wills and living will;

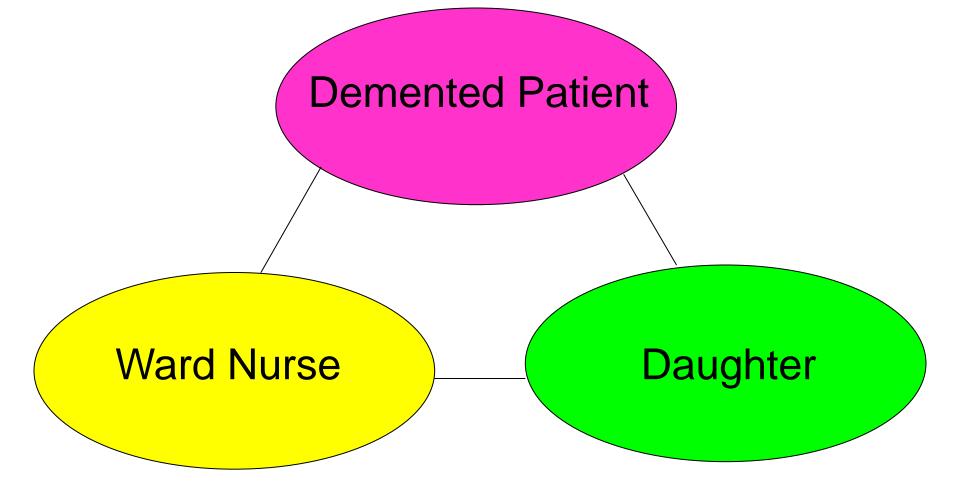
Driving, services, research, EOL care

#### Cooperative Communication in Special Care (The Geron 2007; 47(4): 504-515)

- Disagreement is common
- Shared goal of optimal QOL for resident
- Relatives tend to withhold suggestions for improving care, fearing negative repercussions
- Nursing home staff, working with resident's families is stressful
- Racial, cultural, socioeconomic

Ms. A provided care for *her father* since he was diagnosed dementia in his early 90s. On An episode of acute illness in August 2001, Ms A realized that she could not take care of Her father alone at home. He was subsequently admitted into a *nursing home*. Since then, *eating difficulties* became the major issue. The nursing home staff had discussed with Ms A several times on commencing long-term tube feeding. However, Ms A *resisted* the idea as she knew that her *father loved food* very much, forgoing oral feeding meant taking away the only pleasure from him (EMPATHY AND LOVE). She was able to *learn* over time how to *feed her father* (FILIAL CARING). In October 2003, her father an episode of *acute illness* that rendered him warded in an acute Hospital. On admission, she told the ward staff that she would bring food to her father, and asked them not to tube feed the patient. It was the post SARS period when restricted visiting was observed. When her father was transferred to the convalescent *hospital*, she noted that her father was already *put on tube feeding*. This was done *without her knowledge* (RESPECT AND ACKNOWLEDGMENT). She noted that her father's sad and fearful face. Her father died in early January 2004, *two more months* after tube feeding commenced. Ms A was still in *grief* at the interview, which took place in September 2005. She could not forgive herself and the healthcare providers; or the pain that had inflicted on her father in the last two months of his life (GUILT, REGRET and ANGER).

**A Daughter's Reflection** 



#### **Collective Decision Making**

Conflict Resolution ( DOI: 10.1089/jpm.2008.9882)

- 1) Separate people from the **issues**
- 2) Focus on interests
- 3) Invent solutions
- 4) Outline objective criteria

## **Mediated Communication**

**Issues :** Feeding in a person with advanced dementia

#### **Parties and Positions:**

Daughter (No suffering);

Nursing home( facilitate task; no risk);

Hospital (rules and accountability, professional)

#### **Common interests:**

needs, fear and concern

#### **Reframing to change Perception:**

Quality of life and care, Dignity

Skills : active listening, acknowledging, creating options

**Options :** palliative approach, consensus in care outcomes, allow hand feeding by daughter

### Lesson to learn : advance care planning

# **Minimize Regret**

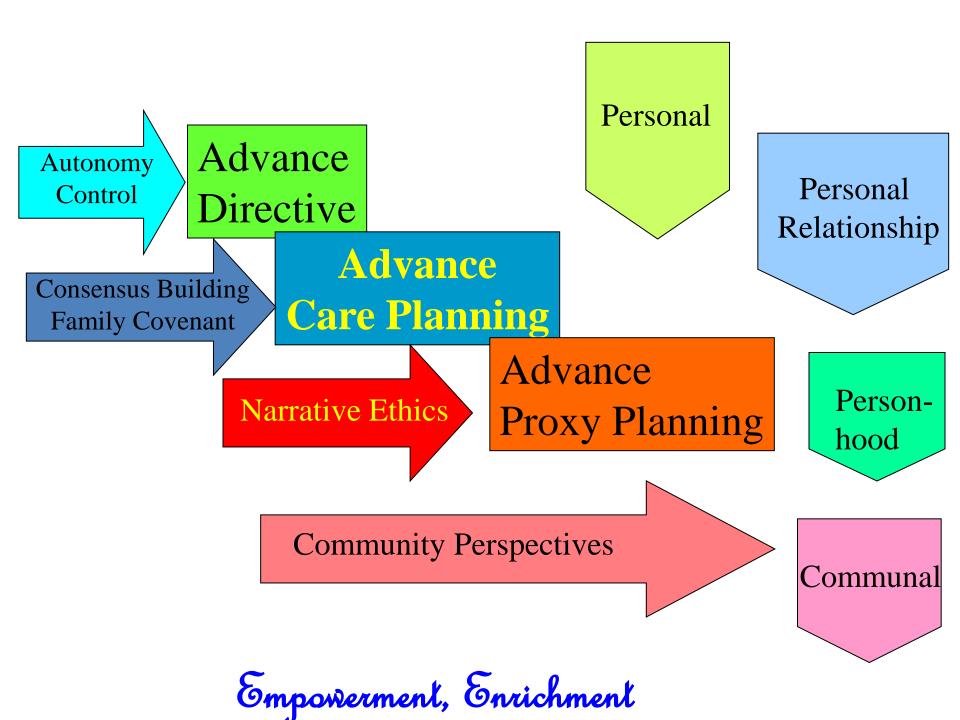
#### **Advance Care planning**

Connection

Narration

Anticipatory Grief

Preparation



# A Personal Story



# 爸媽,我在這裡! 照顧失智雙親心路歷程

🖉 白象

台灣第一本失智症家屬照顧後全記錄! 本書真實紀錄雙親罹患失智症的發病過程,照護期間家屬所遭受的恐懼 無奈,更說出一位失智患者,在清醒的片刻所表達出的内心世界……

一龍祥燕著

聯合推薦 春禾範團藝術總監郎祖筠/台灣失智症協會名譽理事長陳榮基/行政院漸生署口腔醫學委員會主任委員韓良俊 臺大醫院神經科教授暨天主教康泰醫療教育基金會畫事長葉防強/天主教失智老人基金會執行長籃耕華醫院永和分院院長鄧世雄

# **Filial**

### EVEN WHEN SHE FORGOT MY NAME

ET.

Love, Life and My Mother's

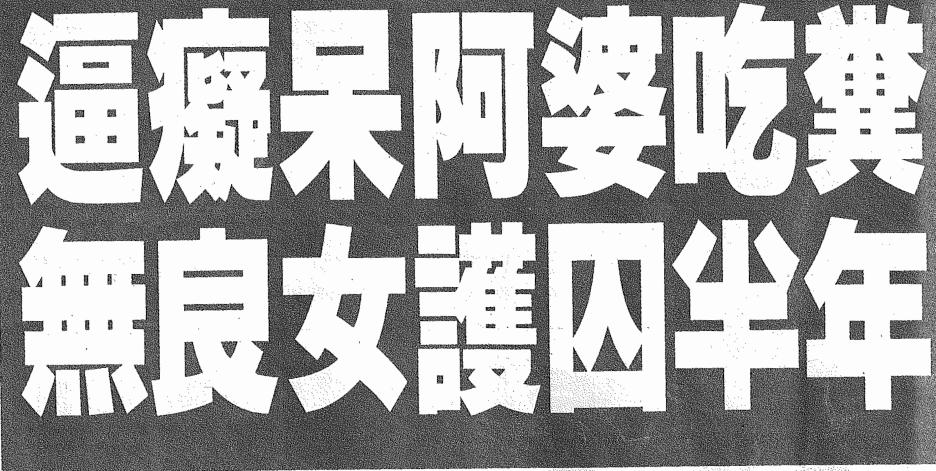
Alzheimer's

WONG

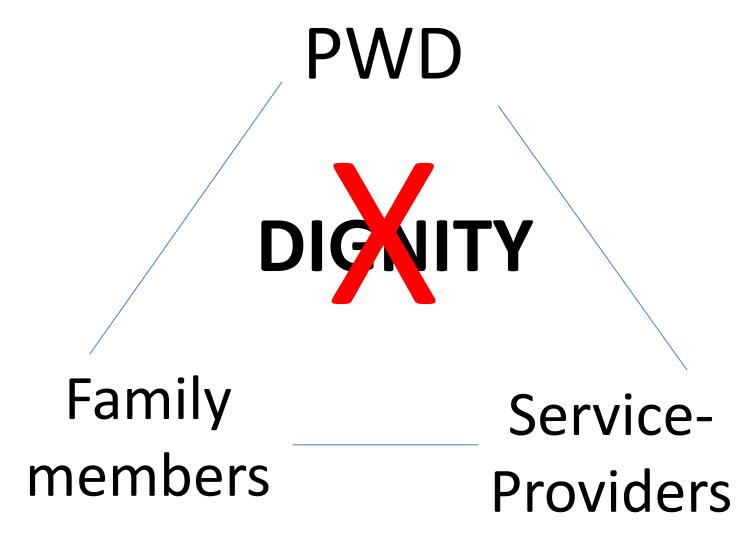
CHAI

KEE





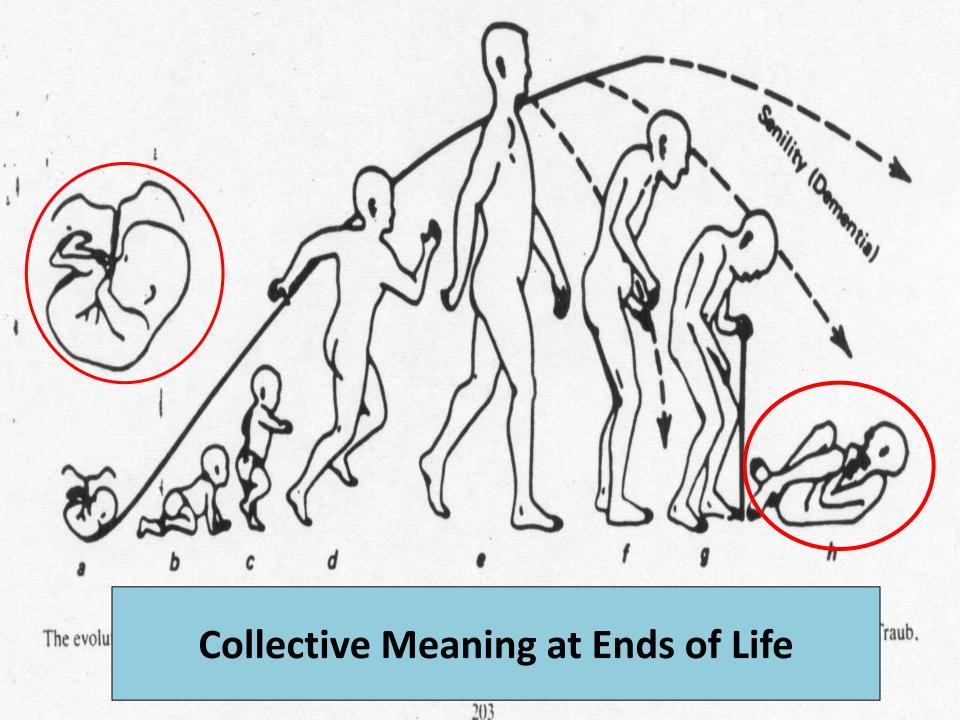
A residential staff fed human feces to a client with dementia





# Dignity

- Acceptance of identity
- Inclusion
- Safety
- Acknowledgment
- Recognition
- Fairness
- Benefit of doubt
- Understanding
- Independence
- Accountability



Sanctity of Life

# **Dignity rises above Sanctity of Life: Restore the** Fading Personhood

**The Elder** 

Two Riveting Novels Celebrating the Journey of Ageing The Forgotten River • Listening to Letter from America

Grace

Dignity

#### **KUA EE HEOK**

"A compelling, provocative and totally absorbing book." Henry Lim, President, Gerontological Society, Singapore

"Greatly pleased and grateful." Alistair Cooke, New York, (1908-2004) Legendary Broadcaster of Radio Programme Letter from America Dignity and Respect



Harvey Max Chochinov (J Pall Med 2008, 11(5): 674-675)

Dignity-conserving Care for the dying

- A: attitude
- B: behaviour
- C: compassion
- D: dialogue

Every Person has his and her inherent value and worth Therapeutic Advocacy (Geriatrics 2003, 58(2): 9-15)

**Doctor's role:** 

Teacher and Advocate



- Helping children help their patients make decisions
- Educate, inform and convince older patients about what is in their best interest
- Covert relatives into "therapeutic advocates" to your recommendations

#### The Doctor' Role (Chest 2002; 121(3): 683-686)

We do our best to help our patients overcome the obstacles during this journey that are posed by various illnesses and accidents...The intent at that time ( end of this journey) is not to cure, but to palliate; ....to be a sensitive and compassionate physician who respects the

**Dignity** of the patient and family, and their right to refuse (and receive appropriate ) treatment ( in a collective decision process).