

Managing the Transition to Palliative Care

Kenneth J. Doka, Ph.D.

Professor of Gerontology, The
College of New Rochelle

Senior Consultant, The Hospice
Foundation of America

Objectives

- Identify factors and barriers that inhibit communication around end of life issues
- Describe sensitivities and alternative communication approaches
- Offer suggestions for more effective end of life communication

Paradox

- Family members often want to preserve hope yet they often regret they did not know death was imminent and missed opportunities for meaningful end-of-life communication

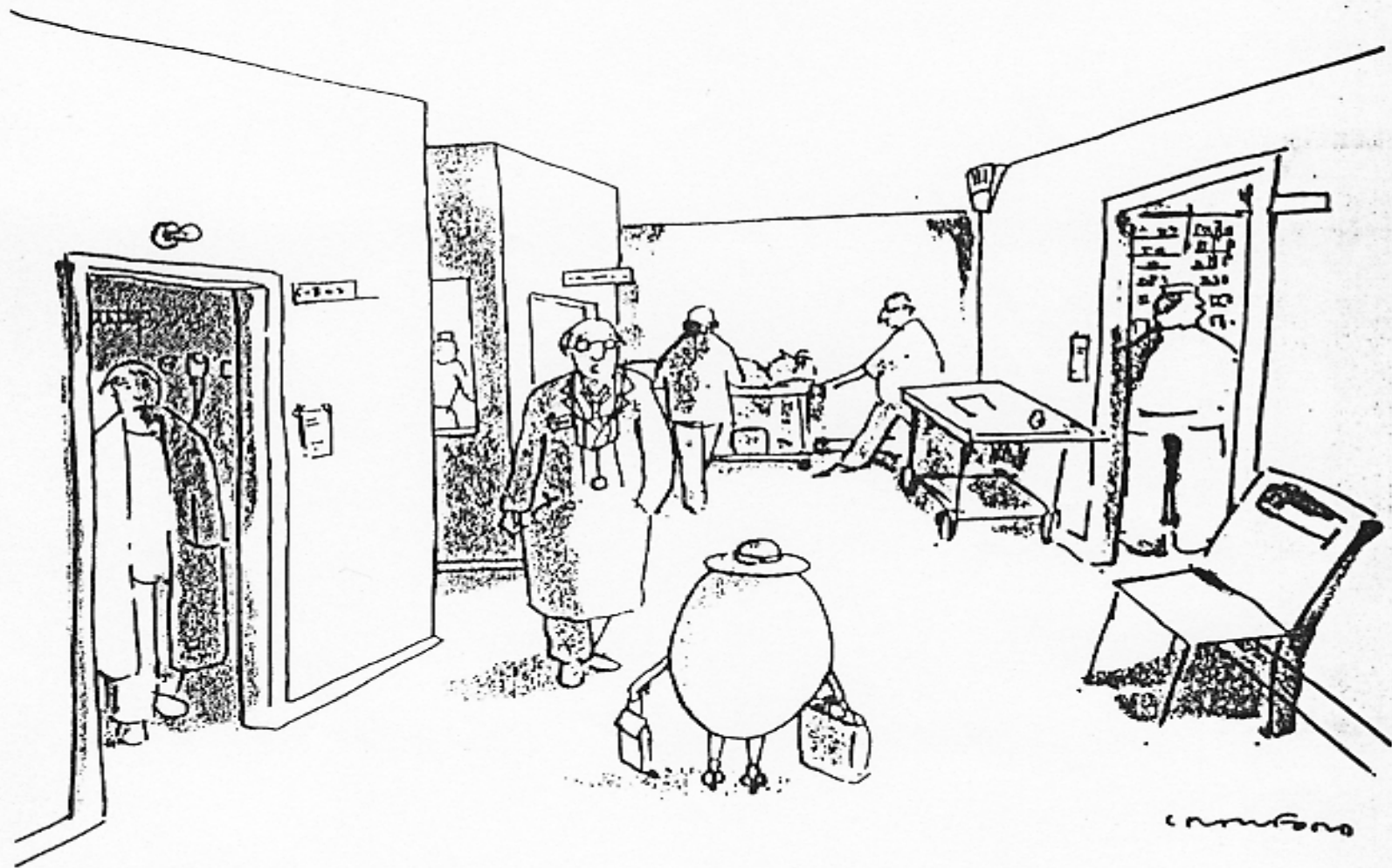


Managing the Transition to Palliative Care

Importance



- Research has indicated that aggressive treatment at the end of life is expensive and offers little benefit (Reichner et al, 2006; Sharma, et al, 2008)
- Connor (2007) found that patients in hospice actually survived 39 days longer on average compared to a sample receiving more aggressive care
- Ethics and cost of futile care



"You might want to sit down, Mrs. Dumpty."

Managing the Transition to Palliative Care

Barriers

- The Primacy of Hope
- Developmental
- Patient
- Family
- Cultural
- Communication
- Social and Psychological
- Professional
- Institutional



The Primacy of Hope

There is nothing so illuminating as...

HOPE

- “Hope should not die much before the patient dies” Gunther. *Death Be Not Proud*
- The Language and Metaphors of Illness
Fight vs. give up
- Restructuring and redefining hope

Developmental Barriers

- Throughout life, our orientation toward death changes

Recognition

Realization

Reconciliation

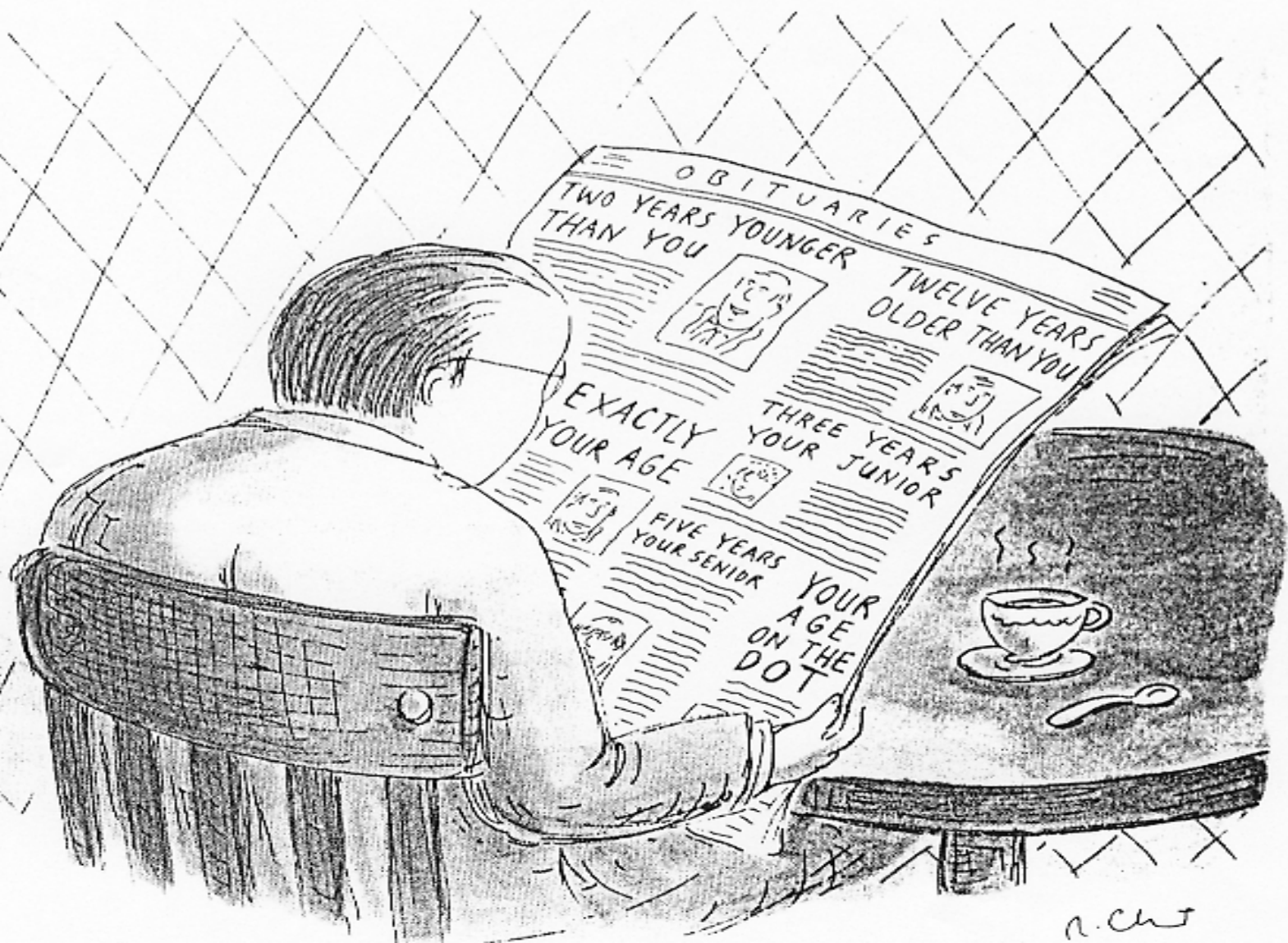
Recognition

- Conceptualizing Death
 - Universality
 - Nonfunctionality
 - Irreversibility
 - Causality
 - Continuation
- Other Development

Realization

- The Awareness of Mortality
 - Parents die
 - Death of peers
 - Evidence of aging
- Implications





OBITUARIES

TWO YEARS YOUNGER THAN YOU



TWELVE YEARS OLDER THAN YOU



EXACTLY YOUR AGE



THREE YEARS YOUR JUNIOR



FIVE YEARS YOUR SENIOR

YOUR AGE ON THE DOT



A. CH

Reconciliation



- The Awareness of Finitude
- Making Sense of Life and Death

The End of Life Paradox

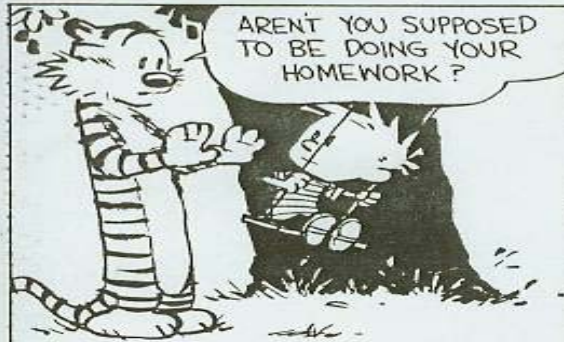
Older parents may wish to communicate about end of life issues just at the time that their adult children are most resistant

Patient Barriers

Middle Knowledge

CALVIN and HOBBS

by Bill Watterson



Patient Barriers

- Fear and Anxiety
- The Authority Gap
- Anticipatory Grief
 - Yet, anticipatory bereavement





9/11

Linger

***"Your doctor wants to marry me
if you don't make it."***

Family Barriers

- Privacy and Confidentiality
- Fears and Anxieties
- Differing Values and Perspectives
- Conflict and Miscommunication



Cultural Barriers



- Culture as a Way of Life
- Sensitivity to Cultural Experiences and Possible Mistrust
- Cultural Patterns of Communication – The Right of Informed Refusal
- The Value of Cultural Dialogue

Communication Barriers

- Medical and Moral Complexity
 - Studies show difficulty of predicting survival times
- The Right Time
 - Families can help create context



Understanding a Philosophy of Communication



Talking About Death

What to say to a loved one and how to say it

- Prohibitory
- Protective
- Truth-Telling
- Open Communication

Social and Psychological Barriers



- Death as a Taboo Topic

Professional Barriers

- Lack of Education and Training
- Personal Fears
 - Being blamed
 - Unknown and untaught
 - Unleashed Reactions
 - Own emotions
 - Not knowing all answers, what to say
 - Fears of mortality



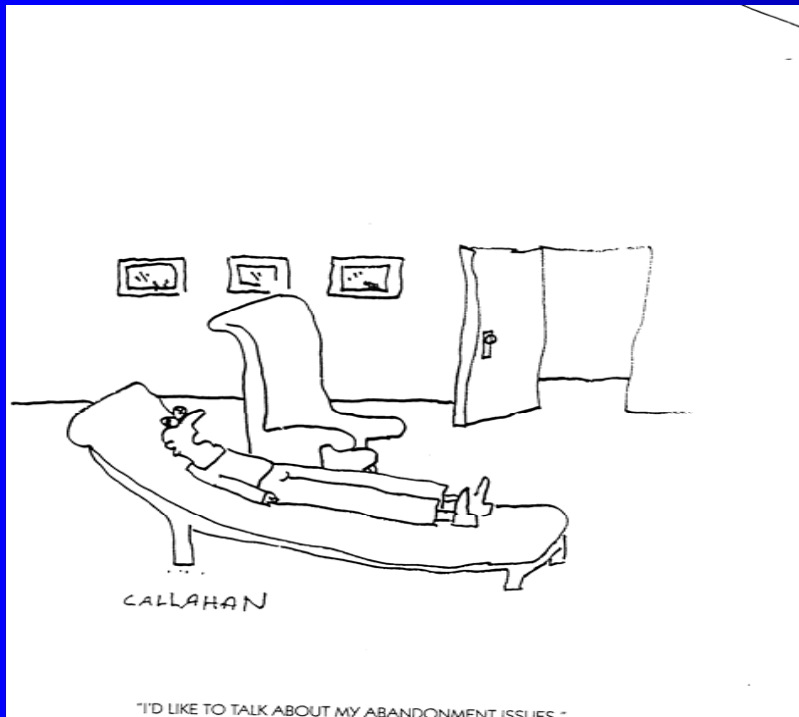
Institutional Barriers



- Lack of Options
- Lack of Professional Support
- Lack of Personal Support
- Lack of Time

Effective communication
about end of life issues is
essential to the patient's and
family's ability to cope

Demoralization



- A sense of burden
- A perception of lack of control over physical condition
- Limited social support
- A sense of futility of life

Effective Communication Empowers

- Enables decisions that might make suffering meaningful
- Allows persons to find external and internal strengths

SPIKES Program

- **S** SETTING
- P** PERCEPTION
- I** INVITATION
- K** KNOWLEDGE
- E** EXPLORE & EMPATHIZE
- S** STRATEGY & SUMMARY

ABCDE Program

- A Advance Preparation
- B Build a Therapeutic Relationship
- C Communicate Well
- D Deal with Patient/Family Reactions
- E Encourage and Validate Emotion

Common Emphases

- Need for personal communication
- Need for on-going training, assessment and feedback
- Support for own grief

Managing the Transition

Program Options



- Some hospices now offer Open Access or Bridge Programs
- These programs allow patients to receive services such as pain relief, symptom control, and psychosocial support while continuing with curative/life extending therapies
- Tidewell Palliative Care Partners Program

Managing the Transition

Pulling It All Together

- Maintain ongoing empathic dialog
- Acknowledge communication also is about emotion
- Elicit patient and families expectations, hopes, questions, and fears
- Emphasize quality of life goals



Managing the Transition

Pulling It All Together



- Ask, tell, ask – assess feedback
- Use *I wish* statements
- Refocus hope – “Hope for best – prepare for worst”
- Care with language
“nothing more to do”
- Murphy “Hospice (or palliative care) is
“aggressive comfort care”

Managing the Transition

Pulling It All Together

- Emphasize what still can be done
- Help families meet spiritual needs of dying patient
- Assist transition to alleviate fears of abandonment
- Take care of self



Frank and Ernest

I AM JUST SO TENSE! --- I THINK I'LL GO DOWN TO THE RANGER STATION AND GET SHOT WITH A TRANQUILIZER DART.



THE FAMILY CIRCUS by Bill Keane



4-26

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Bill Keane

"...and last but not least, Dear Lord, take care of yourself. If you don't, we're all in trouble."

Frank and Ernest



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