Communication in Late Life Dementia Care

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Primary Health Care Integrated Geriatric Service Initiative Workshop 3

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PHC IGSI: College of Family Physicians Canada Conflict of Interest slide

Faculty/Presenter Disclosure

- **Faculty/Presenter:** Dr. Kim Adzich

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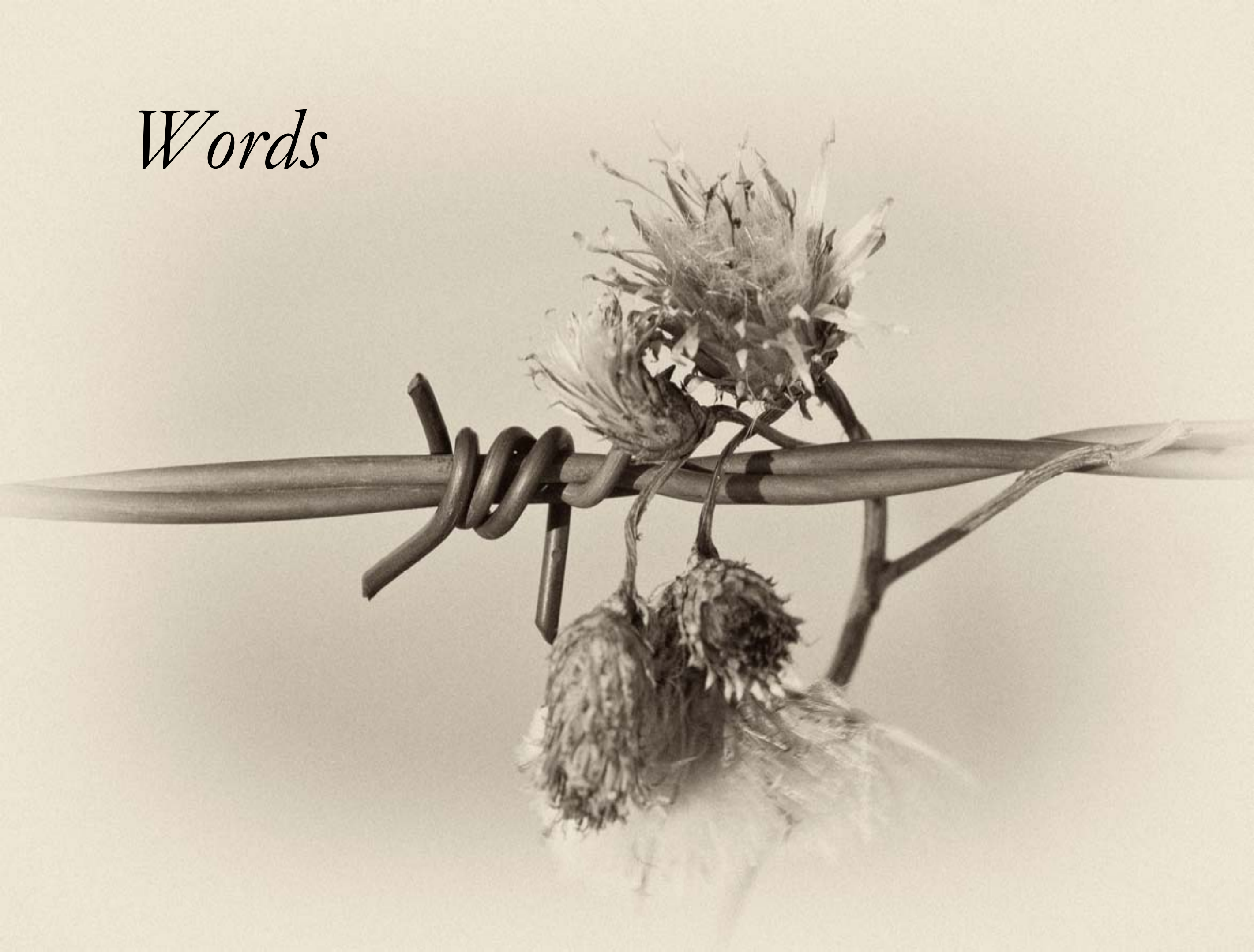
Words



Non-verbal

Why is communication important?

3 Primary Goals of Palliative Care :

- to relieve pain and emotional suffering
- to improve patient-physician communication and decision-making
- to facilitate co-ordination/continuity of care across all care settings

Ragan, et al 2008

Importance of Communication in Palliative Care

"The quality of communications with patients, family, and team members was indeed found by medical specialists to be fundamental to the quality of care for the dying. Ineffective communication was found to be one of the major barriers to optimal end-of-life care at the health provider level."

De Haes, H., and Teunissen, S. (2005) Communication in Palliative Care: A review of recent literature.
Current Opinion in Oncology, 17(4), 345-50.

What are your biggest challenges?


DEEP END
NO CLIMBING
ON WALLS
BETWEEN POOLS

3 MILLION COPIES SOLD

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NEW RESEARCH • CASE STUDIES • RESOURCES

crucial conversations

TOOLS FOR TALKING WHEN STAKES ARE HIGH

NEW FOREWORD BY STEPHEN R. COVEY

***NEW YORK TIMES* BESTSELLING AUTHORS**

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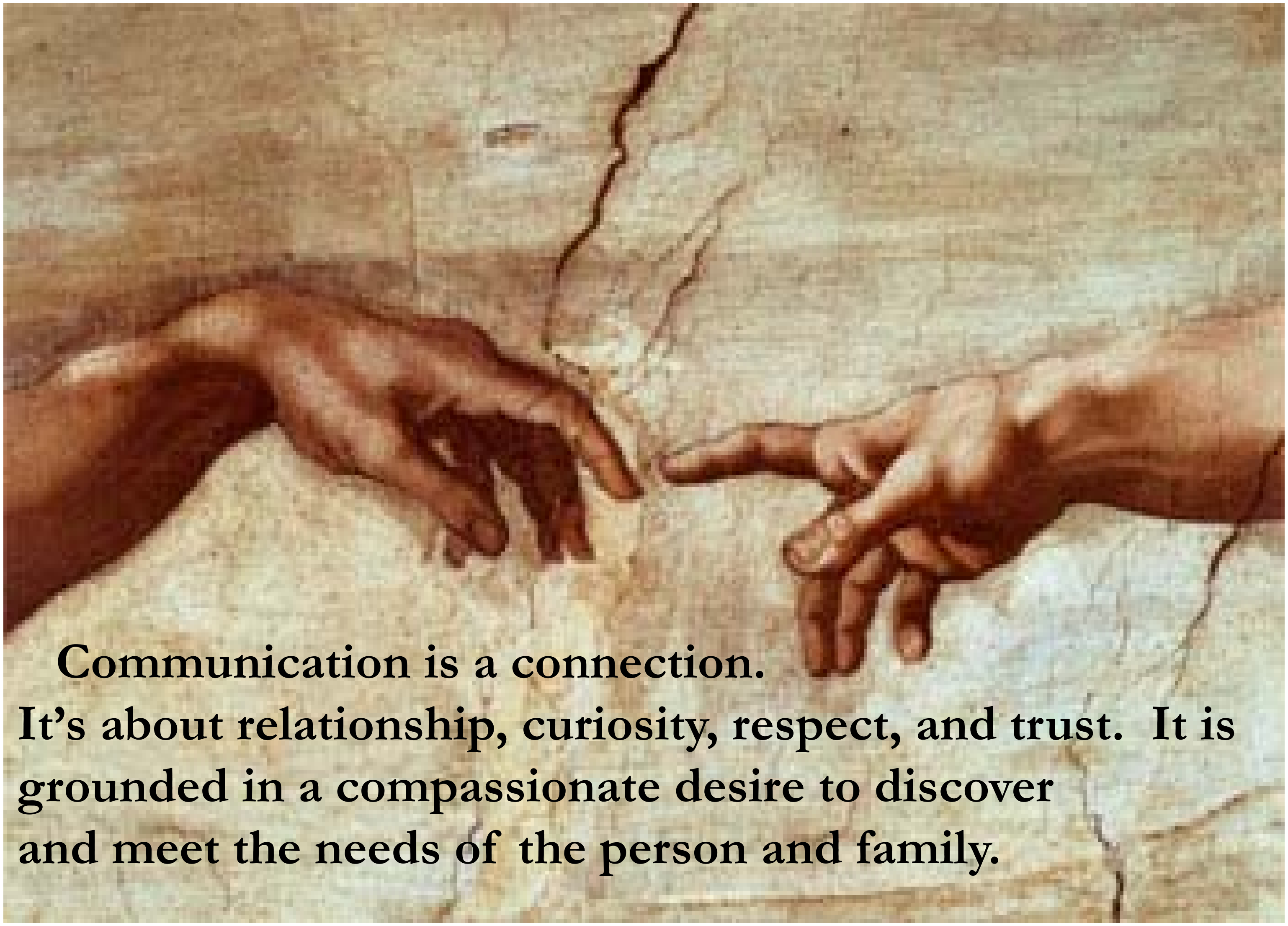
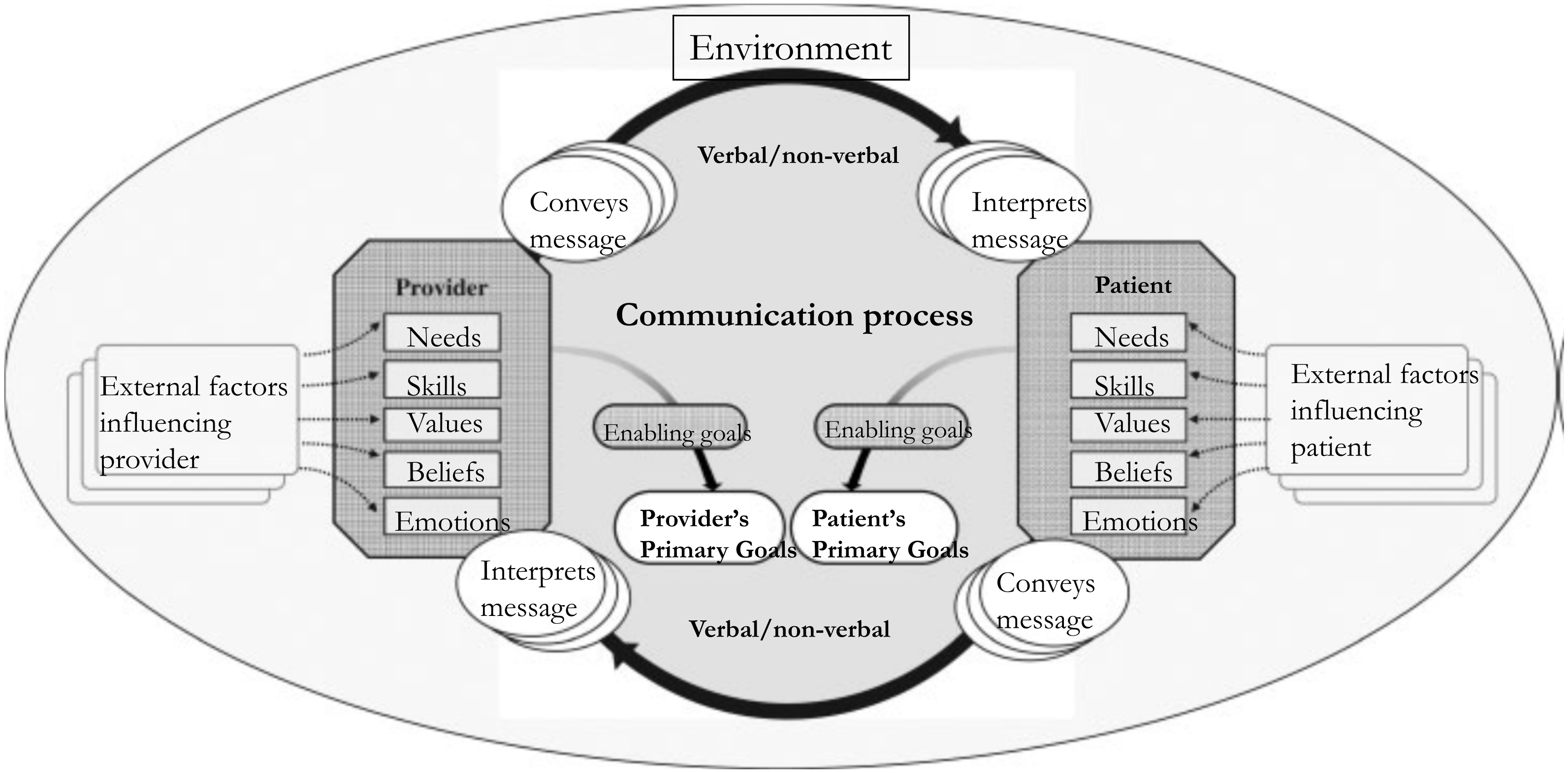


Communication is a connection.
It's about relationship, curiosity, respect, and trust. It is grounded in a compassionate desire to discover and meet the needs of the person and family.

Communication is a bridge between worlds

Communication: A Model



Feldman-Stewart D, Brundage MD, Tiehelman C. Psycho-Oncology 2005; 14: 801–809

Case for discussion: Mrs. B.

First asked to see her in late November ‘17. Family doctor’s referral stated that she was an 87 year old woman with dementia, frailty, and anxiety. She is at home with her daughter, Mary, and son-in-law and her daughter wants to keep her at home until the end of her life.

Born to a Jewish family in Italy. Many family members died in the Holocaust, including her father. She has lived with her daughter for many years. She loves music. She was a painter.

Medically, she has multiple co-morbidities: CAD with an MI, OA, chronic back pain, and peripheral neuropathy. She is on ASA, Gabapentin 300 mg BID, Alendronate once a week, Irbesartan 150 mg daily, Synthroid, Tylenol #3 for pain prn, Pantoprazole, and Risperidone 0.5 mg qhs.

Mrs. B. - continued

October – admitted to hospital with UTI and delirium. Was ambulatory before that time, but now mostly in bed. Frequent falls if she tries to get up. Dependent on her daughter for care. Often restless. ? Hallucinations.

Risperidone has helped her sleep but she is restless during the day and anxious. PPS 30% (most of the time in bed, total care, reduced intake, confusion).

Mrs. B. - continued

Transition point: initiating a palliative approach to care.

Would she benefit from a palliative approach? Why do you say that?
Surprise Question: Would you be surprised if she died in the next 12 months?
Does she have general indicators of decline?
Does she have specific indicators of decline for advanced dementia?

How would you talk to her daughter Mary about these things? What could you offer?

SPICT – Supportive and Palliative Care Indicators Tool

THE UNIVERSITY of EDINBURGH

Supportive and Palliative Care Indicators Tool (SPICT-4ALL™)

The SPICT™ helps us to look for people who are less well with one or more health problems. These people need more help and care now, and a plan for care in the future. Ask these questions:

Does this person have signs of poor or worsening health?

- Unplanned (emergency) admission(s) to hospital.
- General health is poor or getting worse; the person never quite recovers from being more unwell. (This can mean the person is less able to manage and often stays in bed or in a chair for more than half the day)
- Needs help from others for care due to increasing physical and/ or mental health problems.
- The person's carer needs more help and support.
- Has lost a noticeable amount of weight over the last few months; or stays underweight.
- Has troublesome symptoms most of the time despite good treatment of their health problems.
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

Does this person have any of these health problems?

Cancer

Less able to manage usual activities and getting worse.

Not well enough for cancer treatment or treatment is to help with symptoms.

Dementia/ frailty

Unable to dress, walk or eat without help.

Eating and drinking less; difficulty with swallowing.

Has lost control of bladder and bowel.

Not able to communicate by speaking; not responding much to other people.

Frequent falls; fractured hip.

Frequent infections; pneumonia.

Nervous system problems
(eg Parkinson's, MS, stroke, motor neurone disease)

Physical and mental health are getting worse.

More problems with speaking and communicating; swallowing is getting worse.

Chest infections or pneumonia; breathing problems.

Severe stroke with loss of movement and ongoing disability.

Heart or circulation problems

Heart failure or has bad attacks of chest pain. Short of breath when resting, moving or walking a few steps.

Very poor circulation in the legs; surgery is not possible.

Lung problems

Unwell with long term lung problems. Short of breath when resting, moving or walking a few steps even when the chest at its best.

Needs to use oxygen for most of the day and night.

Has needed treatment with a breathing machine in the hospital.

Kidney problems

Kidneys are failing and general health is getting poorer.

Stopping kidney dialysis or choosing supportive care instead of starting dialysis.

Liver problems

Worsening liver problems in the past year with complications like:
- fluid building up in the belly
- being confused at times
- kidneys not working well
- infections
- bleeding from the gullet

A liver transplant is not possible.

Other conditions

People who are less well and may die from other health problems or complications. There is no treatment available or it will not work well.

What we can do to help this person and their family.

- Start talking with the person and their family about why making plans for care is important.
- Ask for help and advice from a nurse, doctor or other professional who can assess the person and their family and help plan care.
- We can look at the person's medicines and other treatments to make sure we are giving them the best care or get advice from a specialist if problems are complicated or hard to manage.
- We need to plan early if the person might not be able to decide things in the future.
- We make a record of the care plan and share it with people who need to see it.

Please register on the SPICT website (www.spict.org.uk) for information and updates.

SPICT-4ALL™, June 2017

www.spict.org.uk

Mrs. B. – transition to a palliative approach

Ask-Tell-Ask

Ask: What are some of the things you are seeing? How quickly have these changes been happening?

Tell: These are some of the things we see as dementia progresses. It is the <u>natural progression</u> of the disease. Unfortunately, they are indicators that she may be getting much closer to the end of her life. Even though it is very difficult to predict when she might die, we would not be surprised if she were to die in the next 6-12 months.

Ask: Is what I've shared with you a surprise? Tell me how you are feeling about this.

Advance Care Planning/Goals of Care

“This is what we see…”

“This is what happens as dementia progresses…”

“This is not uncommon…”

“These are the things we watch for…”

Box 6.1: Communication suggestions

- How does [name of resident] seem to you?
- Have you noticed any changes in [name’s] condition?
- We feel that [name] is less able to do things than previously? (try to give an example of change in the individual) ……Would you agree?
- Dementia is a progressive disease, in that the person with dementia, over time, gradually becomes less well.
- The signs that the dementia is progressing include loss of appetite and difficulty swallowing, difficulty walking without help, more infections, increasing difficulties with talking and interacting with other people. Again, try to relate this to changes the family may have seen in their family member
- Such symptoms indicate to us that [name] may be entering the final stages of life. It is of course difficult to know just how long someone has left to live, as everyone is different. [Name] may have a few months, or even years. There is also the possibility that [name] has less than a few months. We don’t know but we will be monitoring them closely and will of course keep in regular contact with family.

Toolkit for implementing the Namaste Care programme for people with advanced dementia living in care homes
Stacpoole, Thompsell and Hockley, St. Christopher’s, 2016.

Mrs. B. – transition to a palliative approach

How might you explain a “palliative approach”? What if the word ”palliative” causes concern with Mary?

Palliative care focuses on improving quality of life in all domains of a person’s life to maximize comfort as well as helps to support families and caregivers.

What if Mary asks “how long do you think she will live?”

Advance Care Planning/Goals of Care

What would your mom want? Has she expressed her wishes in the past? How can we honour those wishes?

Has she asked someone to make decisions for her when she no longer can? Who is that person(s)?

Can we focus on comfort? What does comfort look like?

Where would she like to be for her final days?

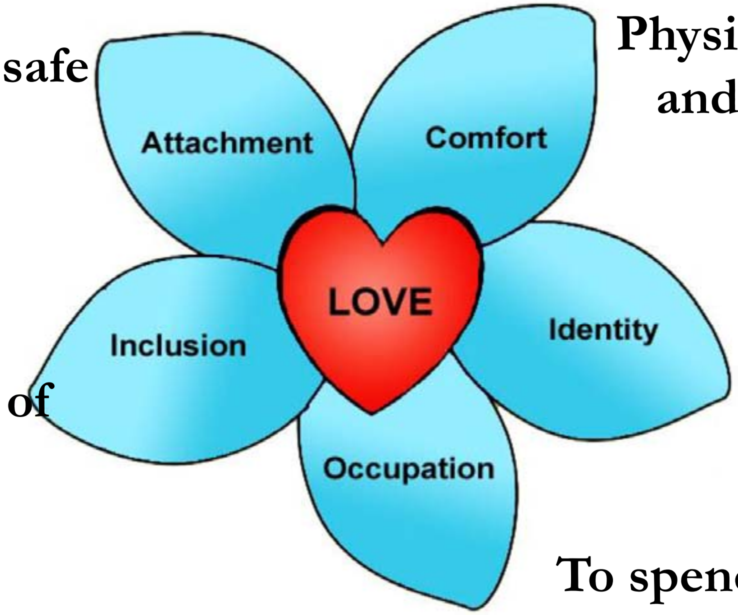
Advance Care Planning/Goals of Care

These decisions are difficult.

What can we do to support you as a family?

What are your needs to be able to care for her?

Fundamental Needs of People with Dementia – Kitwood (1997)



To feel loved and safe

Physically and mentally relaxed
and not in pain.

To be respected as a unique individual and have a sense of self-worth

Companionship, feel part of the world, not lonely or excluded.

To spend your time meaningfully and not be bored.

Reproduced with permission from Kitwood T (1997). 'Dementia Reconsidered the person comes first'. Fig. 5.2 page 82. Open University Press, Maidenhead, UK

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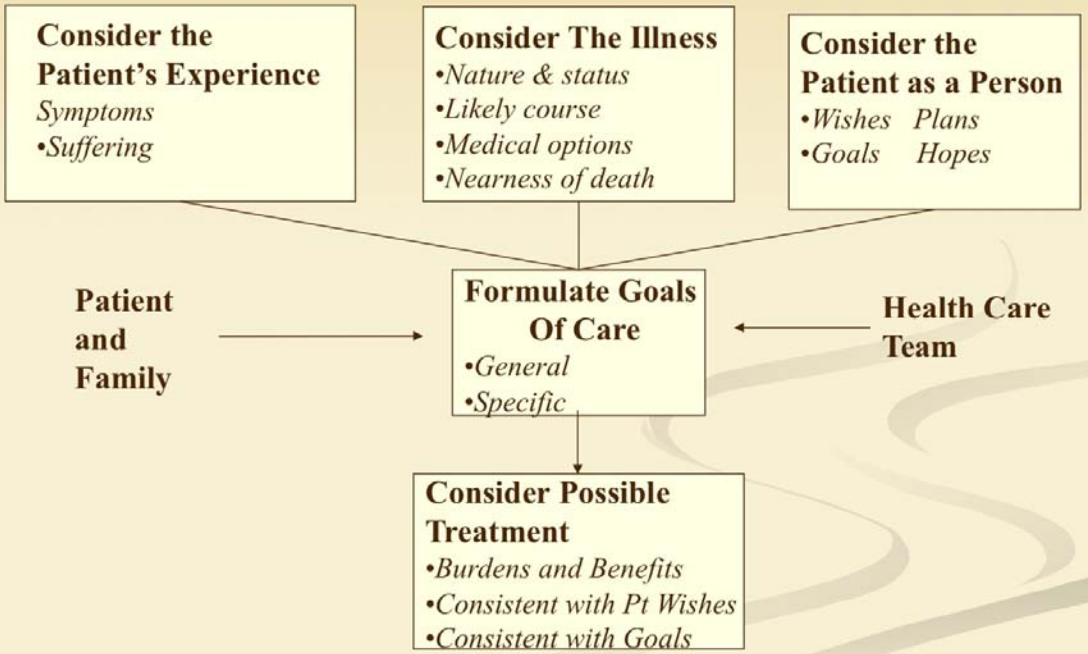
Mrs. B. – transition to a palliative approach

How might you lead a discussion regarding Goals of Care? Treatment options, such as resuscitation, or trips to the Emergency Department, hospital admissions?

Latimer Ethical Decision Model



Consider the Patient's Experience

Symptoms

- *Suffering*

Consider The Illness

- *Nature & status*
- *Likely course*
- *Medical options*
- *Nearness of death*

Consider the Patient as a Person

- *Wishes Plans*
- *Goals Hopes*

Patient and Family

Formulate Goals Of Care

- *General*
- *Specific*

Health Care Team

Consider Possible Treatment

- *Burdens and Benefits*
- *Consistent with Pt Wishes*
- *Consistent with Goals*

Adapted from:

Latimer, E. (1991). Ethical decision-making in the care of the dying and its applications to clinical practice. *Journal of Pain and Symptom Management, 6*(5), 329-336.

Some of the things we might talk about…

Resuscitation/DNR – "allow natural death"

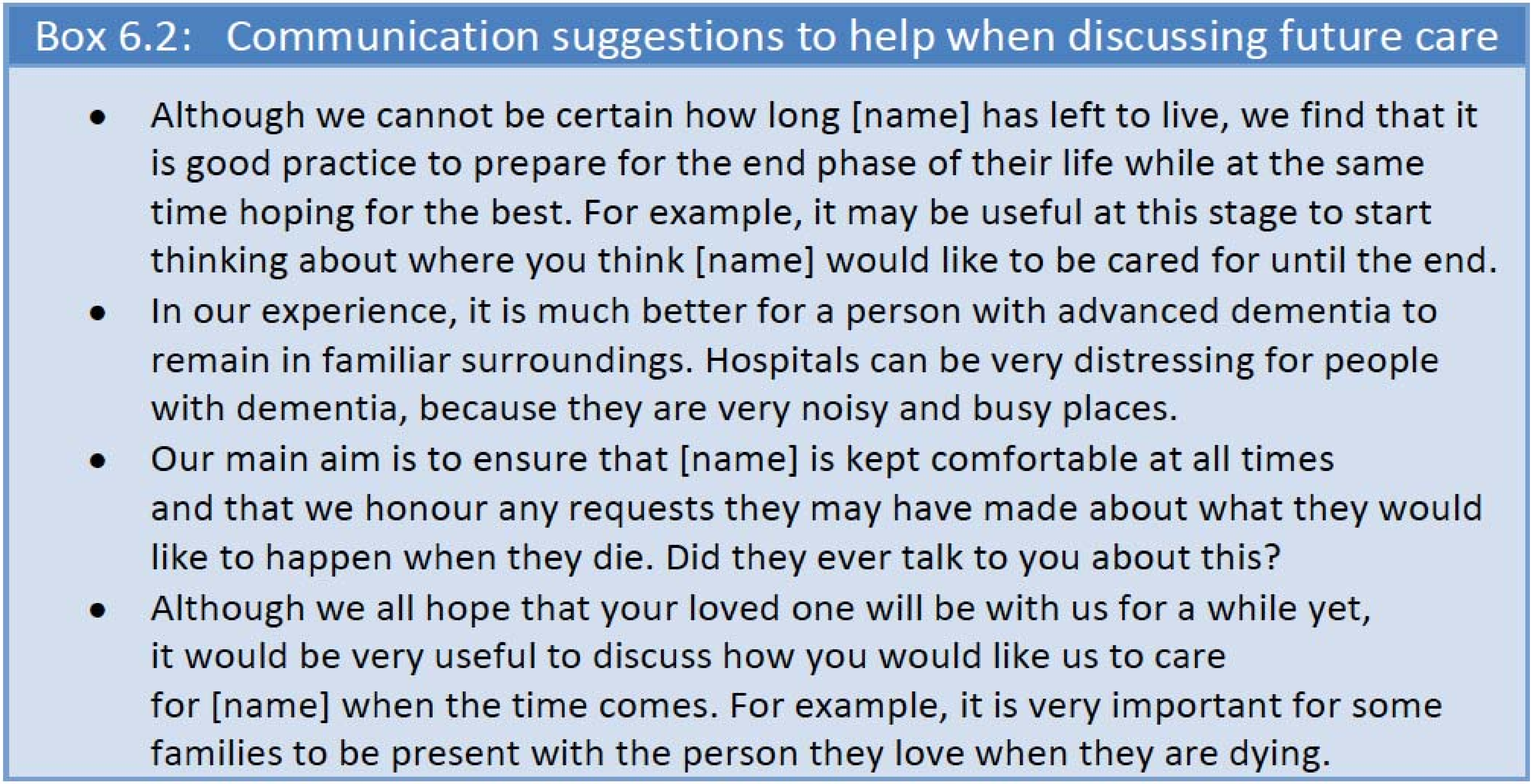
Artificial hydration and nutrition when not eating or drinking as much

Treating infections like pneumonia.

Under what circumstances would we ever call 911 or transfer to hospital?

Who to call after hours if something happens.

Decreasing mobility and care needs if in bed.



Box 6.2: Communication suggestions to help when discussing future care

- Although we cannot be certain how long [name] has left to live, we find that it is good practice to prepare for the end phase of their life while at the same time hoping for the best. For example, it may be useful at this stage to start thinking about where you think [name] would like to be cared for until the end.
- In our experience, it is much better for a person with advanced dementia to remain in familiar surroundings. Hospitals can be very distressing for people with dementia, because they are very noisy and busy places.
- Our main aim is to ensure that [name] is kept comfortable at all times and that we honour any requests they may have made about what they would like to happen when they die. Did they ever talk to you about this?
- Although we all hope that your loved one will be with us for a while yet, it would be very useful to discuss how you would like us to care for [name] when the time comes. For example, it is very important for some families to be present with the person they love when they are dying.

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Mrs. B – continued…

February: She develops a chest infection and is treated with a course of oral antibiotic. She has minimal oral intake and is no longer able to get out of bed.

A family meeting was held to discuss GOC and confirm DNR.

Proactive planning for the future…

Mrs. B – continued…

How might you address the issue of CPR/resuscitation?

Mum,
You would have wanted to go
quickly and peacefully with
lillies by your bedside. Instead
it took three days and three
broken ribs.
I'm sorry I didnt talk
about it.

Mrs. B – continued…

Transition point: No longer eating and drinking.

How would you address family concerns regarding hydration, nutrition, swallowing medication? What about clysis or an IV?

Will she “starve to death”? How can they continue to support her physical needs?

Mrs. B – continued…

Transition point: Preparing for final days.

March: Worsening cough. No response to antibiotic Mary had left over from before. More pain, poor oral intake and not able to swallow oral medications. Coughs when she tries to swallow food. Bed-confined. Almost no urine output and increased, distressing respiratory secretions.

Mrs. B – continued…

Transition point: Preparing for final days.

Next steps? Conversations that need to happen at this time?

Mrs. B – continued…

Transition point: Preparing for final days.

Reassurance about stopping oral meds.

End of life subcutaneous meds in the home - pain, dyspnea, respiratory secretions and potential delirium/terminal restlessness. How to use them and for what indications?

? Catheterize for comfort

Review who to call, when to call.

Mrs. B – continued…

Transition point: Preparing for final days.

Review goals of care – stressing comfort measures.
Increase support for the family – shift nursing with subcut meds.
Is there a need for continuous subcutaneous infusion for pain?

Family conference

Use the SPIKES formula

- Who will attend? (patient, family, other support, health care team members)
- Introductions, getting to know who is there
- Review goals of the meeting
- Ground rules

SPIKES

- **S Setting – physical setting & agenda negotiation**
- **P Perception**
- **I Invitation**
- **K Knowledge**
- **E Empathize/Emotions**
- **S Summary/Strategy**

Robert Buckman

Setup

- **Plan.**
- **Have the information you need.**
- **Who should be there? (team members, patient, family, support person)**
- **Where: environment: noise, privacy, seating**
- **When: timing – allow enough time, convenient time for family/support person to be there**
- **Agenda: what you want to talk about**
  ask what they want to talk about
  may need to negotiate agenda

(Bylund, et al 2006; Josephine et al, 2007)

Perception

- **Tell me what you understand about your mother's illness.**
- **What are you seeing?**
- **What have you been told? Do you have questions about her illness?**
- **Ask individual family members if they have questions or concerns.**

Invitation

- How do they prefer to receive information?
- Lots of information now or "bits at a time"?
- Details or the "big picture"?
- Cultural factors to consider?
- Stage of disease- may want different amounts of information at different stages.
- Who makes decisions? How should decisions be made?

Family conference

- Review medical status/illness/treatment
- Are there questions about status or treatment?
- Review goals of care
- Discuss options
- Explore family support
- Next steps
- Summarize and wrap up

Knowledge

- Tailor the information based on what the family wants and needs at this time.
- Check understanding, summarize
- Provide an opportunity for questions, questions and more questions.
- “tell me more about what you are thinking…”
- What worries you the most about going forward?

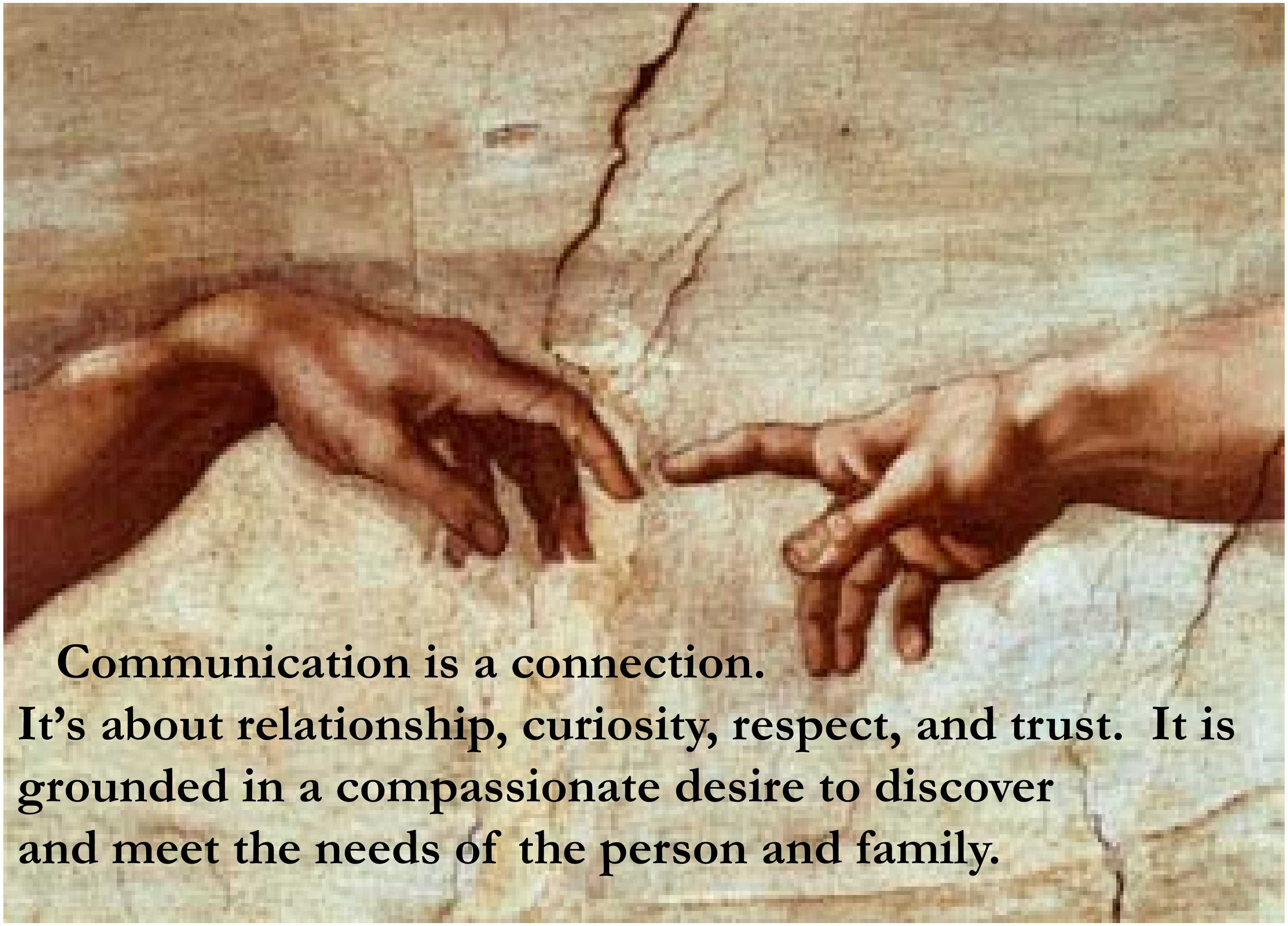
Empathize

- **Allow time to integrate the information**
- **Acknowledge, normalize or validate their response.**
- **Respond to emotional cues**
- **“I can only imagine how hard this must be.” “These are hard decisions to make, but we want to honour her wishes as well.”**

Summarize

- Summarize what's been discussed and what next steps will be.
- Assess understanding of the discussion
- Next contact, who will do what and when.
- Document, share information with other providers.

Mrs. B – the story continues…



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Any other questions?

Thank you!