

***Heart* Café: Talking About
Dementia & End of Life
Decision-Making**

Monday March 7, 2016

*Dementia Care 2016:
Quality Care; Quality of Life*

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Winnipeg Regional
Health Authority
Caring for Health

Office régional de la
santé de Winnipeg
À l'écoute de notre santé

Why Heart Café?

Heart Café is a brief heart to heart talk as health care providers about what gives life meaning and how end of life decisions for people living with dementia can support quality of life.



A MOMENT TO PAUSE

OBJECTIVES

- ❖ ***To explore personal self-awareness and comfort with end of life conversations***
- ❖ ***To discuss challenges around dementia and end of life decisions***
- ❖ ***To explore a Worksheet: Considerations for Quality of Life as it may/may not support health care providers involved with end of life decisions and dementia***
- ❖ ***Questions and evaluative comments***

Safety

Agreements

- ❖ **Value every person as a human “being”**
- ❖ **Value life-giving relationships**
- ❖ **Value person’s end of life wishes; align EOL wishes with decisions**
- ❖ **Be present; Use “I” statements; Feeling is okay**
- ❖ **Pause and BREATHE if uncomfortable**

Name intention for gathering: share facts, practice communication skills and consensus decision-making tool

Define spirituality

Spirituality

Spirituality is a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions and practices. (2014)

Worksheet 1

End of Life (Left Column)

- 1. What gives your life most joy? What do you feel you have come here to accomplish in your lifetime?***
- 2. Do you understand your life in relation to a higher power or not? Does your culture impact your life and health care choices?***
- 3. Do you see yourself as a person who decides what is best for your self?***
- 4. Knowing yourself as a psychospiritual person, what would a “good death” be?***

Worksheet 1

End of Life and Dementia (Middle Column)

- ❖ ***What did he/she love and enjoy most in life?***
- ❖ ***Was a faith community/practice part of who she/he was and did culture influence their life choices?***
- ❖ ***Did he/she insist on making independent choices before dementia?***
- ❖ ***How would you define the psychospiritual identity of the person now facing EOL? What do you imagine a “good death” would be for him/her at the end of life?***

Worksheet 1

Common End of Life Questions with Dementia

1. Does _____ have a healthcare directive?

- i) Speaks for person's wishes if cannot speak for self. It can designate a Proxy (Substitute Decision Maker) and Goals of Care. Legally binding in MB...(fewer than 10% MB have one)**
- ii) Helps proxy respond to ?s Advance Care Planning*

2. What about Tube Feeding?

Natural End stage Dementia: Dysphagia & poor intake. After 1st pneumonia 50% die in 6 months

3. What about Dialysis?

median 1 year extended life (not quality of life)

Worksheet 1: NOTE in (right) column any questions/end of life decisions relating to dementia that you have experienced in your health care provider role..

Long Term Care & End of Life

*Carol Taylor PhD, RN “Facilitating Good Dying for Cognitively Impaired Persons” 2015 identifies **3 things the health care system can offer over the human life span: i) cure ii) support recovery or iii) support person to move towards death with as much quality of life as possible.***

Dr. Strang, “Dispelling Myths” LTC Ethics Forum 2014

By age 80, 10% live in LTC, 30% by age 85. Life expectancy is Long Term Care median about 2 years

At 80, 1 in 10 die each year.

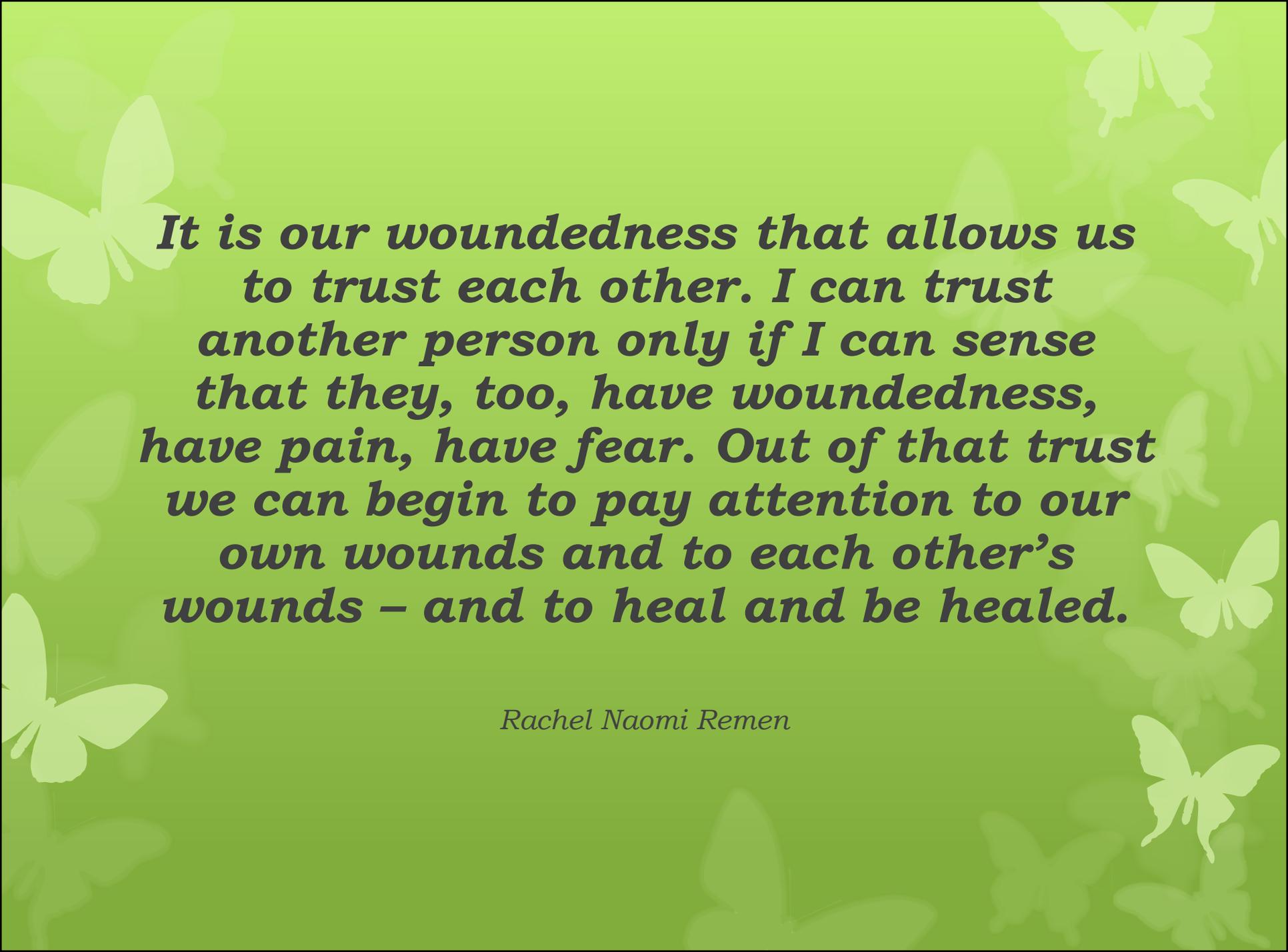
Primary cause of death : dementia 30%, cardiac/ stroke 30%, respiratory 20%.....60% in PCH have dementia

What can the health care system provide for persons of advanced age living with dementia?

Worksheet 2

Considerations for Quality of Life

- 1. Definitely want treatments that might keep the person alive.***
- 2. Probably would want treatments that might keep the person alive.***
- 3. Unsure of what to do.***
- 4. Probably would NOT want treatments that might keep the person alive.***
- 5. Definitely do NOT want treatments that might keep the person alive.***



It is our woundedness that allows us to trust each other. I can trust another person only if I can sense that they, too, have woundedness, have pain, have fear. Out of that trust we can begin to pay attention to our own wounds and to each other's wounds – and to heal and be healed.

Rachel Naomi Remen

Bibliography

- ❖ **Death Cafes in Winnipeg (PCH and community)**
- ❖ **E.R.I.K. (Emergency response Information Kit)**
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- ❖ **Manitoba's Spiritual Health Strategic Plan "Health and the Human Spirit" 2012**
- ❖ **Puchalski, Christina, M. MD, MS, FAPC, Robert Vitillo, MSW, ACSW, Sharon K. Hull, MD, MPH, and Nancy Reller. (2013). "Improving the Spiritual Dimension of Whole Person Care: Reaching National and International Consensus"**
- ❖ **Virtual Hospice website. "Nearing the end of Life When Someone has Dementia" and "When Death is Near"**
www.virtualhospice.ca/en_US?MainWhen+Death+Is+Near.aspx
- ❖ **Dr. Strang (2014) "Dispelling Myths" , Winnipeg Health Ethics Forum**
- ❖ **Dr. Carol Taylor, PhD, RN "Facilitating Good Dying for Cognitively Impaired Patients and Their Families" and "Worksheet: Considerations for Quality of Life" Oct. 26, 2015 at University of Manitoba.**
- ❖ **WRHA "Care in the Final Days Toolkit" Resource Guide D" Spirituality and Faith-based considerations in Death and Dying" 2014.**