Starting the MOST Conversation

- Begin conversation with normalizing language about Advance Care Planning:

> "Traditionally in health care we have not always done a good job of ensuring that we ask patients and their families about their goals and preferences regarding their care and ensuring that people have their preferences recorded in Advance Directives."

MOST Conversation Questions

- It's not easy to talk about how you want the end of your life to be, but it's one of the most important conversations you can have with your loved ones. That's why we are here.
- **Values Question**:
  - *When you think about how you want to live at the end of your life, what's most important to you?*
- **Medical Question**:
  - *What is your understanding now of where you are with your illness?*

MOST Conversation - Values

- Determine the individual's views and values for life-sustaining treatment.
  - Review The Conversation Project Starter Kit
  - **What matters to me at the end of life is…** (For example, being able to recognize my children; being in the hospital with excellent nursing care; being able to say goodbye to the ones I love.)
  - Ask questions and spend most of your time listening.

MOST Conversation - Values

- Where do you want (or not want) to receive care?
  (Home, nursing facility, hospital)

- When would it be okay to shift from a focus on curative care to a focus on comfort care alone?

- What does ‘quality of life’ mean to you?
  - Very important to get specific about what quality of life means to them

Decision
Tools for section A

MOST - Medical Questions

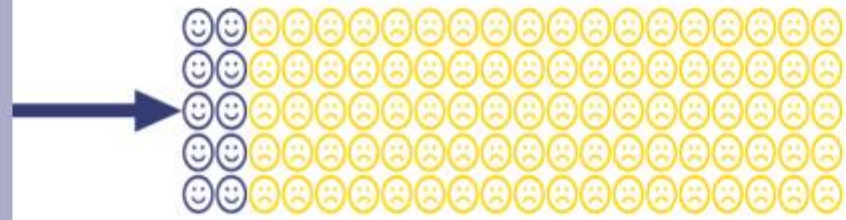
- What is your understanding of CPR?
- What is your understanding of full vs. limited medical interventions vs. comfort care?
- What is your understanding of artificial nutrition?
- Review the Serious Illness Conversation Guide for other possible questions

4. How well does CPR work?

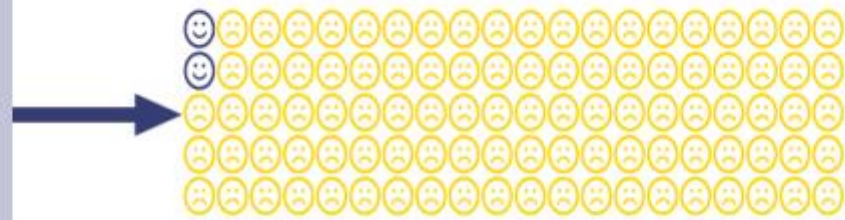
How well CPR works depends on the health of the patient. Studies have shown the chance of success with CPR. (See more details and References on page 8.)

In the overall population:
82 out of 100 will die
18 will survive and leave the hospital

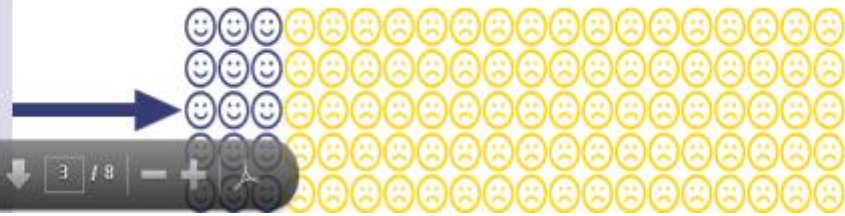
People with serious illnesses like cancer, heart or kidney disease:
90 out of 100 will die
10 will survive CPR



People who have critical illness and are in the intensive care unit:
98 out of 100 will die
2 out of 100 will survive CPR

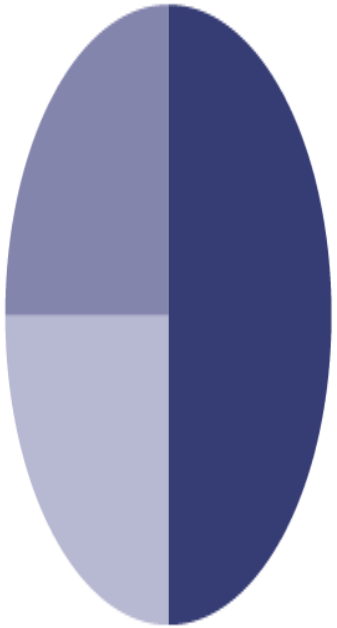


In the overall population over age 75:
85 out of 100 will die
15 out of 100 will survive CPR



Outcome for CPR Survivors

What is the chance of survivors going home from hospital?

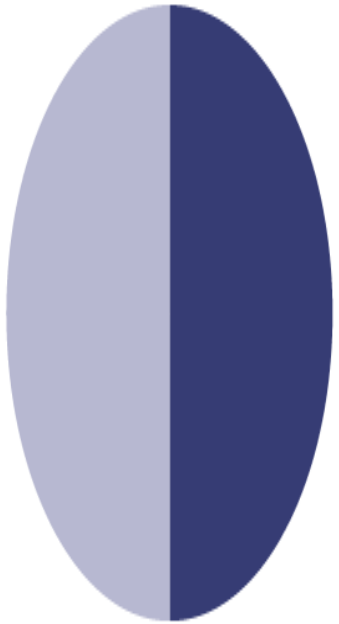


About ¼ will go home independently.

Another ¼ will go home but require help at home.

About ½ will need to live in an institution – like a nursing home or rehab centre

What is the chance that survivors will have thinking or communication difficulties?



About ½ will have problems such as memory loss, problems with attention and problems getting things done.

Medical Interventions

- Full Treatment
- Selective Treatment
- Comfort-focused Treatment

Artificial Nutrition Hydration risk and benefits

Decision Support for Artificial Nutrition

Monroe County Medical Society Community-wide Guidelines

Tube Feeding/PEG Placement for Adults

mcmc QUALITY COLLABORATIVE

Benefits and Burdens of PEG Placement

	Dysphagic Stroke (Patients with previous good quality of life, high functional status[1] and minimal co-morbidities)	Dysphagic Stroke (Patients with decreased level of consciousness, multiple co-morbidities, poor functional status[1] prior to CVA)	Neurodegenerative Disease [e.g., Amyotrophic Lateral Sclerosis (ALS)]	Persistent Vegetative State (PVS)	Frailty (Patients with multiple co-morbidities, poor functional status, failure to thrive and pressure ulcers[2])	Advanced Dementia (Patients needing help with daily care, having trouble communicating, and/or incontinent)	Advanced Cancer (Excludes patients with early stage esophageal & oral cancer)	Advanced Organ Failure (Patients with CHF, renal or liver failure, COPD, anorexia-cachexia syndrome)
Prolongs Life	*Likely*	*Likely in the short term* Not likely in the long term	*Likely*	*Likely*	Not Likely	Not Likely[3]	Not Likely	Not Likely
Improves Quality of Life and/or Functional Status	up to 25% regain swallowing capabilities	Not Likely	Uncertain	Not Likely	Not Likely	Not Likely	Not Likely	Not Likely
Enables Potentially Curative Therapy/Reverses the Disease Process	Not Likely	Not Likely	Not Likely	Not Likely	Not Likely	Not Likely	Not Likely	Not Likely

Benefits of PEG placement rather than feeding orally:

- For dysphagic stroke patients in previous good health, patients with ALS, and patients in a persistent vegetative state, may prolong life
- For dysphagic stroke patients in previous poor health, may prolong life in the short-term (days to weeks)
- Enables family members/caregivers to maintain hope for future improvement
- Enables family members/caregivers to avoid guilt/conflict associate with choosing other treatment options
- Allows family/caregivers additional time to adjust to possibility of impending death

Burdens of PEG placement rather than feeding orally:

- 75% of stroke patients previously in good health not likely to have improved quality of life and/or functional status
- PVS patients not likely to have improved quality of life and/or functional status
- Possible patient agitation resulting in use of restraints
- Risk of aspiration pneumonia is the same or greater than that of patient being handfed
- Stroke patients previously in poor health, frail patients, and patients w/advanced dementia, cancer or organ failure have been reported to experience side effects: PEG site irritation or leaking (21%), diarrhea (22%), nausea (13%) and vomiting (20%)

Benefits of feeding orally rather than inserting a PEG:

- Patient able to enjoy the taste of food
- Patient has greater opportunity for social interaction
- Patient's wishes and circumstances can be taken into consideration as pertains to pace, timing and volume of feeding

Burdens of feeding orally rather than inserting a PEG:

- Requires longer period of time to feed a patient
- Patient/family worry about "not doing everything in their power" to address the feeding problem and/or "starving patient"
- Patient/family feel that in not choosing option that could possibly prolong life, they are hastening death

This information is based predominately on a consensus of current expert opinion. It is not exhaustive. There are always patients who prove exceptions to the rule.

1. Functional Status refers to Activities of Daily Living. (Refer to Clinical Frailty Scale (CFS) on page 8. For more information on the CFS visit http://geriatricresearch.medicine.dal.ca/clinical_frailty_scale.htm) A poor functional status means full or partial dependency in bathing, dressing, toileting, feeding, ambulation, or transfers.
2. Matched residents with and without a PEG insertion showed comparable sociodemographic characteristic, rates of feeding tube risk factors, and mortality. Adjusted for risk factors, hospitalized NH residents receiving a PEG tube were 2.27 times more likely to develop a new pressure ulcer (95% CI, 1.95-2.65). Conversely, those with a pressure ulcer were less likely to have the ulcer heal when they had a PEG tube inserted (OR 0.70 [95% CI, 0.55-0.89]). Teno JM, Gozalo P, Mitchell SL, Kuo S, Fulton AT, Mor V. Feeding Tubes and the Prevention or Healing of Pressure Ulcers. Archives of internal medicine. 2012;172(9):697-701. doi:10.1001/archinternmed.2012.1200.
3. There is a small group of patients who fall into this category whose life could be prolonged.
4. Callahan CM, Haag KM, Weinberger M, et.al. Outcomes of Percutaneous Endoscopic Gastrostomy among Older Adults in a Community Setting. J Am Geriatr Soc. 2000 Sep; 48(9):1048-54.

Guidelines are intended to be flexible. They serve as reference points or recommendations, not rigid criteria. Guidelines should be followed in most cases, but there is an understanding that, depending on the patient, the setting, the circumstances, or other factors, care can and should be tailored to fit individual needs.