Palliative Care and Hospice for Persons with Dementia

Mimi Pattison, MD
Medical Director Hospice and Palliative Care

May 24, 2024
ECHO Dementia

Virginia Mason Franciscan Health

Learning Objectives

The learner will be able to:

- Define Hospice and Palliative Care
- List the differences between Hospice and Palliative Care as they relate to persons with dementia
- Dispel common myths about Hospice care
- Discuss the differences between dying ‘with’ and dying ‘from’ dementia

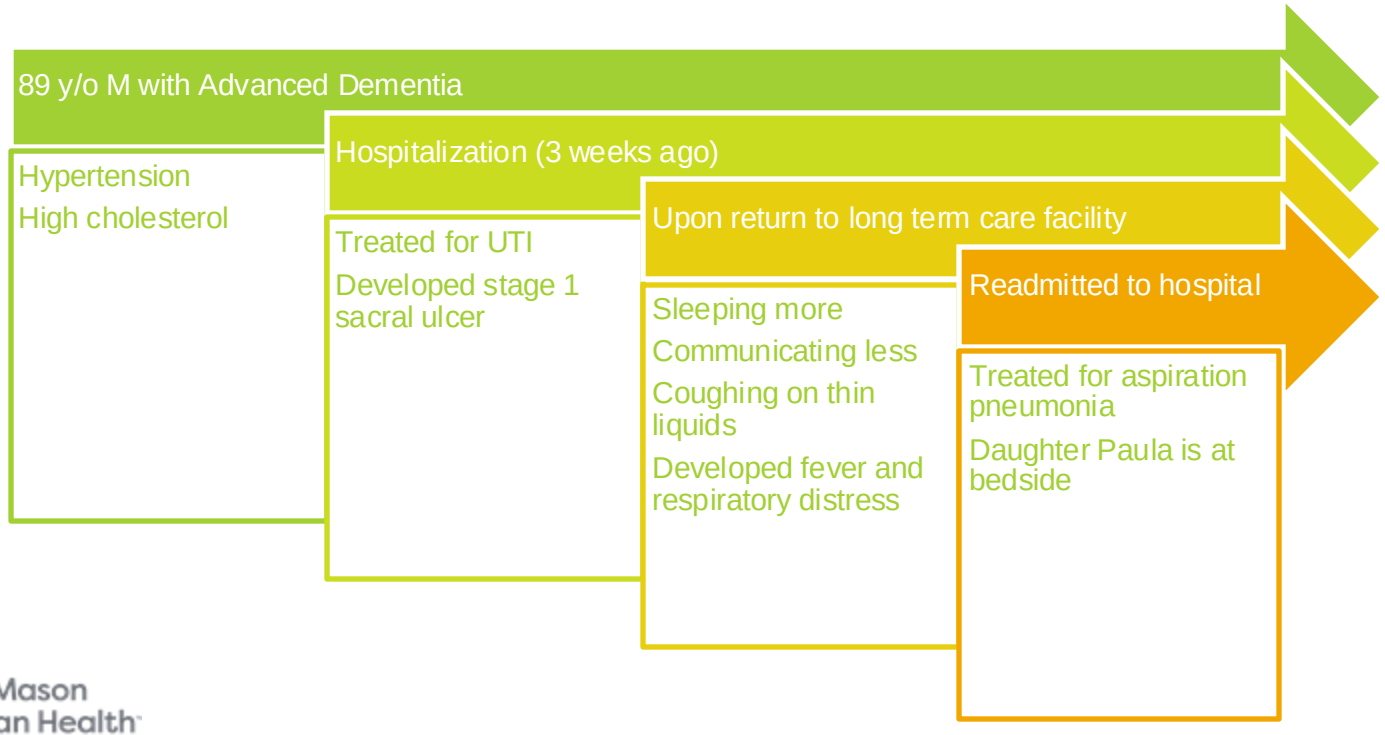
Virginia Mason Franciscan Health

Headlines……

- Dementia is a terminal illness
- Palliative Care is Everyone's Job
- Palliative Care is Preventive Care
- Dying With vs. Dying From Dementia

Virginia Mason Franciscan Health

The patient: Mr. B.



Virginia Mason Franciscan Health

“Big picture” considerations:

What is happening to Mr. B?

- He has advanced dementia

Would you be surprised if he were to die within the next 6 months?

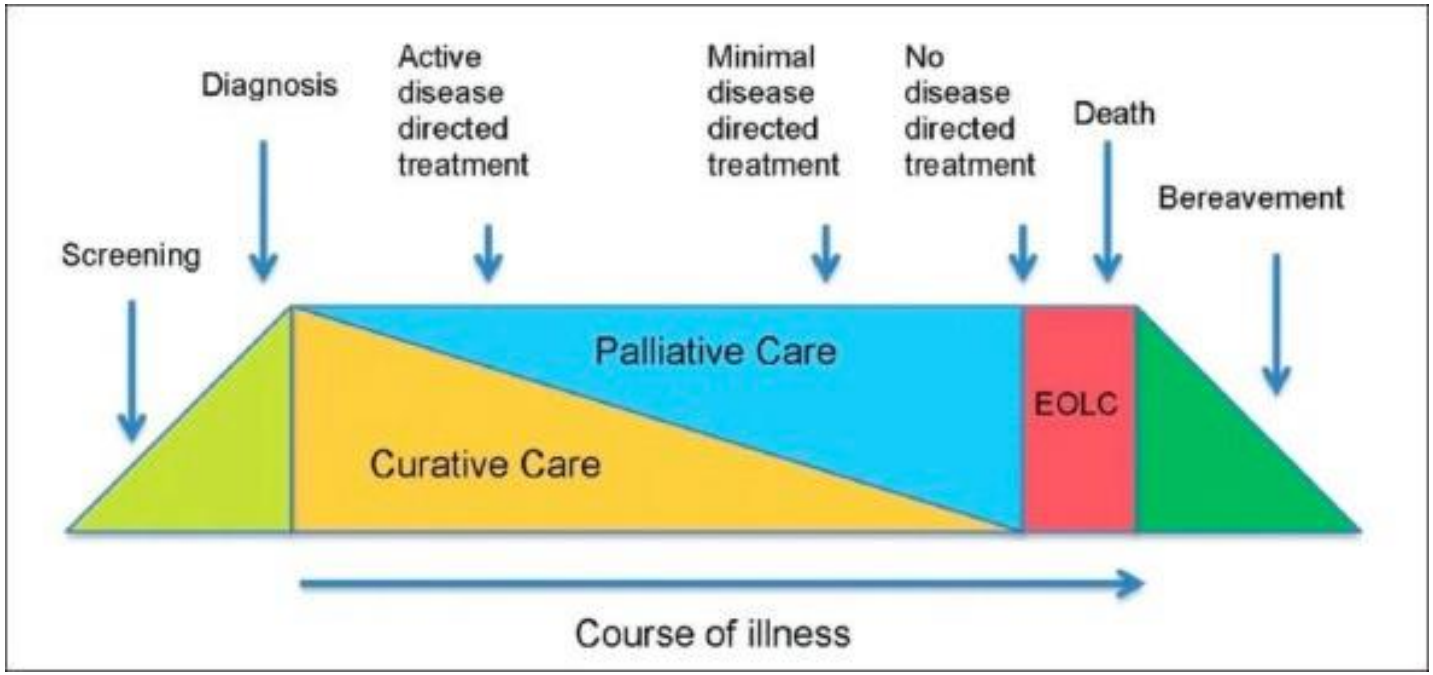
- He is at risk for dying within weeks to months.

What is Paula likely to be feeling? Is this conversation likely to be a high-intensity or low-intensity emotionally?

- High. Potential for feeling grief, fear, or perhaps even shame.

Virginia Mason Franciscan Health

Spectrum of Palliative Care services



Virginia Mason Franciscan Health

Hospice Care is……

- Care for persons in the last 6 months of living.

  How do I know? Wonder if I am wrong?

  Surprise question-good screening question

  Would I surprised if this patient dies in the next 6 months?
- Care includes Hospice team, medications and equipment

  Majority of care in homes
- An Insurance Benefit-most modeled after Medicare

  Does not pay room and board

Virginia Mason Franciscan Health

Palliative Care is . . .

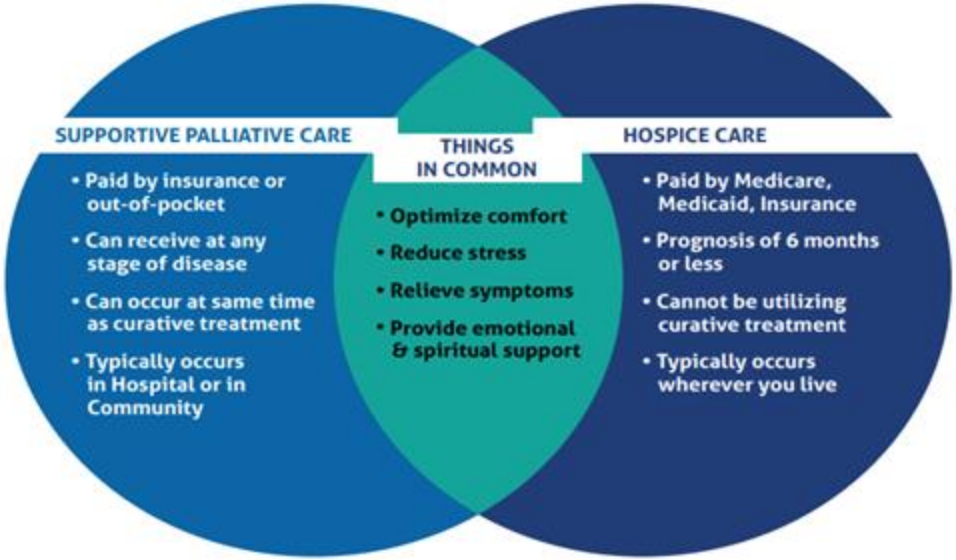
- Specialized medical care for people living with a serious illness
- Focused on providing relief from the symptoms and stress of the illness
  - Goal: to improve quality of life for both the patient and the family
- Based on the needs of the patient, not on the patient's prognosis
  - Appropriate at any age and at any stage in a serious illness
  - Can be provided along with curative treatment

- All of hospice is palliative care- comfort and quality at the end of life

- All of Palliative Care is NOT hospice

Virginia Mason Franciscan Health

Comparison of Supportive Palliative Care vs. Hospice Care



TEXAS
Health and Human Services

Virginia Mason Franciscan Health

Hospice Criteria

FAST 7 or higher AND

One of the following in the last year

- Aspiration pneumonia
- Pyelonephritis
- Septicemia
- Multiple decubitus ulcers greater than or equal to stage 3
- Recurrent fever after antibiotics
- Inability to maintain sufficient fluid and calorie intake with 10% weight loss in previous 6 months , or
- Serum albumin < 2.5 g/dL

Centers for Medicare & Medicaid Services. (n.d.). Hospice. Retrieved from Hospice | CMS

Virginia Mason Franciscan Health

Hospice Screening……

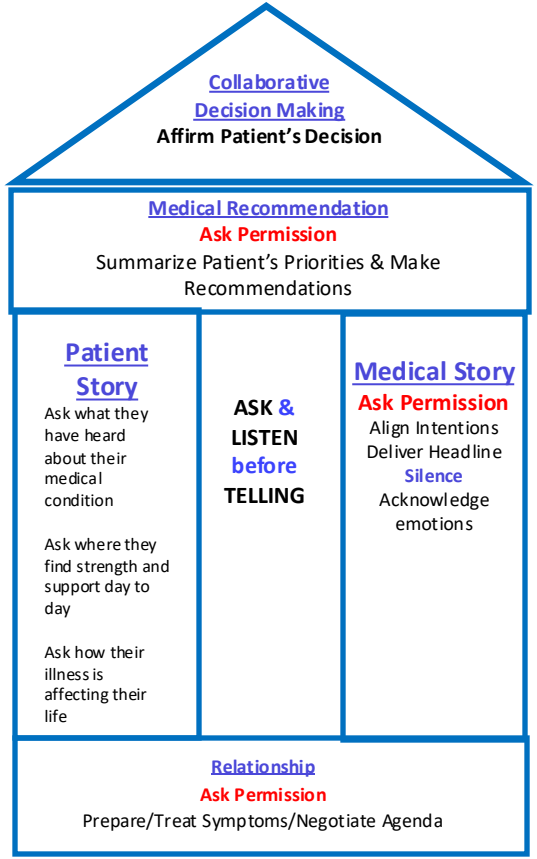
Would you be surprised if
this person dies in the next 6 months?

Virginia Mason Franciscan Health

Barriers to Hospice Care

- Late referrals
- Inexperience in Hospice referral
- Discomfort with the conversation
- Fear of audits
- Estimating life expectancy
- Family

Virginia Mason Franciscan Health



	WAYS	WORDS
Relationship	· Quiet space, silence phones and pager, request permission to enter, sit down, eye contact · Assess symptoms first · Elicit their agenda first · Review medical records, talk to rest of the team	· ***Ask permission "Is this a good time to talk?"*** · Are you comfortable enough to talk now? · What are your expectations for our conversation today? · We want to provide you the ***Best Care Possible from your perspective***. Can we talk about that?
Patient Story	· Match the pace of the patient · Listen carefully · Don't interrupt · Anticipate emotions	***Obtain Patient Story***: "can you tell me, ***in your own words***, what you have heard about your medical condition? Are you able to do the things you enjoy? Where do you get strength and support? What is your body telling you?
Medical Story	· If they do not want to talk, don't proceed · Offer only realistic hope · Deliver information in "Headlines" (15 words or less) · Avoid medical jargon	· ***Ask permission***: Would it be okay if I share medical information now? · ***Deliver headline*** & **BE SILENT (let them break silence!)** "I am worried that what we are hoping for may not happen" "The cancer has come back" · ***Name Emotion/Empathetic Statement/Align Hope*** "This is hard" "I cannot imagine" "I wish I could make this into good news, but I can't" "This is upsetting" ***Align hope/intention***: *My hope is that you/your loved one will get better. I also want us to have a plan if what we are hoping for doesn't happen.* "Given your medical situation, what is most important to you?"
Recommend	· Make a medical recommendation that aligns patient priorities **AND** reflects what is medically possible · When you recommend limiting interventions, make sure you first offer what you WILL do	***Before Making a Recommendation***: · This is what I hear is important to you: (list them) · Is this correct? (confirm that the list is correct) · Would it be okay if I make a recommendation? (**ASK PERMISSION**) **When making a recommendation:** "Based on what is important to you, I recommend the following" Make recommendations that match their goals. **After making a recommendation:** What do you think about this as a plan? (Obtain their opinion about your recommendations)

Virginia Mason Franciscan Health

Palliative Care along the way….

'Wondering and Worried'

Mild Cognitive Impairment-Early Stage

- Responding to Emotions
- Ask before you tell
- How much information do you want (Ask permission)
- Directives–DPOA most important

Virginia Mason Franciscan Health

Mid-Stage Dementia…….

- Agitation
- Swallowing Difficulties
- Pain
- Caregiver Experience and Support
- Transition

Virginia Mason Franciscan Health

Late Stage Dementia……..

- Tube feeding
- Recurrent hospitalization
- Infections
- Treatment for other conditions
- Consideration for hospice care

https://www.choosingwisely.org/clinician-lists/american-academy-hospice-palliative-med-percutaneous-feeding-tubes-in-patients-with-dementia/

Virginia Mason Franciscan Health

Myths about Hospice….

- You cannot have hospice care longer than 6 months-or live longer than 6 months
- The person must stop all meds except comfort meds
- The person can no longer see their usual doctors
- Hospice does not allow hospitalizations, IV fluids, or antibiotics
- If I chose to go on hospice I will die

Virginia Mason Franciscan Health

Making visible the invisible……..

- Ask before you tell
- Respond to the emotion
- Speak in headlines
- Use teach-back
  - **Palliative Care is Preventive care**

Virginia Mason Franciscan Health

What are the possible options for ongoing care?

Options to consider:

- Artificial feeding via PEG tube
  - *Does not positively impact weight nor pressure ulcers, may increase morbidity, does not improve survival vs those who are carefully hand fed*
- Time-limited trial of tube feedings via Dobhoff / Keofeed with specific goals
- Comfort feedings: 1:1 hand feeding (every 4 hours while awake), managing symptoms, engaging Hospice and allowing natural death.
- What about TPN?
  - *No. TPN is meant as a short-term intervention to foster recovery after surgery, chemotherapy, radiation etc.*

Virginia Mason Franciscan Health

Family concerns vs clinician concerns regarding ANH in Advanced Dementia

What concerns families?

What concerns clinicians?

Virginia Mason Franciscan Health

Why do we eat?

Write top 2 reasons you eat in chat box.

FOOD = LOVE

Virginia Mason Franciscan Health

Of the possible options for Mr. B, which is the best match for the reasons most of us eat?

A) Artificial feeding via PEG tube

B) Time-limited trial of tube feedings via Dobhoff / Keofeed with specific goals

C) Comfort feedings: 1:1 hand feeding (every 4 hours while awake), managing symptoms, engaging Hospice and allowing natural death.

Review of Literature

American Academy of Hospice and Palliative Medicine

Released February 21, 2013; Revised January 14, 2021

Don’t recommend percutaneous feeding tubes in patients with advanced dementia; instead, offer oral assisted feeding.

In advanced dementia, studies have found feeding tubes do not result in improved survival, prevention of aspiration pneumonia, or improved healing of pressure ulcers. Feeding tube use in such patients has actually been associated with pressure ulcer development, use of physical and pharmacological restraints, and patient distress about the tube itself. Assistance with oral feeding is an evidence-based approach to provide nutrition for patients with advanced dementia and feeding problems; in the final phase of this disease, assisted feeding may focus on comfort and human interaction more than nutritional goals.

https://www.choosingwisely.org/clinician-lists/american-academy-hospice-palliative-care-percutaneous-feeding-tubes-in-patients-with-dementia/

Virginia Mason Franciscan Health

Talking with Paula

- Build relationship

  Only child, lives in New Jersey, talks regularly to staff who care for her

  Father, not sure what is going on, knows little about advanced dementia

- Obtain patient story–2 stories here

  Always been close to her Father, Family traditions around food

  Master builder, widowed 4 years ago, quiet-not much of a talker, never talked about healthcare directives, avoided doctors at all cost

  Anything else? “If I can’t pound a nail–let me go”

Virginia Mason Franciscan Health

Talking with Paula

- Medical story

  End stage dementia, risk for dying in weeks to months
- Offer medical recommendation

  Hospice support and Comfort Feedings
- Ask if she agrees
- Collaborative decision making

Virginia Mason Franciscan Health

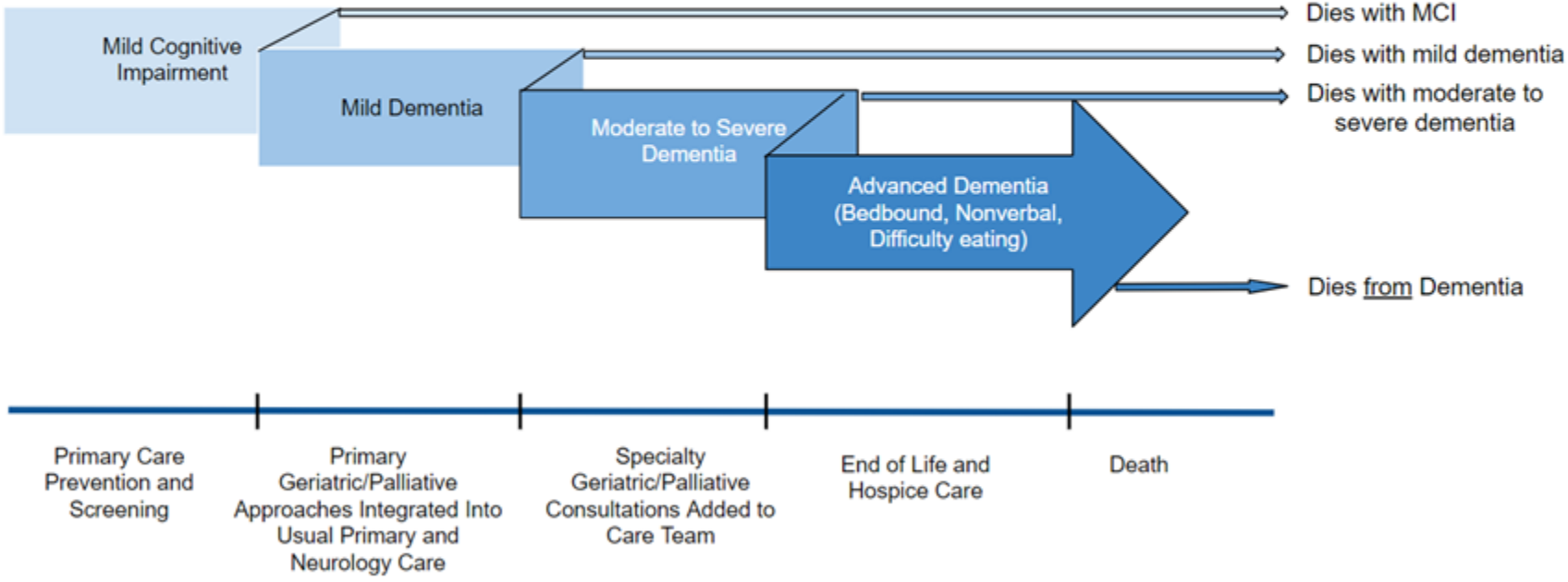
Dying With Dementia: Underrecognized and Stigmatized

- Elephant in the room: death
- 30% of all decedents over 65 yrs die with or from dementia
- $61,000 out of pocket expense-twice as much as other conditions
- High symptom burden
- Frequent hospitalizations
- Invasive procedures
- Brink of death referrals vs. long lengths of stay

Virginia Mason Franciscan Health

JAGS 67:1548-1551

Tailoring of geriatric, palliative care and hospice services for other terminal conditions to address cognitive and functional impairments of dementia



JAGS 67:1548-1551, 2019

Case of Mrs. S.

- 76 yo female presents to you with weight loss and chronic cough
- CXR show suspicious spiculated mass in RUL
- Medical diagnoses are HTN, COPD, and Dementia-Probably Alzheimer's type

  Fast is 6–needs help all ADLs, incontinent

Now what ???

Which headline is most important here?

Virginia Mason Franciscan Health

Headlines……..

- Dementia is a Terminal Illness
- Palliative Care is Everyone's Job
- Palliative Care is Preventive Care
- Dying With vs. Dying From Dementia

Virginia Mason Franciscan Health

Please remember…

Dying can be Successful……

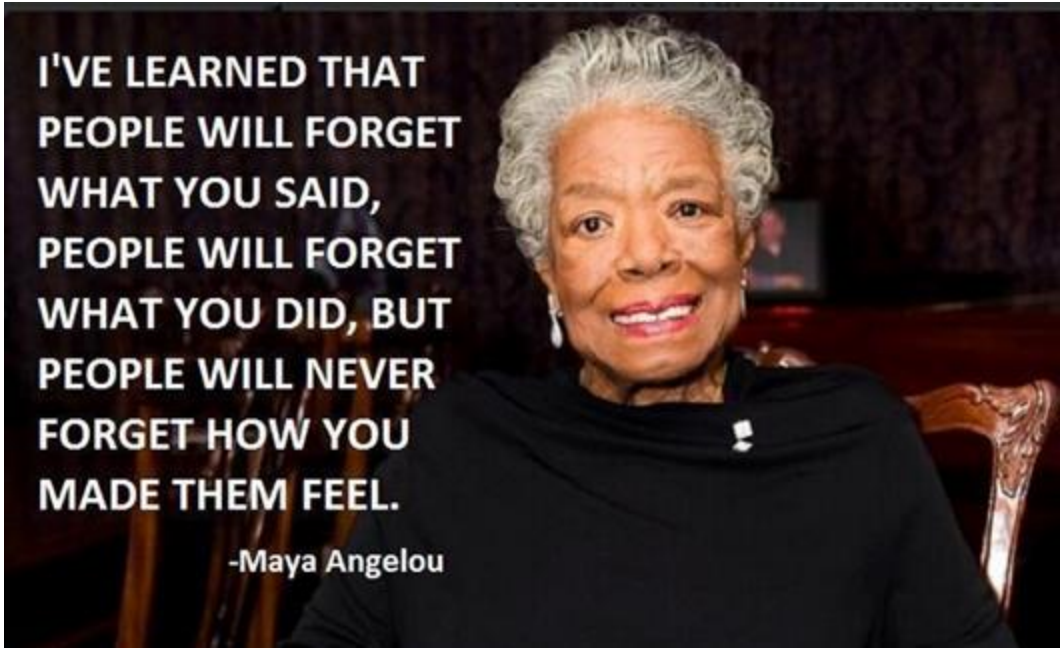
Virginia Mason Franciscan Health

Always…….

Know Your Headlines

Virginia Mason Franciscan Health

Reflection……..



Virginia Mason Franciscan Health

Virginia Mason Franciscan Health