Aligning goals of care with family wishes

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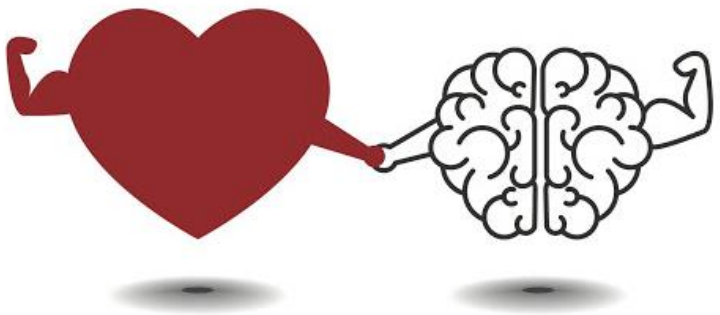
BRAINS
ARE
AWESOME
I WISH EVERYBODY HAD ONE.

Case Presentation

- José is a 94-year-old Hispanic gentleman, lives alone
- Primary caregiver is his eldest son, who lives 4 blocks from him
  - Very little caregiving from other family members, although they are in the area
    - Medical concerns include anticoagulation on Coumadin, myocardial infarction 3 years ago requiring pacemaker. Hypertension, hyperlipidemia. No tobacco, drinks alcohol when he can afford it "only beer". Falls occasionally, very sedentary. Uses a cane for ambulation
      - Medications are Coumadin and over-the-counter supplements as needed

Care plan

- Recently started to see neurology. Fairly functional and social until major myocardial infarction 3 years ago requiring pacemaker.
- Primary care provider recently left the area, has not yet established with a new provider
- Cardiology clinic follows Coumadin closely, he has had 5 cardiologists in 3 years



Patient's goals of care

José is very content to live at home, does not want to live with family. Feels that he has good quality of life. Would like a dog but agrees that he cannot take care of an animal. Would like to see family more, tells me "they are always very busy". Eats two times a day, whenever family brings him food. Compliant with medications. Likes to go to the corner store for alcohol when he has money.

Setting Up a Family Meeting

Running a Family Meeting

- One staff should take lead, explaining format and goals of meeting
  - Rapport
  - Interviewing Skills

Who's coming?

- Ask the client to bring/invite any involved caregivers, family members (including family of choice) to the meeting.
  - ROIs
  - Some clients decline/refuse to include family

- Does client have capacity to make medical decisions?

- Consider which medical team members come.
  - interdisciplinary meeting with the whole team?
  - 1-3 relevant staff members?
  - phone call or telehealth?

Introductions

- Have all team members introduce themselves and explain their role
- Ask family members to introduce selves and ask about level of involvement

Outline Goals

- Review medical problems and recent work with patient
- Don’t assume that family all know what the medical conditions are

Why Are We Here?

Our team wants to collaborate with you on client's health problems. We are working with client on….

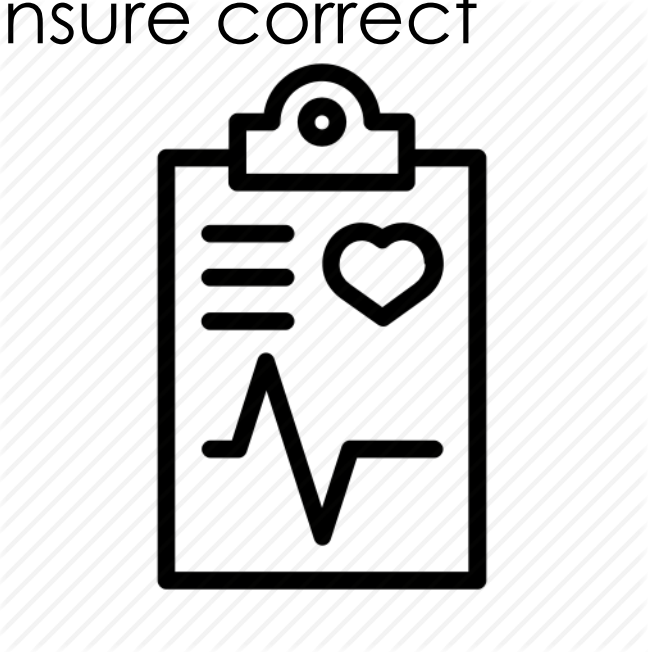
We are concerned about….

What do you think about that?

- What are your goals? (individual and family goals)
- How could we support you?
- What help might you need?
- What barriers do you see?

- Team members may need to update family on specific information related to medical history or solutions that have been tried but failed.

- Leader of meeting should offer reflective statements and summaries of what is being said to ensure correct understanding.



Understanding Family Structure

Who is the primary caregiver, if any?

Who is the POA for Health Care? Who is the POA for Finances?

Consider cultural or interpersonal factors

- Rigid hierarchical structures?
- Enmeshed vs. Disengaged families?
- High vs. Low communication?
- Who typically makes decisions?
- How are decisions made in this family?
- Who has the most power in this family?
- Who isn't in the room, or who is being very quiet?
- Be aware of other factors, such as interpersonal abuse or substance use histories that might be affecting family members.

Accept the things you can't control…

You can give advice, but patients will make the ultimate decision (or non-decisions) about their care.

- Practice some Radical Acceptance
- Point-Out Contradictions
- Be willing to walk beside them, even if you don't like the path

Summarize

Meeting leader offers a brief verbal summary of the plan

- Note roles that different people have offered to take
- Set specific follow-up plan/person(s)/time
- If time allows—write a brief summary or bullet points

Resources

Aligning Goals of Care with Family Wishes

Alzheimer's Association

- Living with Alzheimer's : For caregivers (3 separate courses)
- Free E-Learning courses
- Early Stages: Maximizing independence, provides practical answers to questions from diagnosis of early dementia
- Middle Stages: The role of a caregiver, strategies to provide safe and comfortable care
- Late Stages: Resources, care and ways to engage in meaningful connections
- Caregiver support
- Legal and financial documents checklist

- National Family Caregiver Support Program: https://acl.gov/programs/support-caregivers/national-family-caregiver-support-program
  - Provides grants to states and territories to fund various supports that help family and informal caregivers care for older adults in their homes for as long as possible.

- VA Caregiver Support Program: https://www.caregiver.va.gov/
  - Provides resources and funding to veterans and caregivers

- Wyoming Department of Health, Aging Division: https://health.wyo.gov/aging/

- Wyoming Center on Aging, Caregiver Support Program:
  - Providing education and support to people with dementia, their families and friends, and the community. Mission: Enhance the dementia-capability of our community through education, and provision of home and community-based services.
  - Services include: Family Caregiver Support; SHARE—Support and care planning for people with dementia and their families; Dementia Caregiver Support Group; Individual Counseling; Companionship/respite services; and Education. Contact DSC: wycoa@uwyo.edu | www.uwyo.edu/dsc | (307) 766-2829

"Dementia is like shaking a bookshelf, with the short term memory being one of the books at the top that falls off, while the emotional memories linked to music are some of the books at the foot of the bookcase that stay on the shelf."

~Gemma Jones

www.the lancet.com/neurology
"Creating a personal music playlist to help treat dementia"

Questions?