

What It's Like...

trying to take care of seriously ill patients in
the current healthcare financing system

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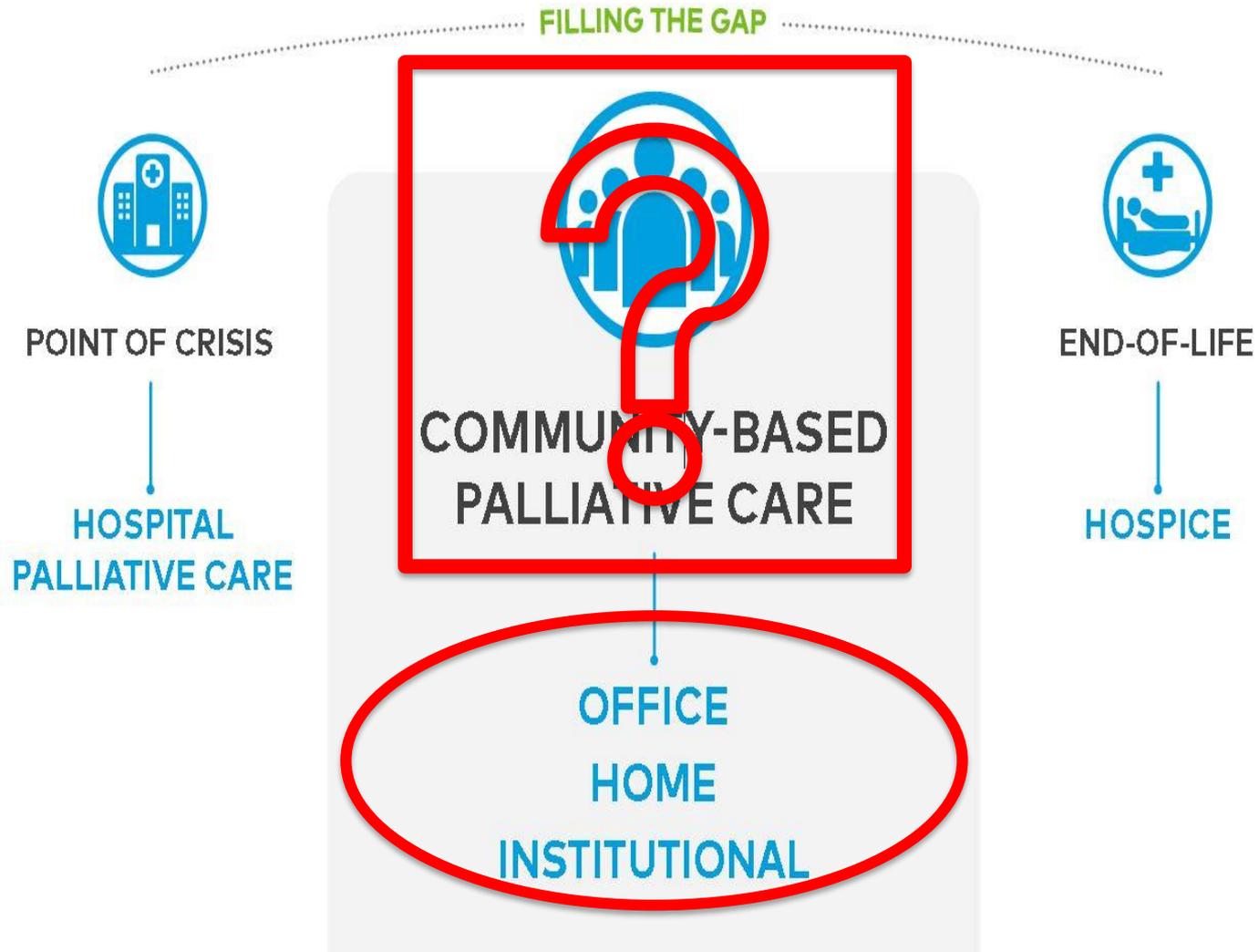
Center to Advance Palliative Care

NAM Roundtable on Quality of Care of
People with Serious Illness

November 28, 2017

THE CONTINUUM OF PALLIATIVE CARE

Palliative care can be – and must be – available across all settings, offering an array of services in venues that matter most to patients and families, in ways that ensure smooth transitions between settings.





HELP!

5:47 AM



I'M SO TIRED.
SHE DIDN'T FALL
ASLEEP TIL 3.
PLEASE LET
HER GO BACK
TO SLEEP.



IT'S ANOTHER DAY.
JUST LIKE *YESTERDAY*.
I DON'T KNOW HOW I
CAN DO THIS *AGAIN*.

3 MINUTES LATER...

OOOWWWOOO!

WHAT HAPPENED??
ARE YOU OKAY?

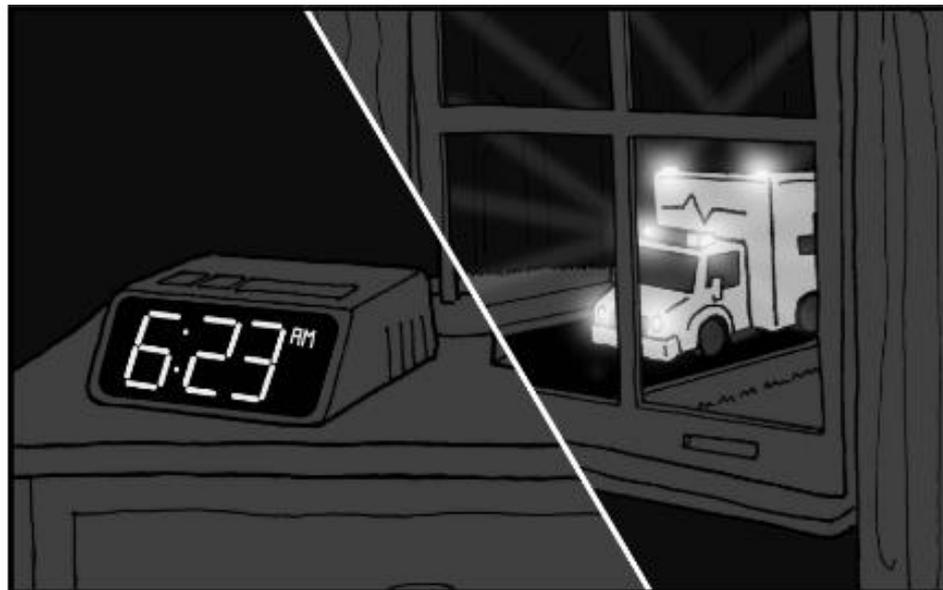
OOOWWWOOO

OOOWOO!

THE DOCTOR'S
OFFICE IS CLOSED.
IF THIS IS AN
EMERGENCY, HANG
UP AND CALL 9-1-1!

UNHH
S

IS THIS AN EMERGENCY? I
CAN'T GET HER UP AND SHE'S
PANICKING. I JUST CAN'T WATCH
THIS ANY LONGER.



Primary care doc Dr. Jones

“I know they keep showing up in the ED in the middle of the night, but what can I do about her back pain? The orthopedist and the neurologist say surgery is not an option. Tylenol doesn’t work and her diabetes doctor says she can’t take NSAIDS because of her kidneys. And we can’t use opioids in someone like her!”

Martha and Bernard: The Faces of Dementia

Bernard and Martha spent the morning in the ED and Martha was admitted for fecal impaction. After discharge, Bernard calls your office to schedule a follow-up appointment. He reports that Martha's agitation is no better since starting the laxatives, and that she is still awake much of night moaning and crying out. He sounds exhausted and your staff is worried about both of them. Bernard is not sure that he will be able to get Martha into a cab for the appointment and the team is arranging for an ambulance for the visit.



Martha's Story



Bernard tells you, "I'm at my wits end. I have forgotten to give her medicines several times this week. Yesterday, I fell asleep on the couch in the afternoon and woke up to find her on the floor again in the bathroom. She's been restless and upset and neither of us can sleep."

After determining that Martha does not have decision-making capacity, ? you talk to Bernard about what kind of person Martha was before she got sick, what she cared about most, and what he thinks she would have said about what is happening to her now. Bernard tells you that Martha was terrified that she might have to leave her home and made him promise repeatedly never to put her in a nursing home. He says, "Martha just wants to be at home with me."

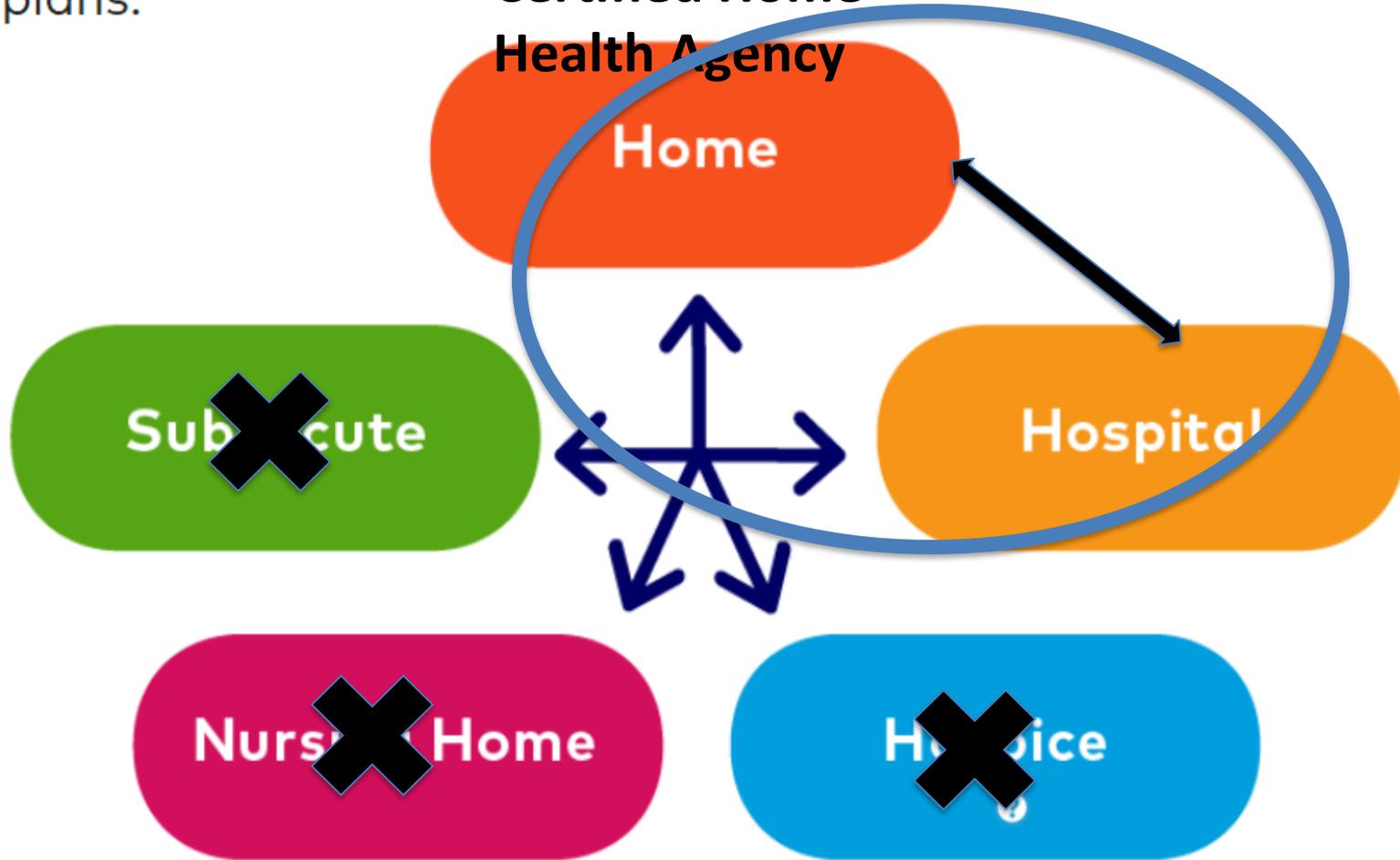


Dr. Jones, continued...

“I’ve sent home care in there several times, but they just discharge her after a few weeks because they say she doesn’t have a ‘skilled need.’ She’s not even close to hospice eligible and Bernard refuses to talk about nursing home with me. What am I supposed to do?”

Persons with dementia routinely transition back and forth across settings. This is often because the medical care, personal care, and family support needs that would enable patients to stay safely at home are often not covered by Medicare, Medicaid, or commercial health plans.

Certified Home Health Agency



Dr. Jones saw an email about a house calls program for complex patients in the new Medicare ACO, and he calls the number...

You arrange home primary and palliative care for Martha with a house calls practice in her community. The house calls team visits several times a week until Martha stabilizes. Bernard knows to call their number 24/7 if after hours problems arise or your office is closed.

They call you to report that the refrigerator is nearly empty because Bernard cannot leave Martha alone to go food shopping. There are no grab bars or elevated toilet seat in the bathroom and there are loose rugs and electrical wires everywhere. The apartment is a mess and Bernard says he has not gotten downstairs to do laundry in over a month.

Your office arranges for a home health care agency to visit for a home safety evaluation and equipment including grab bars, elevated toilet seat, a chair that helps Martha stand up, and a hospital bed. The team also arranges Meals on Wheels to deliver hot dinners.

With their permission, the team calls Bernard and Martha's church and arranges for their friendly visitor program for "shut-ins" to provide companions for Martha 3 afternoons a week so that Bernard can get out to shop and see his friends. The church sends a car to bring them both to church and lunch and then home again on Sundays.

After talking to a palliative care colleague on the house calls team, Dr. Jones okays trying a little morphine...

You decide to try Martha on low-dose opioids at bedtime and during the day as needed since she continues to moan and cry out in pain at night. You also start a daily bowel regimen. Bernard knows when and how to administer the morphine and to call right away if he notices anything unusual.



HELP!

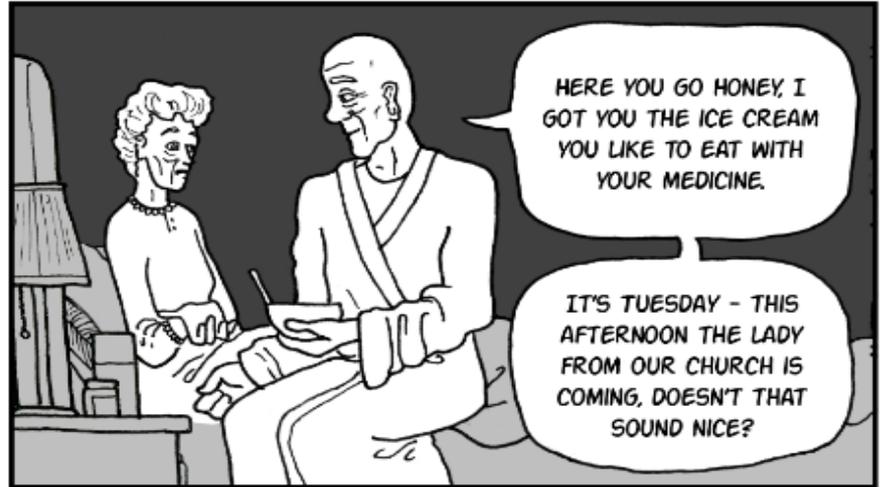
5:47 AM



UH-OH, HER BACK MUST BE BOTHERING HER. IF I GIVE HER THE PAIN MEDS SHE MIGHT FEEL BETTER AND STAY IN BED - AND I CAN'T FORGET THE LAXATIVE THAT GOES WITH IT.



SIGH IT'S SO EARLY. I HOPE SHE TAKES HER PILLS...BUT AT LEAST IT'S TUESDAY, I HAVE MY CARD GAME TODAY!



HERE YOU GO HONEY, I GOT YOU THE ICE CREAM YOU LIKE TO EAT WITH YOUR MEDICINE.

IT'S TUESDAY - THIS AFTERNOON THE LADY FROM OUR CHURCH IS COMING, DOESN'T THAT SOUND NICE?



IT'S GOING TO TAKE A BIT FOR THE MEDICINE TO WORK, I'LL PUT ON HER FAVORITE RECORD



30 MINUTES LATER...

6:23 AM

When you next see Bernard in the office he has gained some weight, is smiling, and no longer appears drawn and depressed. He says he is sleeping at night for the first time in months, and so is Martha. The occupational therapist from the home health agency asked Bernard about Martha's favorite music and they downloaded Broadway show tunes onto an iPod for her. She sings along with great gusto! Bernard is happy to see her taking pleasure in life again. He tells you "I have my wife back."

In conversation with the housecalls team, Dr. Jones learns about eligibility for hospice in dementia patients...

Bernard has not needed to call 911 or go to the ED in the last 18 months. Based on Martha's disease progression (she has begun to refuse food and fluids and choke on her food) you are considering hospice referral so that Martha can continue to remain comfortable at home.

Before and After

Usual Care

- 4 calls to 911 in a 3 month period, leading to
- 4 ED visits and
- 3 hospitalizations, leading to
- Hospital acquired infection
- Functional decline
- Family distress

Palliative Care

- Housecalls referral
- Pain management
- 24/7 phone coverage
- Support for caregiver
- Meals on Wheels
- Friendly visitor program
- **No 911 calls, ED visits, or hospitalizations in last 18 months**
- **Hospice referral 5 months before a peaceful death at home**

What made this care possible?

A new payment mechanism enabled by a risk bearing entity (in this case, a Medicare ACO).

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