Dementia & Hospice Cheatsheet by Krista Montague, CDP

Purpose of This Cheatsheet

A question all of us have wondered is what will the end of this journey look like? This cheatsheet will help answer that question and how hospice can help. *This cheatsheet is based on information from an interview I did with @hospicenursejulie.*

Hospice vs. Palliative Care

Hospice care is federally funded meaning all hospices should act the same (usually Medicare funds it). It requires a terminal diagnosis or less than 6 months to live. Hospice is about living the way you want to live, usually at home and keeping you comfortable. Some people live on hospice for a long time and others only for a few days.

Palliative care is about symptom management. Not federally funded. There is more freedom in services and it is less uniform. Qualifications is 1 year or less to live and sometimes helps manage chronic conditions.

What You Get With Hospice & Dementia

1. 24 hour access to call your hospice nurse with questions
2. Nurse comes when there is an acute medical need.
3. A nurse comes in 1 time a week if there isn't an active issue.
4. Help finding programs to help you.
5. Respite care for 5 days.
6. Occasional help with activities of daily living (showering etc.) from hospice CNAs and occasionally nurses. Most of the daily work of ADLs usually falls on the family.

Requirements For Medicare To Cover Hospice with Dementia

Medicare is strict on allowing folks with dementia on. Hospice first looks at your person with dementia fast score and it needs to be around a 7c aka late stage dementia. Examples of symptoms they would be looking for would be: bed bound, not eating or drinking, bed sores, signs they have malnutrition, recent hospitalization from sepsis or aspiration. To summarize, physical symptoms of active dying. You need to prove to Medicare that they will die within 6 months.

Not Qualifying or Losing Hospice Care in Dementia

If your person with dementia is "too well" or what qualified them resolves, it is possible to get off of hospice.

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How Hospice Works in Facilities with Dementia

Family or healthcare workers can get hospice to evaluate someone with dementia for hospice.

Paying for Hospice with Dementia

Medicare or paying out of pocket for hospice and palliative care if your person with dementia doesn't qualify under Medicare.

Death with Dignity & Dementia (ie Physician Assisted Suicide)

Hospice does not include death with dignity even in states where this is legal due to the nature of dementia taking away decision making abilities.

Hospice & Being On Longer Than 6 Months

Sometimes but your person with dementia will keep getting evaluated every 2 months and will stay on if they keep showing decline.

Hospice Allowing Folks To Not Eat Or Drink

This is the body actively dying. They have forgotten how to swallow and shuts down the mechanism that makes you hungry and thirsty. It mostly makes them sleepy. Focus on them being clean,safe and comfortable.

Signs of End Stage Dementia & Active Dying

Having a rally (ie temporarily getting better right before dying), restlessness, sleeping, changes in breathing, long pauses between breaths, big gasps out of nowhere etc.

Signs They Are Close To Death

Biggest sign is when they stop eating, drinking and are not swallowing. Additionally when they are sleeping and not waking up at all.

Sleep & End Stage Dementia

This is a sign of this stage of dementia. Make sure they are clean and safe. If your person with dementia is falling asleep while you're trying to feed them, you risk aspiration pneumonia.