Final Days: Lessons From a Family Caregiver

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Goals
1. Describe the caregiving experience during the final days
2. Identify opportunities to improve the experience of the final days for family members
3. Create strategies for improving care for family members in the final days

A Personal 42 Month Journey
“I hope to be pain free and excited about the end. Knowing that these things don't always work out, at minimum I hope Debbie is holding my hand and lying by my side. It would be great if I were aware of her presence and of others who may be surrounding me, but again, this may not be likely either. At least it feels good to think that it may happen this way.”

What do we know about last 7 days?

- Changes occurring quickly
- Denial is becoming difficult
- Caregiving demands lesson as patient sleeps
- Stress in family is very high
- Stress will get worse

Hospice Care Data

- 12.3% pts no visit in last 2 days
- Varied between 3% and 19%
- Black pts less likely to get visit in last 2 days
- Nursing home 1.74 times less likely to get visit in last two days
- Dying on Sunday 3.37 times less likely to get visit in last two days
The SIA Payment amount shall equal:

- The number of hours (in 15 minute increments) of service provided by an RN or social worker during the last seven days of life for a minimum of 15 minutes and up to 4 hours total per day

Interventions for final days/hours

- DON'T WAIT until final week!
  - Assess how the caregiver learns
  - Initiate discussions for a plan
  - Warning shots about what to expect
  - Assist with legacy suggestions

Suggested Interventions

- Sit down and discuss "Blue Book"-talk about how to COPE with those changes

- Identify small "things" that can provide comfort, intimacy, and control
  - Massage- hand or foot
  - Oral care
  - Basin and warm/cool clothes
  - Writing things down to keep track!
Suggested Interventions

- Talk about sights, sounds, smells of death and identify things that may help
  - Oils, music, noise machines, blankets, pillow cases, etc
- Plan for help!! Who, when, how, etc
  - Plan for Rest and Relieve
- HOW do I know When to call hospice???
  - Don’t assume they will call!!
  - BE PROACTIVE; Social Work and RN call every day - yes both of you - coordinate!!

Suggested Interventions

- Talk about environment: mattress on floor, chairs and beds
- Care plan for caregiver; rest, eat, liquids,
- Teach how to say goodbye and give permission - when to say goodbye
- Suggest Skype or Face-time for others

Resources

Sitting Vigil at the Death Bed: A Checklist
http://www.onthewaytodying.com/sitting-vigil-at-a-death-bed-a-checklist/

Mor, V., Teno, J. Regulating and Paying for Hospice and Palliative Care: Reflections on the Medicare Hospice Benefit. J Health Polit Policy Law 2016 41(4) 607-716

Legacies From The Living Room: A Love Grief Equation by Debra Parker Oliver