

Talking Points as a Caregiver

Background Info

1. Intro: Lauren Smith from Hyde Park.

- Thank you for the opportunity share my personal experience as a caregiver with you today.

*** Masters in Special Education, taught 27 yrs. How difficult focusing on & putting my thoughts down on paper was for me. As a Caretaker - My brain is FRIED !

- Care for my both my elderly parents

- 61 yrs old, eldest daughter, 4 siblings

Mom: 84, Diagnosed with Dementia in 2010, mini strokes, totally incontinent, wheelchair bound

Dad: 87, is mentally sharp, Physical difficulties- needs walker,

Medical issues: 3 artificial heart valves since age 65, on blood thinners

2. Why I'm caring for M&D

- Moved Mom & Dad to Vermont from Virginia (where they lived near my younger sister) in June, 2013

- Caring for them long distance became too difficult & frustrating for me

- Became too difficult for my sister & husband who work and have a young daughter

- Dad became physically unable to assist mom as her needs became greater

- My husband, Gary & I "semi" retired, have no children

Rewards & Benefits of Caring for M&D

1. Choices for Care (Mom has Medicaid Waiver) - Best option for our situation

- M&D can remain together in their own home for as long as possible.... Married 65 years!

- Dad: some sense of independence

- Able to live the way they have been used to: smokers

- (No assisted living situation in our area would allow them to live together...& no smoking)

- I can choose & hire caregivers & have them work the hours I need for Mom's care

- Allows me the ability to coordinate, monitor, & be "hands-on" with Mom & Dad's care

2. Personal Rewards

- Able to be there for my parents & spend quality time with them as they grow older

- Feel personal satisfaction & at ease, knowing they are safe, well cared for, comfortable, & happy.

- People ask me if I regret having moved them here? As difficult as it is to care for them, I say no because Mom & Dad express their appreciation every day for all I do for them.

- Those rare moments when Mom knows who I am and is "herself" make it all worthwhile!

- Dad told me: he was "waiting to die" in VA

*Read Dad's thank you note to me

Challenges of Caring for M&D

1. #1 Challenge - Caregiver Turnover!! - 24 plus in 2 ½ yrs!

- Keeping steady caregivers is extremely difficult!

- Having to constantly introduce new caregivers: Very stressful & creates anxiety for Mom & Dad!

- Hard for M&D to lose caregivers that they get to know, like & become comfortable with

2. Responsibilities as an Employer

- Finding, interviewing, hiring, training, & supervising, caregivers who are qualified, reliable & trustworthy

- Schedule caregiver shifts, find/provide coverage for people who call in sick or who quit

- Prepare & submit caregivers time sheets bi-weekly

3. I'm "On Call" 24/7

- Responsible for M&D's medications, scheduling & transporting them to Dr. appointments
- Groceries, medical supplies, etc. , Pay all M&D's bills -
- I have to be available for any & all problems that arise with M&D, caregivers, etc.

4. Only one Home Health Agency in our Area

- Restricted in services they can provide. LNA comes 3 x per week to bathe Mom & wash her hair. They used to change her brief, even give her a shower.
- As of 6 months ago, agency will not allow the LNA to transfer Mom at all! Bed bath only! I, or one of my caregivers must be there to transfer Mom

5. Impact on My Personal Life

- Caring for M&D has completely changed my & my husband's life!
- I am unable to commit to any plans!
- Gave up craft fairs, selling my artwork. I haven't been to gym in the past year!
- Set Design/painting at Hyde Park OH : I had to cut back from 4 to 1 show a year.
- Gary & I no longer have the freedom to travel, visit family, friends
- Financial burden on us both: Took money from our savings to purchase house for M&D.
- We pay for repairs.
- Gary does all repairs himself inside & out! Plows, shovels snow, etc.
- No financial help or respite from my siblings! M&D only have SS.

MY CONCERNS

- Things will only become more difficult as M&D get older & their health declines further
- I am exhausted most of the time! I worry about my own health.
- How will Gary & I manage as we grow older? We have no children to care for us.
- I know many families in similar situation : caring for a parent/parents who don't qualify for Medicaid Waiver

Recommendations/ Suggestions for VT Lawmakers

1. Incentive for Caregivers

- Increased pay - Caregivers paid only \$11.28 p/hr for "personal" care
- Provide some sick pay, overtime pay for weekend & overnight hours

2. Increased Home Care Hours per/day for Seniors

- Can only offer caregivers part time work - Mom has 45 hrs per/wk personal care time
- Caregivers have to travel to work only 4.5 or 3.5 hrs.

3. Training For Caregivers

- I strongly believe we need to begin to find ways to encourage young people to see caregiving as a valued career path.
As Vermonters & all Americans are living longer, & with families members living further apart, the need for dedicated, well trained caregivers is only going to increase
- It is my hope that the state will invest in education/training in order to build this much needed workforce.

4. Better/ More Alternatives for Assisted Living Situations