

How to support what is often “the worst day of their lives.”

November 12, 2014



“older people fear losing their independence and being admitted to a nursing home than they fear death.”

Brownie et al., 2014



In today's session

- Consider the move to a long-term care home from the person and family's perspective
- Explore the various components of the move beyond the suitcase
- Look at ways to lessen the stress of the move.



Your wife of 63 years is moving out
today

How must it feel?



Your father for whom you have supported and provided daily care in your home for 5 years is leaving.

How must it feel?



You were diagnosed with
Alzheimer's disease 7 years ago,
you have hardly left your husband's
side in the last 6 years. He just left
you in a room you don't recognize
– he was crying

How must it feel ?



Jenny and Tom's Story



Components of the move

- The person's perspective
- The caregiver's perspective
- The family's perspective
- The physical "stuff"
- The paperwork



Components of the move: The person's perspective

- Fear – unsure of what is happening
- Disoriented – doesn't recognize environment
- Sad – caregiver looking stressed and sad
- Confused – doesn't feel like home but some recognizable belongings are in room



Components of the move: The caregiver's feelings

- Fear – about person's adjustment
- Guilt – broken promise
- Betrayal – leaving person in "jail"
- Embarrassment – view as inability to provide care or feeling relief
- Loss of control – no longer managing care
- Sad – disease is progressing
- Anger – why me?



Components of the move: The family's

- Fear – not sure how person will adjust
- Anger/denial – does not feel it is time for the move
- Sad – watching person and caregiver struggle
- Powerless – cannot see what can be done to help make this time better



Components of the move: Bringing history and home

- Ensuring information about the person, likes, dislikes, history, values are brought and recorded so all staff “know” the person
- Making sure room is set up with familiar objects that provide comfort to the person



Components of the move: The paperwork

- “Necessary evil” – must get done, likely the last thing families want to deal with
- “DNR”- can be a surprise, upsetting piece of required documentation



What can teams do to make it easier?

Person

- If possible have person make short visits if possible in the days leading up to move
- Remember to keep the person engaged
- Adaptation takes a few weeks



What can teams to make it easier?

Caregiver/family

- Acknowledge the feelings they may be having and talk to them about them
- Developing a visiting plan that works for everyone
- Encourage them to connect with social network & support services
- Involve them in providing personal information to help staff get to know person including strategies for daily life (All About Me) – set up an opportunity for family to share with staff



What can teams to make it easier?(2)

Caregiver/family

- Engage family in setting up the room in a way that provides comfort to the person with dementia
- If possible, provide a list of paperwork that needs to be done, highlighting DNR – so if needed families can have a conversation about it
- Follow-up support phone calls with primary caregiver can help to lessen the stress of transition.



QUESTIONS?



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THANK YOU

