

The Face Behind the Case



Journeying through Alzheimer's

- Shirley J. Neitzel

Why Am I Here?



- z My purpose is to:
 - y share 'our story'
 - y demonstrate the importance of LTC insurance
 - y emphasize the relational aspects between case managers and recipients
 - y provide a layman's viewpoint on the industry, *i.e.*, policies, trends, and impacts
 - y function as the poster person for LTC--the Face Behind the Case

LTC Insurance and Us



- z Read about it during the late '70s
- z We fit the typical “planner” profile
- z Decided to purchase either through a group plan or independently
- z Purchased two policies through Argonne
 - y Aetna
 - y dual-mode policies (institutional and at-home)
 - y tax-qualified plan
 - y maintained my policy through portability

About Us



- z The way we were
 - y When and how we met
 - x our relationship
 - y A portrait of David
 - x personality
 - x work
 - x characteristics
 - x social life
 - x activities
 - y Just a little bit about me

Alzheimer's Came on Little Cat Feet



- z Early to mid-1980s
 - y noticed subtle changes
 - y eccentricities?
- z Never suspected disease
- z My attitude
 - y Everyone changes
 - x gradually
 - x mid-life crisis?
 - x male menopause?

The Times, They Kept A-Changin'



- z Dave's personality and habits
- z Friends began to comment
- z Fisher Body
 - y change in management
 - y unhappy at work
- z 1985, early retirement
- z Big plans: nursery/greenhouse
- z Part-time jobs
- z Missed appointments
- z Personal habits changed

1991:

Diagnosis Alzheimer's




- z Elmhurst Alzheimer's Assessment Center
- z Living Wills, Advance Directives, Healthcare Powers of Attorney
- z Conferred with physician
- z Began Cognex therapy [generic: Tacrin]
- z Hired informal "companions"
- z Hired CNAs
 - y the good, the bad, and the ugly

The Beginning of the End



- z 1991 through 1994
 - y undeniable changes
 - y confusion and frustration
 - y dealing with our changing relationship and new restrictions
 - y research, research, research
 - y renewing and cementing our commitment to each other
 - y dealing with rolling grief daily
 - x the keeper of my secrets is gone
 - x an invalidated life

1993/1994: Aetna Benefits Began



- z Initial phone inquiry
- z Assigned case manager: Judy Meister
 - y knowledgeable, courteous, helpful, empathetic
 - y developed a relationship of trust
 - y relationship grew into a 'partnership'

Coping Mechanisms



- z My role continued to expand
- z “Snow-plowing” Dave’s life
- z Adjusting my work
 - y went virtual
 - y stopped traveling
- z Changing mindset:
 - y admitting strangers into our home
 - y learning to depend on others
 - y finding and training good help

The Plan is to:



- z Care for Dave at home, no warehousing, no matter what
 - y arranged legally in case of my demise
- z Keep him happy and content
- z Bolster his ego; keep him involved
- z Turn the bad times into loving opportunities
- z Maintain his dignity! He is NOT a child!
 - y Vocabulary (the mommy syndrome)
 - y body language
 - y provide choices
 - y keep his life participatory

Catastrophic Moments



There are some things one cannot plan for:

- z Small events that cause temper spikes
 - y how handled
 - y what worked, what didn't
- z Physical degeneration
 - y balance
 - y legs
 - x the first meltdown

Plan for the Worst; Expect the Best



- z Divested ourselves of our toys
- z Downsized the residence
- z Weaned ourselves away from Dave driving
- z Sold car #2
- z Chose a new locale
- z Purchased small home w/amenities for our anticipated physical challenges
- z Maintain semblance of 'normalcy'
- z Make every moment count!

Interesting Observations



- z Blood is not necessarily thicker than water
- z Some people do not like sick people...and they tell you so
- z The U.S. has a long way to go to be user-friendly to the physically inconvenienced
- z Like divorce, the social dynamics change significantly
- z Caregivers are relegated to robo-servers and can easily lose their identity

1996-Present



- z The disease accelerates
- z Dave's present condition
- z Exacerbating conditions
 - y Arthritis
 - y CHF
 - y Cataracts

Hands-on Caregiving



- z Put yourself in his place--ask yourself, what would please me if I were him?
- z Remember, this is not about *you!*
 - y Focus on your loved one
 - y He's doing the best he can (my mantra)
- z Requires the 4 Cs of caregiving:
 - y Commitment
 - y Compassion
 - y Consistency
 - y Control (self-control)

A Typical Day



- z Rise at 4 a.m., log on, answer email, set up appointments
- z 4:30 a.m., coffee/breakfast
- z 5 a.m., shower
- z 6 a.m., awaken Dave
 - y give meds
 - y give Ensure
 - y refresh him, change disposable briefs
 - y roll him onto his side, prop with pillows

A Typical Day (contd)



- z 6:30 to 9:00 a.m. - Work
- z 9:00 to 9:15 a.m. - Converse with CNA
- z 9:15 to 1:00 p.m. - Work
- z 1:00 to 1:30 p.m. - Check on Dave, talk a little, make sure he's hydrated, make physical contact, rub him/love him/laugh with him
- z 1:30 to 3:00 p.m. - Work

A Typical Day (contd)



- z 3:00 - give afternoon meds, push fluids, quick chat, smile, and a kiss
- z 4:00 to 5:00 p.m. - sit with Dave, talk, watch TV with him
- z 5:00 p.m. - start dinner
- z 5:30 - 6:30 p.m. - serve dinner, feed Dave
- z 6:30 - 7:00 p.m. - evening meds, more fluids, brush his teeth, transfer to bed (Hoyer lift)

A Typical Day (contd)



- z 7:00 - 7:45 p.m., undress Dave, bathe him, roll him on his side to sleep
- z 7:45 - 8:00 p.m., clean up kitchen, have tea
- z 8:00 - 10:00 p.m., either work or study
- z 10:00 - 10:45 p.m., eat something
- z 10:45 p.m. - Wake Dave, reposition him to keep lungs clear and avoid pressure spots, offer a drink
- z 11:00 p.m. - midnight: read, have tea

A Typical Day (contd)



- z Midnight to 2:00 a.m., sleep
- z 2:00 a.m., reposition Dave again
- z 2:15 a.m. - 4:00 a.m., sleep
- z 4:00 a.m., rise, a new day begins.

"He Ain't Heavy, He's my Honey"



- z Smile. It is still very possible to have fun and enjoy your loved one--find new ways--simple pleasures
- z He's the same person he always was, let your love be a laser that penetrates the mask of disease--see your loved one for who he really is--he's still in there, draw him out
- z Touch, pat, pet, connect, hold hands! Take pleasure in communing through physicality--it speaks volumes and much louder than words

Grow from this ...



- z Turn the challenge into an opportunity
- z Take pride in your work as a caregiver
 - y next to parenting, it is one of the most important and fulfilling jobs
 - y "...in sickness and in health ..."
- z Help right the injustices in society
 - y articulate problems
 - y write letters; get involved
 - y talk to people; help them plan; raise their consciousness

LTC Makes All the Difference



LTC:

- z allows me to continue my career
- z has slowed down our rate of savings depletion
- z is something positive in a less-than-positive situation
- z enables me minimal scheduling flexibility
- z means I can still have a life

My Views on LTC



- z LTC should be part of the basic corporate insurance package
- z The government needs to partially fund LTC
- z Society needs more exposure to LTC and needs to assimilate the idea that LTC is as normal and common as a savings account
- z LTC needs to be better marketed
 - y higher profile
 - y much younger audience

My Views on LTC (contd)



- z Suggest that LTC for the elderly be optionally arranged in the form of a reverse mortgage--use the equity to fund the payments
- z Need to stress the economy of LTC when purchased when young!
- z Is there a way to 'rider' auto and LTC insurance or partner the two so the majority of people are introduced to it very early?

Some Policy Concerns



- z Managed LTC, a double-edged sword
 - y a fine balance is required to obtain the benefit of group discounts v. individual freedom
 - y HMOs redux. Over managing does not work.
 - y people need self-determination of their benefits
 - x the cash to make their own best deals without strings
 - x benefits must not be tied to specific 'approved' providers, however,
 - x approved-provider discounts could be offered as incentives

Summary



- z With the changing demographics, society needs to seriously change the way we care for the frail and elderly
- z Home care is best; it's doable; it's the right thing to do
- z LTC enjoys a good reputation, keep it that way
- z 'Partner' with your clients
- z Remember: Today's *Provider* is potentially tomorrow's *Recipient*.

... and finally, know that ...

Life is Good, We are Blessed,
and We Are, *The Face Behind
the Case*

What is the meaning of love?

*Love is when we believe that we alone can love,
that no one has ever loved so before us, and that no
one will ever love in the same way after us,
This is the true meaning of love.*

- Goethe