Slide 1

The Caregiver Journey

“When one is sick, two need help”

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The Caregiver Journey

Today’s family caregivers...

- Provide 80% of all long term care
- 43.5 million (18+) care for adults 50+
  - Help ill or disabled adults aged 50+ with activities of daily living
  - 15% care for someone aged 50+ with main diagnosis of dementia, 20% as secondary dx
  - 28% are spousal caregivers (adults age 18+ caring for husband, wife, partner age 50+)
- Will increase by 85% by the year 2050

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The Caregiver Journey

SPOUSAL CAREGIVERS...

- After a diagnosis or injury, 80% of marriages break up
- Estimate: 6-8 million caring long-term for a husband, wife or partner
The Caregiver Journey

The cost of care...
- Family caregivers provide $350 billion dollars of care a year – for “free”
  - Paid home healthcare -- $32 billion
  - Nursing home services -- $92 billion
- Care for Alzheimer's patients costs families approximately $23,436

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The physical & emotional toll on caregivers...
- Higher mortality rate
- Depression in 30-59% of family caregivers
- Increased risk for chronic conditions such as coronary heart disease, cancer, and diabetes

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When Illness and/or Disability Strike...
- Acute illness
- Injury or Accidents
- Chronic Illness
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Impact of the Initial Diagnosis –
The Acute Emotions
- Shock
- Denial/Minimization
- Emotional Overdrive
- Life is put on hold to deal with crisis

Impact of the Initial Diagnosis –
The Chronic Emotions
- Sadness, grief, depression
- Dread
- Anger, anxiety
- Guilt
- Loneliness, isolation

Three Stages –
- The Heroic Stage
- The Ambivalence Stage
- The “New Normal”
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The Caregiver Journey

The **Heroic Stage**
- Productive panic
- Active research
- Optimism
- Hope Fades

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The **Ambivalence Stage**
- Conflicting feelings
  - Cycles: Anger, guilt, anger
- Exhaustion
- Powerlessness

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The **“New Normal” Stage**
- Coming to terms
- Finding purpose
- Achieving resilience
- Defining goals and commitments
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**The Caregiver Journey**

**TRANSITIONS**

"The caregiver journey is not a steady progression from one stage to the next. It is not uncommon to go back and forth between stages.

"Many caregivers never achieve a “new normal.” And those who do may transition back to the ambivalence stage from time to time."

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**The Caregiver Journey**

Tips for Creating a "New Normal":

- Take time for yourself (respite)
- Ask for and accept help
- Seek counseling
- Consider medical treatment for depression and anxiety
- Join a support group
- Consult a financial planner or eldercare attorney
- Develop greater self-awareness
- Honor your spiritual or religious beliefs
- Eat right, exercise, and sleep

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**The Caregiver Journey**

The Well Spouse Association is an international non-profit membership organization which provides support to the individuals caring for chronically ill or disabled partners.

1-800-838-0879
support@wellspouse.org
www.wellspouse.org
Ownership of the Caregiver Journey.

Membership in the Well Spouse Association includes:
- www.wellspouse.org
- Mainstay Newsletter
- Support groups
- Respite weekends
- National Conference
- Online Forum for Well Spouses
- Mentorship program
- “Round Robin” letter writing groups

Resources:
- Well Spouse Association: www.wellspouse.org
- Administration on Aging: www.aoa.gov
- Social Security Administration: www.ssa.gov
- Medicare: http://www.medicare.gov

Resources:
- National Family Caregiver's Association: www.nfcacares.org
- National Alliance for Caregiving: www.caregiving.org
- Family Caregiver Alliance: www.caregiver.org
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The Caregiver Journey

Resources: Books on Caregiving

- **The Emotional Survival Guide for Caregivers** by Barry J. Jacobs, PsyD
- **Mainstay** by Maggie Strong
- **The Chronic Illness Experience** by Glenn Bridger
- **Love, Honor, & Value** by Suzanne Mintz
- **The Anatomy of Hope: How People Prevail in the Face of Illness** by Jerome Groopman

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The Caregiver Journey

Resources: Books on Coping with Grief, Death & Dying

- **Life Lessons** by Elisabeth Kübler-Ross
- **Living with Grief When Illness is Prolonged** by Kenneth J. Doka
- **Dying Well** by Ira Byock, MD
- **Final Gifts** by Maggie Callanan
- **Safe Passage: Words to Help the Grieving** by Molly Fumia

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The Caregiver Journey

References: