



Common Family Dynamics and Possible Remedies



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The Martyrdom Syndrome

- Many factors may trigger or perpetuate the martyrdom syndrome. These factors include:
 - A desire to express love and devotion
 - Guilt regarding past actions, inactions or situations
 - Survivor guilt
 - Fear of being judged by others (this may be more likely in blended families)
 - Sublimation of painful feelings
 - Avoidance
- The major risk of the martyrdom syndrome is that the caregiver who has slipped into this pattern is actually jeopardizing the safety and well-being of the patient AND him- or herself.



The Martyrdom Syndrome: A Potential Remedy

- Perhaps the most consistently helpful remedy for this pattern of behavior in a caregiver is to explain to the caregiver how essential he or she is to the well-being of the individual who is living with dementia.
- In essence, the caregiver needs to be reminded that, although their devotion may arise from the most noble of motives, it is, ultimately a strategy that is likely to backfire and to cause more harm than good.
- Specifically, the caregiver, especially caregiving spouses, need to be reminded that no one knows the patient better and no one is more qualified to provide care or supervise care. If martyrdom causes the spousal caregiver to become ill or to die, then the spouse with dementia will be placed in a potentially very precarious situation.



The Out-of-Town Family Member

- One fairly common challenge is keeping out-of-town family members accurately informed of the patient's status
- Out-of-town family members are often unaware of the level of impairment of the person living with Alzheimer's disease
- Often this lack of understanding is the result of
 - The family member with Alzheimer's having preserved social skills
 - The style and content of communication between the out-of-town family members and the family member living with Alzheimer's
 - No recent, or only very minimal recent, contact between the person living with dementia and the out-of-town family member
 - The common tendency for individuals and family members to experience denial in the face of tragic life threatening illnesses like the various forms of irreversible dementia
 - Pre-existing trust or communication issues between family members



The Out-of-Town Family Member: Remedies

- Invite out-of-town family members to visit as often as possible
- When out-of-town family members do visit, engage them actively in caregiving
- Consider letting the out-of-town family member provide respite care when the primary caregiver is on vacation
- Request that a neutral third-person explain to the out-of-town family member the nature and extent of the cognitive losses that the person with dementia is experiencing
- Look for opportunities to explore with the out-of-town family member what it means to him or her that his or her family member is living with dementia
- Encourage the out-of-town family member to attend a Alzheimer's caregiver support group



The Parent who Refuses Help from Adult Children

- Once a parent, always a parent
- For most parents, regardless of their age and the age of their children, it feels wrong to “lean on” or “burden” their children
- Many individuals living with dementia and many spousal caregivers of patient’s with dementia
 - Minimize the symptoms of the patient
 - Minimize the challenges of care for the patient
 - Refuse offers of help from adult children



The Parent who Refuses Help from Adult Children: A Potential Remedy

- Every stage of life has important psychological developmental tasks.
- An important developmental task for individuals who are middle aged is to adequately thank their parents for all that their parents did to help the child grow up and become a reasonably healthy, successful adult.
- Although this gratitude can be expressed verbally and this is helpful, it is generally not as helpful as actually having opportunities to express gratitude through helpful actions or behaviors.
- If a parent is able to allow for their adult child or adult children to provide help then this parent is doing the adult child or children a favor and helping the child or children accomplish an age appropriate developmental task.



The Adult Child with Unrealistic Expectations

- Watch out for the adult child who, perhaps due to denial, has unrealistic expectations of what the person with dementia can accomplish (e.g. resolve an issue from childhood, travel, etc.).
- Another important developmental task of mid-life is to resolve residual conflicts with one's parents.
- If the parent who was party to these unresolved or enduring conflicts has dementia then it may no longer be possible for the parent and child to achieve resolution of the conflict and repeatedly attempting to do this will only make matters worse.
- Each time the adult child attempts to resolve the conflict the adult child may end up feeling re-injured or re-traumatized.



The Adult Child with Unrealistic Expectations: Potential Remedies

- Work to help the adult child understand that their goal may be healthy and reasonable but their method is no longer realistic
- Encourage the adult child to find some other pathway to achieve resolution of the conflict:
 - Individual psychotherapy
 - Group psychotherapy
 - An Alzheimer's support group



References

- 1) What's Happening to Grandpa? by Maria Shriver. New York: Little, Brown and Company and Warner Books, 2004
- 2) The 36-Hour Day by Nancy L. Mace and Peter V. Rabins. New York: Warner Books, Inc. 1981, 1991



Resources

1) Alzheimer's Association

www.alz.org/sandiego

24/7 Helpline 1-800-272-3900

2) Alzheimer's San Diego

Help & Info: 858-492-4400

Information: info@alzsd.org

Alzheimer's San Diego Shiley Center for Education and Support

6632 Convoy Court

San Diego, CA 92111

3) The George G. Glenner Alzheimer's Family Centers, Inc.

www.glenner.org

619-543-4704

3686 Fourth Avenue

San Diego, CA 92103

4) Southern Caregiver Resource Center

www.caregivercenter.org