

Spousal caregiving: the risks and benefits

By Carol Edwards, RN, GCM



Consider this all-too-frequent scenario. Dad has been declining slowly over the last five years. Mom has been aware of the changes, but she has attempted to conceal and compensate for his limitations in front of friends and family. As a result, mom's own tolerance and her mental and physiological health are deteriorating, and her ability to cope is diminishing. She is not, however, willing to discuss the situation with a doctor or with her family.

As a geriatric care manager in private practice, I am generally approached as a last resort by adult children who have noticed that things are dreadfully wrong and their parents are deteriorating at warp speed! My challenge is to be effective in this extremely delicate situation. I need to be non-threatening with the caregiving spouse and family members, while acquiring a foothold on the family dynamics, healthcare risks and possible future plans. Confidences must not be betrayed and “landmines” must be avoided.

hamper the chance of a return to good health and deterioration is usually rapid.

Objective assistance

Perhaps the most important ingredient that a qualified professional can bring to the caregiving situation is objectivity. Additionally, a geriatric care manager, nurse or social worker will recommend a proper assessment and prioritization of tasks, available resources and resolution to the “at-risk” situation.

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The best of intentions

While most spousal efforts are well intentioned, fuelled by love, concern, hope and fear, the caregiver spouse often superimposes their own wishes and needs onto their loved one. That is not to say that spousal caregiving does not have its advantages. However, the caregiver may lack nursing knowledge or resources, and not know how, when or where to get help. Sometimes they will be receiving bad advice from family and friends.

In the presence of dementia or other progressive, complex diseases there is a good chance that the caregiver (often the female partner) will burn out or see declines in her own health. Without any nursing knowledge, it is also common for vital symptoms to be overlooked, resulting in the deterioration of both parties.

While I am frequently able to restore health and quality of life to my clients, problems such as prolonged nutritional deficiency

The risks and benefits of spousal caregiving

Risks

- Difficulty in explaining the situation and needs of loved ones to friends, family and the healthcare system.
- Not recognizing “time-sensitive” symptoms and issues.
- Having unrealistic expectations regarding their nursing and caregiving skills.
- Distracted by their own needs.
- Feelings of loss of companionship.
- Misguided trust in the healthcare system.
- Physical and mental exhaustion.
- Existing spousal relationship dynamics.
- Loss of control.
- Reluctance to spend money to get assistance.

Benefits

- Feeling needed (oxytocin is released, giving a chemical reward).
- Long experience in understanding their spouse's needs and limitations.
- Growing older under altered circumstances.
- Ability to remain in their own home.
- Feeling in control of their situation.
- Financially economical.

“I asked my wife if old men wear boxer shorts. She said, “depends!””

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A geriatric care manager can be a good resource because her varied skill set and understanding of the disease process can help to balance the family's expectations. He or she can also recruit the right healthcare professionals at the right time and discuss matters with the caregiving parent—who often holds the power of attorney (POA)—and their adult children. The objective, of course, is to alleviate some of the pressure of the situation, while resolving health care issues and allowing the caregiving spouse to spend time on their own needs.

What to expect

Families should quickly recognize that only a small percentage of help for the elderly need be addressed by a physician. Much (if not most) can be implemented and monitored by a nurse. On the front line, this may mean hiring a support worker to work in the home under the direction of a skilled nurse.

Other professionals that play a large part in the wellbeing of the elderly are dietitians, physiotherapists, pharmacists and occupational therapists. We must also recognize the value of the family doctor or geriatrician, if one is available. Physicians are key in assessing the mix of diagnosis, condition management and medications.

Who takes charge?

The person who has POA should be spearheading the cause in order to maximize the quality of life of their loved one. This may be the care-

Tips for the caregiving spouse

- Seek objective, professional outside help; caregiving is too much for one person.
- Treat your spouse as an individual and help them to achieve their wishes.
- Do not be afraid to spend money on care: “This is what you saved for.”
- Take time for yourself without feeling guilty.
- Stay socially active.

giving spouse or an adult child. If you receive POA, it is important to be able to delegate, seek the right assistance and ensure that healthcare professionals implement the right solutions in a timely manner. In addition, you will be responsible for carrying out the wishes of your “client,” regardless of your own personal opinions. Adult children are usually more effective at this than the spouse.

Family units often become less coherent in the presence of chronic illness or dementia, with individuals expressing different emotions and voicing a range of opinions. If you have POA, you might wish to involve a neutral party such as a care manager to “go in gently,” neutralize the process and help your parents to get the care and help that they need.

Financial planning to implement the wishes of the person will always be a consideration.

Should resources be limited then a slower, progressive implementation may need to be considered.

In conclusion, while a spouse is always well meaning, he or she will often need assistance with caregiving and health management. An adult child often has greater objectivity and is more likely to seek outside assistance, perhaps due to added stress and the huge time commitment required for care. Additionally, using retirement funds to achieve this outcome often makes better economic sense to the kids than to their parents. ●



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Recommended actions

- Share POA between the spouse and an adult child.
- Obtain professional and objective support (i.e., a lawyer, family physician, care manager and accountant).
- Enlist your family's cooperation for problem solving and sharing duties.
- Obtain professional counselling for the caregiving spouse.
- Encourage your parents to think about financial planning (i.e., reverse mortgage).
- Recruit help from your parents' family physician and the healthcare community.
- Intervention of adult children.
- Respect the wishes of your “client.”