



## **Factors that influence the ability to be a care giver**

by

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Assumptions are made about care giving in the same way they are made about motherhood. That it is natural, everyone can do it and it is instinctive. Wrong. Successful care giving is about learned skill and attitude.

I believe there are at least 6 factors influencing the ability to be a caregiver.

### **1. Life view- timing.**

What were we planning to do with our life when suddenly this responsibility is thrust on our shoulders? Were we into motherhood, or furthering our education; getting to the top in our profession? Or were we retiring and planning to do all the things we had put off, for the sake of others, and now it was our turn? Would our goals have to be put on the back burner or abandoned forever in order to assume the care giving role? Many have previously sacrificed themselves and have delayed gratification - only to be denied reward permanently. They must grieve that loss. Many who do not grieve successfully become resentful and bitter when facing their shattered dreams. Caregivers must have the opportunity to grieve their own loss before they can successfully embark on this new role. Most attention is paid to the losses of the person with the disability or illness. Few realize the care giver is also grieving loss.

### **2. Attitude towards disability/disease.**

In this society there is pressure to place more value on youth, productivity, success, power, beauty and independence. Those who cannot attain or maintain these values are considered burdens to society. The aged, the disabled, the dependent, those requiring

medical services, home supports, social benefit programs etc., become viewed in a different light. They become worth less.

Many of us come from a social structure where disability is seen as a failure. Where a family feels shame at having such a secret. The deformed body is something devoid of all beauty. Indeed the disabled person is not just disabled but is also dehumanized, devalued and degraded. Many of us have politically incorrect attitudes hidden inside. The person who has adopted these prevailing attitudes, will be ill equipped to handle the losses that disease will throw at them and their loved ones. It can lead to marital breakup. Women with disabilities are frequently at risk for spousal abuse. If you, or those around you, consciously or unconsciously marginalize the disabled, sick, dependent or frail, it will be difficult to see joy, purpose and value in the role of caregiver. Shame breeds intolerance and anger.

Peter retired early from the job at which he excelled so he could look after his disabled wife. His friends and colleagues were appalled at his decision. "You are wasting your life. Your job is far more important. Put her in a nursing home and do your job" they said. He retired. All his colleagues abandoned him - they could not relate to him or understand him any more. Their value systems were different. He became a very lonely man. He was not valued for the role he had chosen to play.

Some religious beliefs contend that disability is a punishment. Do we not say, "What have you done to deserve this?" Hear those words. They accuse you of doing something punishable with cancer, MS or Alzheimer's disease. Condolences often include the words "what a shame, what a pity."

Being with a disabled person can lead to embarrassment, fear and discomfort. You cross the street rather than be close; you choose not to gain eye contact with that person in the wheelchair. Then your spouse, your child, your parent gets a terrible diagnosis. You run the risk of being tainted. The person brought up with these beliefs must make monumental changes as to how they view disability. Otherwise they will find great difficulty in coping with the care giving role. I so admire those who embark on a journey with a new belief system, bucking the tide of opinion and learning that through caring one can learn the true nature of one's own existence.

Conversely some get through the care-giving role because of these beliefs - it is their punishment, it is the sacrifice they make, it is their duty. Sometimes those negative connotations get them started but

they later discover the joy. Many never do find the joy and life is wrapped in bitterness, resentment and anger. If bitterness, resentment and anger are colouring your world it is important to examine your attitude to determine your flexibility with this issue. After all, have you chosen to adopt the beliefs of others? Do they really work for you?

### **3. The previous relationship.**

What was the quality of the relationship before disability struck? If you no longer "care about" each other, the ability to give care will have been drained away. It is hard to bath and diaper the parent with compassion when s/he abused you as a child. Can you willingly give care to a spouse who long ago ceased to show you love?

Which child will become the caregiver for the parents? Some siblings remove themselves completely from the situation, oblivious or denying the stress that is placed on their brothers or sisters. If confronted they will often throw up their hands and say – "put them in an institution if it is too much for you - why are you wasting your time?" Unless we understand the dynamics of a given family we will not understand why one child becomes burdened with the responsibility. Researchers believe much will depend on the roles assumed in childhood. If one never had to take responsibility as a child, one may not feel the need, as an adult - especially if another sibling who did assume more responsibility as a child, is present.

Rose became a widow when her two sons were small and she brought them up on her own. Gene was her favourite although she did give his younger brother Tom much love. But Gene didn't have to prove anything. Tom on the other hand took out the garbage, helped his mother around the house and when both sons left home and got married, Tom always kept in touch. As Rose aged she became less safe living alone. Both sons lived many hundreds of miles away from their mother. Looking at these family dynamics it is easy to see that Tom will be the one who takes on the responsibility of transitioning his mother into long-term care. Gene agrees with all decisions made – from a distance. He unconsciously knows he will be loved without doing anything. He will not see himself filling the role of caregiver.

In most families the "unencumbered child" is accepted - because everyone in the family knows from their childhood roles that the individual "wouldn't be able to cope" or they were "entitled" to hang back. In adult life this individual may be a doctor, nurse or social

worker, but still the family does not look to them to take responsibility, based on their previous relationship. In other families the unencumbered child withdraws from the network and suffers the anxiety of loss of the original family fabric, alone. In still other families all the anger, frustration and pain of care giving is projected onto the missing family member. As you can see, not everyone is born to be a caregiver.

However it is sometimes through the role reversal of care giving that relationships blossom in ways that would never have been possible. If father had not become dependent or husband had not needed to take over the housekeeping chores, joy and accomplishment may never have been experienced through the changed role.

#### **4. Knowledge-**

-of the disease, skills needed, supports and resources available, accessing the system, financial assistance, respite care in the home and in institutions, palliative care, home hospice volunteers, friendly visitors who provide respite, transportation for the disabled; Caregiver support groups, day programs... You need all this information on day one. For some caregivers the search is an acceptable challenge, for others it leads to anxiety, panic and fear.

#### **5. Financial and other stresses –**

Priorities- where does the money go? This may be a major factors when it comes to prolonging life or letting it slip away. If the money is going to be used now in care - what about the children, the grandchildren and their university education? What if having the wish to live, stay at home, require care - means selling the home, going into debt? Will the decision be based on our values? Youth v. age. Healthy v. disability. Will the caregiver forgo paying for respite because they see themselves as worth less than some other member of the family?

Many stress filled decisions must be made, often before the wishes of the individual concerned are known. Trying to keep promises made when circumstances were very different is often a major stress.

When her mother said "Joan, promise me you will never put me in a nursing home," it was easier to say, "yes Mother" than have a fight. But when her mother had a massive stroke and needed total nursing care Joan had to face her mother's beseeching and then hurt eyes. Joan was filled with guilt. It takes much strength to have the

conversations that are needed, before they are needed. Perhaps Joan could have said a long time ago "Mother, I love you and I will always do my best for you. But if the time comes when you need more care than I can provide, I will make the decisions that I think are best for you." If Joan was even stronger she could have ended with the words "best for us."

## **6. support systems-**

My Mother cared for my father who had Alzheimer's disease. They came from a social structure where you did not air your dirty linen in public. They believed that one made one's bed and then had to lie on it. They knew that certain crises were crosses they had to bear. Where did this get my Mother? Alone and with no support system. Slowly she became socially isolated. When she took my father to gatherings he would become so repetitive with his stories that people would remove themselves from his company. Indeed the time came when my mother was asked to leave my Father at home when she was invited to a social event. Conceivably if they had realized he was a sick man, they would have been more tolerant and patient. On the other hand my Mother could have been further ostracized.

What is important is how our friends perceive the validity of the role of caregiver. They may be supportive, or they may be not. Firstly it is essential that we surround ourselves with like-minded people who value our role and us. Caregiver support groups have the main purpose of validating the individual's journey. Secondly we will need respite to restore our wholeness. Time away from the responsibility is not a luxury but a necessity.

The ability to cope is dependent on the perception of burden. If we see ourselves as victims we can blame our inability to cope on outside forces. We can stagnate by saying "poor me. " Many people are paralyzed by the fear of having to handle a crisis alone and spend their time worrying about "What if..." When self-esteem has long ago been buried, the individual believes that anything they do will not be good enough. If doomed to failure, why try? All these belief systems can be tested for validity when one is supported by knowledgeable healthcare professionals, supportive people in the same boat and staff of the agencies associated with the relevant disease. Alzheimer's Society, MS, Parkinson's, Heart and Stroke Foundation etc. Without validation for the role we are playing, we burn out as care givers.

It is important to remember that from every crisis we face in this world we can improve the skills needed to face the next. Those who have never learned from past experience will find it more difficult to problem solve and face the uncertainties of the care giving role.

We have looked at 6 factors that will influence care-giving ability. Factors that will affect the feelings, attitude and skills we bring to the task. They will impact on the burden we feel and others perceive, they will influence the quality of life that the disabled person and the carer will experience. If you have identified problems in any of these areas you can, with time and help, start to deal with their influence on your care giving ability.

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