

AN INTRODUCTION TO LONG-TERM CARE PROGRAMS AND SERVICES

Finding and keeping the balance of caregiving

Finding and keeping the balance in the caregiver / loved-one relationship is often a huge challenge. On the one hand, the loved-one's care needs may range from light to very heavy. These needs may change over time or quite suddenly. The family's and loved-one's ability to cope with a long-term illness may be tested.



On the other hand, the family caregiver brings to the relationship skills, abilities, time, energy, willingness to help, and knowledge of community resources. Caregivers often feel caught between the demands of caregiving and other family / work responsibilities. The caregiver has needs too, as well as a life.

Three Caregiving Scenarios:

- 1) **When the loved-one's care needs are modest:** Caregiving often starts out this way. Care may be limited to "light duty" such as preparing a meal or two, keeping the checkbook balanced, and doing the laundry. More often than not, care can be provided with relative ease and in a home setting. Without this care, though, the loved-one may not be able to remain in a home setting. With a little bit of help and by engaging the loved-one's abilities time and energy, independence living can be maintained. A sharing of responsibilities will maintain a healthy balance in the caregiving relationship.
- 2) **When the loved-one's care needs gradually become more demanding:** Both the caregiver and the loved-one may sense that sometime in the future the additional weight of caregiving may, in fact, challenge the limits of the caregiver's skills, ability, time, energy and even desire to provide the needed care. Believe it or not, a gradual increase in care demands may be considered by some as a gift, for it allows both the caregiver and loved-one time to anticipate needs, identify services, learn new skills and plan on how to regain the balance.
- 3) **When the loved-one's care needs increase suddenly or dramatically intensify:** Caregivers often begin the caregiver relationship in a state of shock. The stroke or a debilitating injury, for example, came out of the blue. When care-needs are intense, the caregiver may be unable or unwilling to provide care; often services need to be identified quickly. It may be necessary that the loved-one leave the home environment and move to a nursing home or adult family home. Whether the changes are gradual or dramatic, the weight of the loved-one's care-needs can become too burdensome leaving the caregiver feeling unsettled and overwhelmed...more so if the caregiver doesn't know how or where to seek help.

As the weight of caregiving increases, the caregiver is often challenged by the reality that care for the loved-one is not a short-term commitment. Facing a long-term commitment may mean s/he can no longer do it alone. Accepting help does not mean the caregiver has failed...as a parent, a spouse or a child. Please know that help is available.

One place to find help is from other family members, friends, neighbors, the faith community, volunteers, etc. This approach can be very supportive and cost effective.

In addition, help can be found for both the loved-one and the caregiver through a wide range of programs and services. “Long term care” is the name used to describe the group of programs and services listed below:

- Caregiver support (workshops, support groups, counseling, etc.)
- In-home care (cooking, cleaning, taking care of personal needs, etc.)
- Health care services (wound care, medication management, etc.)
- Nutrition programs (delivered to home, at a meal site, etc.)
- Day care programs (structured day programs at certified facilities)
- Day health programs (as above, but the facility can take care of health needs as well.)
- Respite care options (e.g. giving caregivers a break)
- Housing options
- Home maintenance / safety (minor home repair / modification, etc.)
- Residential care options (assisted living, adult family homes, etc. where care is provided by licensed and credentialed care providers)
- Legal services (advanced directives, living wills, etc.)
- Transportation
- Recreation and social activities
- Technology (emergency response devices, etc.)



How to pay for services is still another challenge. As caregivers identify programs and services, cost considerations often come to mind. In general, the range of costs varies from free, to inexpensive, to very expensive. As a rule of thumb, it is generally cheaper to keep the loved-one at “home” and find services that can be delivered to the home. Paying for services can be complicated. Sometimes the cost of long term care services are covered through insurance or via state / federal funding. For some local, state and federally funded programs, eligibility requirements become a factor and may be linked to income, assets or other financial factors. Age and/or the level of disability may also trigger financial support. Few long-term care services are covered under Medicare.

Where to go for help: In Snohomish County, call the Family Caregiver Resource Telephone Line at 425-290-1240, or, toll-free at 1-800-442-2024. Hearing impaired persons can use the TDD phone number: 425-347-7997.

Last words of advice:

- 1) Be open to and actively seek services.
- 2) Remain your loved-one’s advocate throughout the caregiver process.
- 3) Become politically active. If you are expecting these services to be there when you need them...register with the list-serve on www.snocare.org. Planned are regular program and legislative updates. Your involvement is the best insurance to a healthy and responsive long-term care system.