



David A. Paterson
Governor

Michael J. Burgess
Director

Unpaid caregivers: Their stories



Caregiving in New York State: *Family, friends and neighbors*

The New York State Office for the Aging (NYSOFA) and aging services network has a strong commitment to the millions of informal caregivers in New York State. These caregivers—family, friends and neighbors -- are providing a range of services such as transportation, financial assistance, housekeeping, personal care, and home repairs to older adults.

“You Care for Them, We Care For You”

The many faces of family and friends who provide informal care to loved ones:

- Just like any other expectant mother, she was filled with dreams and hopes. After her baby was born with multiple life threatening challenges, she knew her life would change more than she had imagined.....
- Her parents raised her, taught her many things, supported her through thick and thin. Now Dad's broken his hip and can't live on his own any longer. He gets more frail every day. Care for him....of coursehe's her father.
- With one phone call, suddenly, EVERYTHING changed. They had plans for retirement, looking forward to watching their grandchildren grow. And then the phone call - you're husband has been in an accident. She had to learn how to translate medical jargon, be optimistic and encouraging during the long rehabilitation process, and find a way to mask her own fears for the future. Sharing lessons learned in support groups.... helping to prepare for the next crisis while helping others who are just beginning to navigate through the maze of caring for themselves while caring for a loved one.
- They've been friends since high school, same fraternity in college. Enjoyed cheering for the same teams, helping each other climb the career ladder. Until the accident left one of them with a traumatic brain injury. They're still friends of course. Nothing will change that - but now one friend changes his buddy's clothes and linen, and.....needs help to help him.
- Three trips to the emergency room this year with a frail parent, 2 surgeries last year and more to come. Recovery, rehab, nursing home choices, balancing all that and working for a living, too. Some days caregivers don't have time to eat, let alone make sure Mother's getting the nutritious meals she needs.
- His wife and she meant it, for better or for worse. They've had good times and he has wonderful memories. Unfortunately she doesn't...it's Alzheimer's. She needed 24/7 care. He loved her and always will. But he needed help so he could be there for her. The first few years following diagnosis went reasonably well, with her being able to maintain a near normal life at home until memory loss and her ability to function normally required more care. Family and home aides were called to assist with her care. As a caregiver, her husband managed her medications, prepared meals with the assistance of Meals on Wheels deliveries, managed the

housework, provided transportation for appointments and social outings, and was with her as much as possible for companionship. For the last year at home she had home aides three days a week, including a full weekend day affording her husband welcome respite time. The local Office of Aging Expanded In-home Services for the Elderly Program provided financial assistance for the home aides and respite opportunities. With the exception of respite time, he was able to spend as much time as possible with her.

- Sometimes our kids have kids, but they are not able to be parents. Grandparents have had to step in and manage, just when they were thinking about how to manage their retirement years. PTA meetings, all nighters with a croopy baby, shopping for back to school clothes, new math, paying for it all. There's a lot of pleasure, but a lot of problems too. An extra set of hands and a day off once in awhile help to rejuvenate.
- This journey dramatically changed her life. She was forced to quit her job at a local hospital in order to take care of her granddaughter and apply for assistance through our local Department of Human Services. Two years later, she was making that same journey to pick up her grandson, who also was born premature and would have developmental disabilities. Her daughter was still using drugs. She was able to bring her daughter home, too, hoping that the change would help her to stay clean, but then she returned to her patterns of drug abuse. After the death of her daughter, she and the grandchildren received counseling to help them deal with their loss and grief.
- When her in-laws moved into her home, they changed the living room into a bedroom/sitting room so they wouldn't have to climb stairs. At first, the elderly couple was in reasonably good health, still were independent, driving themselves to appointments and going out for breakfast. At the end of two years, her mother-in-law began having health problems and needed personal care. She never employed outside help, since she was a female helping another female that she loved. But when her father-in-law became ill, she needed help in the home, knew she needed help finding a reliable aide.
- At an age generally associated with becoming independent and separating from family, she became in charge of her mother's life and near-death trauma. Being a young caregiver carries additional struggles as they work on their own personal growth and development while simultaneously caring for others who would typically be caring for them. She was 17 years old, a senior in high school with hopes of attending college away from home when her mother suffered a cerebral aneurysm rupture that left her in a coma for several months. She had no idea what was in store for her family or that she had instantly become a "young caregiver." The incredible amount of responsibility thrust upon her was daunting. Today, 12 years later, her mother is at home with her and joined by her 98 year-old grandmother. While the care they require changes with each illness and passing year, one thing remains reliable – the constancy and ongoing nature of the care and effort required to maintain them safely at home.

