The sandwich generation is a generation of people who are caring for their aging parents while supporting their own children. Social worker Dorothy Miller further defined this population in 1981 as "a segment of the middle-aged generation that provides support to both young and older family members yet does not receive reciprocal support in exchange."

As time has progressed since 1981, the work-life balance of the family has changed. In 1981, the primary caregiver was a woman in the age range of 30-40s who was a homemaker. Today, the caregivers are men and women in the age range of 35-65. With an increase in dual working families, the work-life balance has become more difficult. Other changes that contribute to the increase in sandwich generation include an increase in families delaying having children, lower birth rates, smaller families, advances in healthcare and an increase in life spans. In 1980, there were approximately 720,000 adults over the age of 90. In 2019, that number increased to 1.9 million; it is expected to grow to over 9 million by 2050.

SANDWICH GENERATION FACTS:

- **47 percent** of adults in their 40s-50s have a parent age 65 or older AND are either raising a young child or financially supporting a grown child.
- **15 percent** are providing financial support to both an aging parent AND a child.
- Among all adults with at least one parent age 65 or older, **30 percent** say their parent or parents need help to handle their affairs or care for themselves.

In the United States, the caregiving costs of the unpaid caregiver is $450 billion annually, with 65.7 million unpaid caregivers. Nearly 80 percent of the caregivers spend at least 23 hours a week caregiving. In addition to the care of the older generation, about 30 percent spend about 26 hours a week helping their children. In total, the sandwich generation caregivers spend about 1,350 hours a year helping their parents and children. ([Medicare.gov](https://www.medicare.gov))

CASE MANAGING THE SANDWICH GENERATION

Case managers need to have family-oriented skill sets with a multi-generational approach to include pediatrics to geriatrics and everything in between in order to manage the sandwich generation. The case manager must have an understanding of benefits, to include insurance, VA, and employer benefits. They must have a knowledge of resources that includes community, state and federal resources and programs.

The sandwich generation families may have a variety of care needs, ranging from a simple need of finding resources to having complex cases involving a disabled child or elder. The family assessment is an important tool in discovering the needs of the family unit and must be a multi-generational assessment.

A multi-generational assessment should include the following components:
- The family structure.
- Living situations — in home, independent or assisted living, outside
- The cultural and spiritual needs and support system
- Caregiver employment — single or dual working caregivers
- The physical and mental health of the family
- Benefits available
- The current treatment plan including medications, physicians, DME, services, transportation and resources.
- Medications — current medications
- The family’s financial situation is also an important component of the assessment
- Resources — that are being utilized and what are needed
- Legal — advance directives, durable, medical or behavioral power of attorneys, wills or trusts.

CAREGIVER’S CHALLENGES OF THE SANDWICH GENERATION

There are many challenges that the sandwich generation caregivers face. If asked, they feel like they are either being pulled apart or that they are being squeezed and can’t breathe. They have a difficult time balancing work, family and caregiving. The caregivers may struggle with finances, not have time for themselves and not know where to go for answers. The challenges of caring for an aging parent can cause emotional, mental, physical and financial strain. Caregivers have an increased risk of depression and other health issues. Side effects of caregiving include general burnout, fatigue, self-neglect, depression and family conflicts. This can be a time of chaos, adjusting to new and shifting family roles as children and parents age. The feelings of being overwhelmed, overloaded and exhausted from daily life, work and caregiving are not unusual. It is important that the caregiver know the warning signs of stress, which include anger, guilt, anxiety, irritability, weight loss, exhaustion, inability to concentrate and depression.

One of the greatest stressors for the caregiver is trying to find the balance between caregiving and work. Caregivers may find themselves late to work, requesting additional time off from work, declining promotions, having difficulty concentrating, fatigue, and social isolation. Employers are becoming more aware of the caregiving roles that their employees are having to take on. Communication is important between the employer and the employee. Employee caregivers are reluctant to talk to their employer about being a caregiver, afraid it may cost them their jobs. Having open communication can assist in reducing the stress and financial impact for both the employer and the caregiver employee. It is very important that caregivers know their company’s benefits and policies. These benefits can assist in reducing some of the stress the employee has. It becomes a win-win situation for both the employer and the employee. Employer benefits include but are not limited to the Family Medical Leave Act (FMLA), Employee Assistance Programs (EAP), modified work schedule, job share, work from home and caregiving paid time off.

FINANCIAL IMPACT OF CAREGIVING

The financial impact of caregiving can become an issue. The costs can seem small at first but can add up significantly in a short period of time. On average, a caregiver will spend up to $10,000 out of his or her own finances to cover costs. Some of these costs can include medical expenses, which consist of co-payments, MD visits, hospital costs, skilled and non-skilled care, DME and supplies and pharmacy, to name the most common costs. With additional members of the family, the cost of food and utilities will also increase. If a parent or child requires specialized equipment, that increases costs with modifications to the home or vehicle. Becoming a paid caregiver can offset some of the costs. Paid caregivers include:
• **Caregiver contracts** — assists when family members are providing care. Discuss care needs, wages, schedule, provided services, respite care and how other family members will assist with care.

• **Consult an eldercare lawyer** — this can assist with caregiving contracts, tax requirements or issues, advance directives, medical and financial powers of attorney and trust and inheritances.

• **Eldercare Dependent** — Consult with a financial planner or accountant. You may qualify for tax deductions for some of the caregiving cost. Each state can be different. Keep a journal, and file with all receipts and records for any out-of-pocket expenses. Specify services performed, dates and amount paid. This paperwork is essential if your family member later applies for Medicaid. During the qualification process, a caseworker will examine records for the last five years.

• **Caregiver Taxes** — remember to report all income from caregiving. As with every paid job, caregivers are legally required to report all wages as taxable income.

It is important to have a conversation with the parents, but it can be difficult. The conversation needs to be open, non-confrontational and non-judgmental. Ask about financial information including their current expenses and budget, insurance (Medicare, supplemental, Medicaid, VA, disability, long-term care). Do they receive any retirement income? Do they receive or qualify for any VA retirement or benefits? Prescriptions are an expense that needs to be discussed. What are they currently taking and what is the cost? It is important to assess where and how they are receiving their prescriptions. Is it the best pharmacy for the cost? Is it better to look at a 90-day supply vs. a 30-day supply?

**HAVING A PLAN!**

Being a caregiver is stressful. Having a plan and an organized file will reduce some of the stress. The following information should be kept:

- Address book with all of the providers, services, physicians, attorneys, financial information, DME providers, pharmacies or any services that are necessary. This is also a good place to also keep computer log-ins and passwords.
- Health history, both current and past.
- A daily health journal of physician visits, therapies or services, etc. This is a great resource to bring to the physician’s office. There is a lot that goes on in each day of caregiving. Keeping a journal can assist in remembering what has occurred.
- Insurance policies — policy numbers, contacts and benefits.
- Advances directives, living will, medical power of attorney, DNR and last will and testament.
- Financial information, the budget, bank account information.
- Safe or security box keys — location of box.
- Spiritual information including church, clergy, rabbi…

**CAREGIVER SELF-CARE**

Caregivers tend to take care of everyone else and leave themselves last. If they don’t take care of themselves, it can led to tension, resentment, anger, frustration and depression. Caregiver Syndrome is a state of physical, emotional, and mental exhaustion that may be accompanied by a change in attitude — from positive and caring to negative and unconcerned. Burnout can occur when caregivers don’t get the help they need, or if they try to do more than they are able — either physically, mentally or financially. Caregivers who are "burned out" can experience an increase in stress, fatigue or exhaustion, irritability, anxiety and depression. Caregivers may also experience feelings of guilt if they spend time on themselves rather than on their family members. It is important that caregivers take time out for themselves. Some of the ways for caregivers to take care of themselves include but are not limited to the following:
• **Taking Time Out:** Do something just for you. Find what you enjoy the most; it may be going to coffee or lunch with a friend, going to the movies, having some fun shopping, etc.

• **Exercise:** Physical activity can provide a positive and proactive outlet for stress and anxiety. Taking a walk, hiking, riding a bike, running, yoga or taking an exercise class can help to clear the mind and change your perspective.

• **Eat Right:** Eating a healthy diet and drinking plenty of fluids can assist in reducing the negative effects of stress.

• **Sleep:** Not getting enough sleep can increase stress levels and cause negative physical, emotional and behavioral effects. If you are having a difficult time getting enough sleep, try winding down prior to going to sleep, which could include writing in a journal, talking to someone or making a list for the next day.

• **Sense of Humor:** Keeping a sense of humor can help to reduce stress. It is OK and important to laugh. Laughter can help to reduce stress, lower blood pressure, increase oxygen levels, decrease cortisol levels and bring a positive aspect to stressors.

• **Give Yourself Permission:** Give yourself permission to feel angry, frustrated, stressed, exhausted or even resentful. These are normal feelings to have when you are feeling overwhelmed. Talk to someone you trust — a family member, friend, clergy or a therapist. Talking about it is a great outlet for letting go of some of these feelings.

## RESOURCES

Resources can help provide required services for the family. It is important to research resources from within the community, state and federal levels. These services can also assist to provide an increase in the quality of life and reduce stressors. Resources can be finding required DME and supplies, transportation, respite care and much more. Even a support group is a resource. There are support groups for disease management, health issues, elder and family care, caregiving, etc. Support groups can be located in churches, community centers, medical facilities and educational facilities. They assist in providing an outlet for emotional support and providing educational information.

"The sandwich generation families may have a variety of care needs, ranging from a simple need of finding resources to having complex cases involving a disabled child or elder. The family assessment is an important tool in discovering the needs of the family unit, and must be a multi-generational assessment."

Time-saving resources assist in providing extra time in the day for the caregiver. These resource could include online grocery shopping at local grocery stores, meal services such as Meals on Wheels, and respite care, and senior centers or adult day care can save time during the day.

If at a loss for resources, the internet is a good resource for finding and locating resources. Be sure to verify the source is a reliable resource.

Some examples include but are not limited to the following:

**AARP:** Prepare to Care: A Planning Guide For Families,
**A Place For Mom**
**Caregiver Action Network Toolbox:**
[Caregiver.org](http://Caregiver.org)
[Eldercare.gov](http://Eldercare.gov)
**National Academy of Elder Law Attorneys: NAELA**
**National Association of Professional Geriatric Care Managers**
YOU ARE NOT ALONE!

Remember you are not alone; there are over 65 million caregivers. There are many resources, educational information, guides and services that are available for the sandwich generation. Remember to assess the needs of the family, set realistic goals, get the services resources required and make sure the caregivers are taking care of themselves. One of the most important keys is communication. Keep the lines open, clear and positive.

Debra Bellitter, RN, MBA, CCM, has been in healthcare for 37 years with the past 28 years in case management. She believes case management of the multi-generational family is important. She can be reached at dlbellitter@cox.net.

Laura Bachrach RN, BSN, MSL, CCM, has over 35 years of healthcare experience holding leadership roles in many arenas, with the last 20 years in case management. She can be reached at shlockmark@msn.com.

REFERENCES

- https://www.cmbodyofknowledge.com/content/case-management-knowledge-2