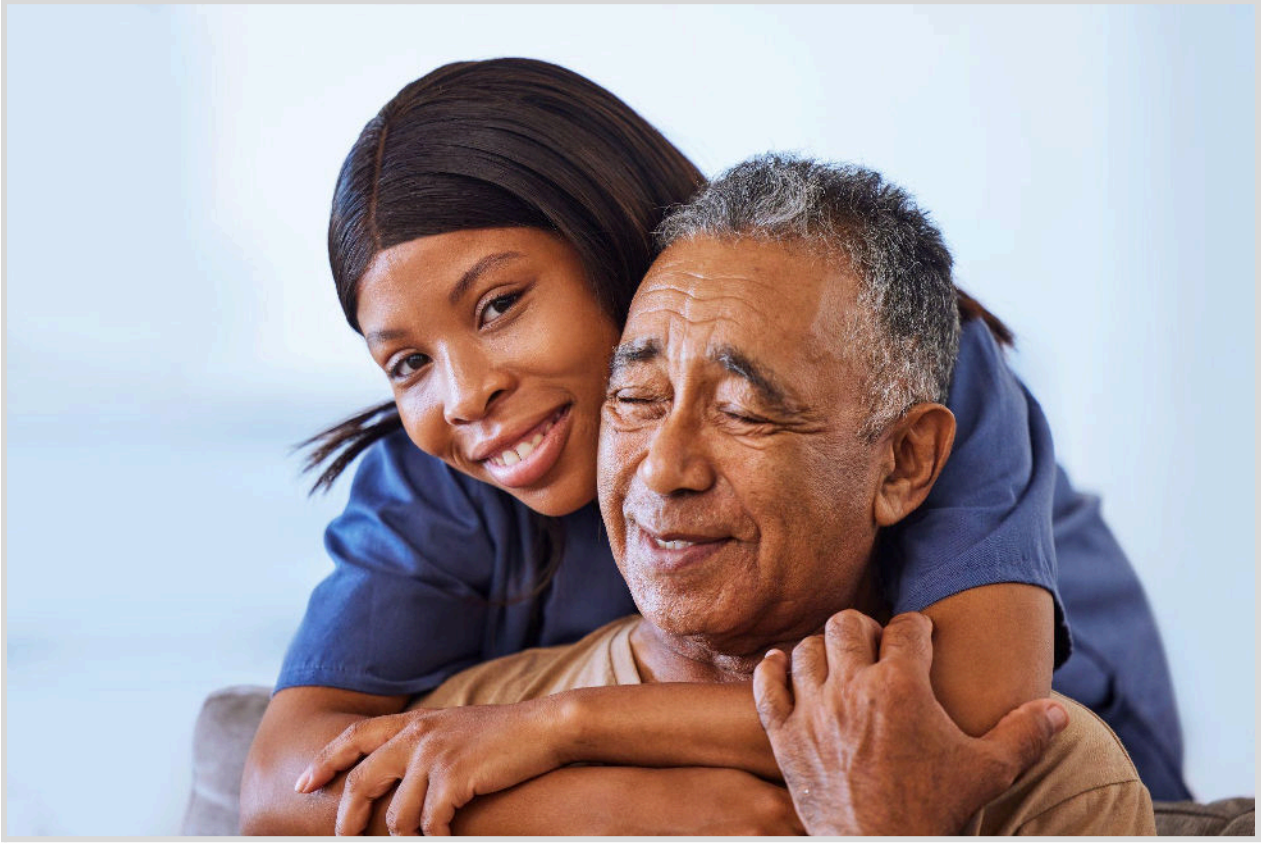
The Senior Alliance™

Caregiver's Guide:

Starting Your Caregiver Journey



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Introduction

*"There are only four kinds of people in the world: **those who have been caregivers**, those who are currently caregivers, those who will be caregivers, and those who will need caregivers."*

- Rosalyn Carter

Sometimes, the transition into caregiving unfolds slowly, with each day bringing you new responsibilities as your loved one's abilities shift. For some, however, the shift is abrupt, caused by an event that thrusts you into a role, where suddenly, you find yourself trying to manage everything. Regardless of how you arrive at caregiving, the journey can be overwhelming, filled with anxiety and challenges. Yet, it can also open doors to personal growth when enriched by support and the right information. This guide was crafted to accompany you as you traverse the nuanced and fulfilling journey of caring for someone dear to you. Whether you're navigating the initial adjustments, or have been in the caregiving role for a while, our goal is to equip you with a resource that addresses the diverse dimensions of caregiving.

Caregiving extends beyond simple tasks and responsibilities like picking up groceries and paying the bills; it encompasses a deep connection with another's life, health, and well-being. Recognizing this, our guide seeks to empower you with knowledge and insights to enhance your caregiving experience. From understanding the foundations of caregiving, assessing needs and planning care, to ensuring your wellness and effective communication, we cover a broad spectrum to prepare you for the challenges and joys of caregiving.

Caregiving is a journey marked by love, challenges, growth, and the profound satisfaction of providing support and comfort to someone in need. It's a role that may have chosen you, rather than one you chose for yourself. Yet, within it lies the opportunity to deepen relationships, develop resilience, and experience the full spectrum of human emotions.

As you embark or continue on this path, remember that you are not alone. This guide, along with the community of fellow caregivers and professionals it connects you to, will be your support network. Together, we will navigate the complexities of caregiving, celebrating the victories and facing the challenges head-on.

Am I a Caregiver?

If you're reading this guide, it's likely you're in the role of a caregiver, though you might not fully identify with that term yet. Many family and informal caregivers struggle to see their contributions as caregiving; to them, it's simply offering help.

Each family caregiver plays a distinct and pivotal role in their loved one's life, adapting to a broad spectrum of needs. On any given morning, a caregiver might be helping a parent with personal care tasks, ensuring their comfort and dignity with activities like bathing and dressing. Meanwhile, others may be immersed in the coordination of medical care, managing medications, and scheduling appointments - tasks that are particularly vital for relatives living with chronic illnesses such as cancer.

Mealtimes present an opportunity for caregivers to prepare and serve nutritious meals for those unable to cook for themselves, while mobility assistance is another critical area, aiding those who struggle with walking or require a wheelchair to move around safely both inside and outside their homes.

Beyond these personal care tasks, caregivers often take on a variety of household responsibilities, from cleaning to grocery shopping, and even managing finances, including bill payments and insurance matters. Emotional support is also a key component of caregiving, offering a listening ear, engaging in meaningful conversations, and providing companionship to combat loneliness and offer comfort.

While some caregivers are tasked with medical responsibilities like wound care or medication administration, it's essential to recognize that not all engage in these activities. The caregiving journey is unique for each individual, shaped by the specific needs of their loved ones. Regardless of their duties, caregivers embody a profound dedication and compassion, making an invaluable difference in the lives of those they support.

If you're regularly providing any form of help mentioned earlier to someone, you indeed are a caregiver. It's not necessary to fulfill every role listed to qualify as one. Caregiving exists on a spectrum, recognizing a wide variety of contributions and levels of involvement.

Caregiver Profile

Nearly one in five American Adults (53 million) are family or informal caregivers (AARP, 2020)

Caregiving is a role that defies the traditional image of an elderly spouse or adult child looking after an aging parent, presenting a far more complex reality that spans across ages, genders, and conventional family dynamics. Insights from the Family Caregiver Alliance and AARP shed light on the vast landscape of caregiving, highlighting the urgent need for more robust support systems.

The majority of caregivers, about 75%, are women who invest more time in caregiving roles compared to their male counterparts. The typical caregiver is around 49 years old, yet the demographic is broad, with nearly half under the age of 49 and a significant portion, a third, over 65. This diversity underscores the array of challenges that younger caregivers face, such as balancing career and family, and those encountered by older caregivers.

Caregivers come from various relationships beyond spouses and children, including friends, neighbors, and even grandchildren, stepping in to fill crucial support roles. Moreover, caregiving crosses racial and ethnic lines, with Hispanic individuals most likely to assume these responsibilities, followed by African-American and Asian-American populations. African-American caregivers, in particular, navigate complex scenarios, often providing care across generations and managing a host of daily tasks while working.

The LGBTQ+ community also plays a significant role in caregiving, with 9% identifying as LGBTQ+. As the number of LGBTQ+ seniors increases, the demand for culturally competent care grows, although male LGBTQ+ caregivers already report a higher caregiving burden. These individuals face additional concerns over financial stability, isolation, and healthcare access, compounded by fears of discrimination which can deter seeking necessary support.

Veteran caregivers represent a distinct group within the caregiving community, facing unique challenges. A vast majority, 96%, are women, often spending decades in their caregiving role, a commitment that exacts a profound emotional and physical toll. The challenges are particularly acute for those caring for post-9/11 veterans, who tend to be younger, employed, and responsible for veterans with complex health conditions, highlighting the pressing need for specialized support and acknowledgment of their sacrifices.

Caregiving tasks range from simple needs to complex healthcare. This commitment demands significant time – a burden that increases with the caregiver's age. Financially, over half of caregivers live in households with an annual income below $50,000, with minority caregivers especially impacted. Caregiving's impact reaches beyond finances – caregivers report high stress and emotional strain, worsening with increasing hours and task complexity. This can harm their health and frequently disrupt their work life, leading to missed days, reduced hours, or leaving the workforce altogether.

Nearly one in five American adults finds themselves in the role of a caregiver, a testament to the compassion and resilience that underpin our society. This diverse group, crossing various demographics, showcases the profound impact of caregiving. They provide indispensable support to aging parents, friends, neighbors, and veterans, frequently without the recognition or resources they deserve. Yet, their narratives are filled with strength, dedication, and love, highlighting the critical need for a more supportive environment. Recognizing the challenges and diversity within caregiving serves as a call to action for communities and policymakers to offer better support to these unsung heroes. By advocating for and enhancing support systems, we can ensure that caregivers' invaluable contributions are acknowledged and celebrated, fostering a more caring and inclusive society.

Assessment & Planning

Assessing Your Loved One’s Care Needs

One of the hardest parts of being a caregiver is knowing precisely what you need to do. Before you jump into trying to take care of every aspect of your loved one’s life, it's important to take a

moment to pause and assess. Your loved one may only need support with a few specific tasks rather than comprehensive care. To accurately determine your role, you must first understand what your loved one actually needs. The best way to know is to ask directly. However, if they are uncomfortable answering or don't know themselves, there are other methods you can employ to gain insights.

Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs) are two key concepts used to evaluate a person's level of functioning and the type of assistance they might require. ADLs are basic self-care tasks that include bathing, dressing, eating, transferring (moving from bed to chair and back), toileting, and continence. On the other hand, IADLs refer to more complex skills needed to live independently, such as managing finances, handling transportation, shopping for groceries, preparing meals, managing medication, and maintaining a household.

You can use the ADL and IADL assessments included in the JourneyMap binder as a starting point. These assessments are designed to help you identify the specific areas where your loved one may need support, making it easier to tailor your care approach to their individual needs. Once you have a clear understanding of what's needed, you can create a comprehensive care plan for your loved one. This plan should address their specific requirements and preferences, ensuring they receive the right level of support while also maintaining as much independence as possible.

A Note on Planning Ahead

In an ideal world, you'd have a caregiving plan ready before you ever need to step into the caregiver role. But often, life doesn't work that way. Sometimes, caregiving responsibilities come on suddenly, without warning. Other times, there might be signs pointing to the need for future caregiving, like a family history of Alzheimer's, an upcoming surgery, or the early stages of an illness or disability in a loved one. If you think you might need to become a caregiver soon, it's important to start discussions with your family early. This preparation can make the transition smoother for everyone involved.

If you're seeing signs that a loved one may need help and you're gearing up to discuss it, it's crucial to handle the conversation with sensitivity, avoiding judgment, and respecting their independence. For instance, if it seems like driving is becoming difficult for them, don't bluntly accuse them of being unsafe or threaten to revoke their license. This approach can hurt and strain your relationship. Instead, start the conversation from a place of concern and concern. You might say, "I noticed you seemed unsure at the stop sign earlier. Is everything okay with your vision or glasses? I'm worried about your safety." This method opens the door to genuine dialogue, rooted in empathy and support.

When your loved one is still able to make decisions, it's key to discuss their wishes for a time they might not be able to do so. This includes filling out a living will and advanced directives, and talking about their preferences for end-of-life care. If your loved one hesitates or resists these discussions, it's important not to pressure them. Understand that these topics can be even scarier for them than they are for you. Approach these crucial conversations gently and in stages. If

resistance persists, consider involving someone else they trust, like another family member, a close friend, or their religious leader, to help ease into the conversation.

Creating a Care Plan

Caring for someone requires understanding, compassion, and a structured plan to ensure their well-being and happiness. A personalized care plan acts as a roadmap to meet the unique needs and preferences of your loved one, enhancing their quality of life. Below are some steps you can follow when creating a care plan.

Step 1: Conduct a Needs Assessment

Begin by evaluating your loved one's ability to perform Activities of Daily Living (ADLs) and Independent Activities of Daily Living (IADLs). This assessment helps determine the level of support they require for tasks such as dressing, managing finances, and meal preparation. It is also a good idea to assess your loved one's living environment for safety risks, and plan necessary changes to prevent accidental injuries and falls. Documenting these needs clarifies the necessary assistance for family and friends, ensuring consistent care.

Step 2: Establish Care Goals

Set immediate and long-term goals focused on improving the care recipient's quality of life, maintaining their independence, and managing health conditions effectively. These objectives guide the care plan's direction and ensure all actions align with the desired outcomes.

Step 3: Identify a Support System

List family members, friends, and community resources that can offer additional support. This may include your local senior center, a transportation or meal service, along with anyone your loved one interacts with on a regular basis.

Step 4: Compile Personal Information

Gather basic information including the care recipient's name, birth date, contact details, and essential documents like birth certificates, social security cards, and any legal paperwork. This information is fundamental to the care plan, ensuring easy access to important documents.

Step 5: Document Health and Medical Information

Detail your loved one's medical history, current health conditions, treatments, medications, allergies, and healthcare providers. A comprehensive medical profile is crucial for managing their health and ensuring continuity of care. Include advanced directives to respect their healthcare wishes in situations where they cannot communicate their decisions.

Step 6: Outline a Schedule and Routine

Develop a schedule that includes daily or weekly routines, care activities, medical appointments, and other key tasks. A structured routine helps organize care effectively, ensuring no important activities are missed.

Step 7: Prepare for Emergencies
Create an emergency plan outlining steps for various scenarios, including medical emergencies, home evacuations, and backup caregiver arrangements. This preparation is essential for responding swiftly and effectively in crisis situations.

Step 8: Record Legal and Financial Information
Incorporate vital legal documents, such as power of attorney or advance directives, and information on insurance policies and financial resources available for care. This section ensures legal and financial matters are in order, supporting the care process.

Step 9: Acknowledge Preferences and Wishes
Consider the personal likes, dislikes, hobbies, and interests of your loved one to personalize the care plan. Incorporating these preferences respects their individuality and contributes to a higher quality of life.

Step 10: Review and Update Mechanism
Set up a process for regularly reviewing and updating the care plan to reflect any changes in the care recipient's condition or needs.

To get started on a care plan, check out TSA's Caregiver Journey Map, a customizable tool that enables you to create a care plan that's as unique as your caregiving journey. Utilizing the JourneyMap Binder for care planning ensures that caregivers have a structured and comprehensive approach to managing their loved one's care, with the flexibility to adapt the plan as their journey evolves.

A Note on End-of-Life Care

When it becomes clear that an illness cannot be cured, the focus of care shifts to providing comfort and making the most of the precious time your loved one has left. This final stage can vary in length depending on their condition. Palliative care focuses on managing pain and symptoms like nausea or difficulty breathing, ensuring your loved one is as comfortable as possible. Hospice care offers additional support – both emotional and spiritual – for the patient and their family throughout this difficult time.

Even the most experienced caregivers find the final stages of caring for a loved one incredibly difficult. Alongside the everyday care you provide, you may face complex choices and feel a mix of painful emotions – sadness, worry, frustration, or even a sense of relief and guilt. It's important to know these feelings are normal, and that you deserve abundant support during this challenging time. This support can look like practical help with caregiving tasks, managing arrangements, or finding resources to ease the burden. It should also include emotional support to help you process the powerful feelings that come with facing the loss of someone you love.

The final stages of care offer a time to connect deeply with your loved one – to mend relationships, express forgiveness, and share your love. While this period is undoubtedly filled with pain, these moments of saying goodbye can become a meaningful part of your journey. They can help you find peace as you begin to process your loss and move toward healing.

Caregiver Wellness & Communication

When you first become a caregiver, it's easy to feel swamped by the sudden increase in tasks and responsibilities. You might rush to absorb all the information you can and squeeze your new caregiving duties into every bit of free time. Initially, this might seem doable, and you may tell yourself, "I've got this under control." However, this approach isn't something you can keep up forever. Before you know it, you're spending nights awake, trying to plan out every moment of your day. This can lead to neglecting other parts of your life, whether it's your job, hobbies, or spending time with friends and family. The stress that seemed manageable at the start now feels overwhelming, pushing you towards burnout. Remember, it's too challenging to handle everything on your own, and seeking help is a wise and necessary step.

Challenges of Caregiving

Every day, millions across the globe dedicate themselves to supporting loved ones – aging parents, children with disabilities, or partners facing illness. While love fuels their actions, the path of caregiving is paved with unspoken challenges.

The emotional weight is perhaps the most profound. Caregivers pour boundless empathy into their roles, often placing their loved one's needs above their own. This selfless act, while beautiful, can lead to exhaustion, isolation, and even depression. Amidst their struggles, they may also grapple with guilt for feeling overwhelmed or saddened while witnessing their loved one's suffering. Caregiving demands navigating a storm of emotions, which can silently erode mental well-being if unaddressed.

The physical toll is equally relentless. Providing care can be physically demanding, particularly when it involves lifting or assisting with movement. This strain can lead to injuries or chronic pain, further complicating the caregiver's life. Those on-call 24/7, may struggle with inadequate rest, accelerating the path to burnout and their health concerns.

Caregiving often strains finances as well. Caregivers might reduce work hours or leave jobs entirely, causing income loss. Meanwhile, medical expenses and care supplies pile up. This financial pressure adds another layer of stress to an already burdened soul.

Yet, through all these challenges, caregivers persevere. This is proof of the resilience of the human spirit. Society must recognize their sacrifices and offer support: affordable healthcare, support groups, and financial aid. By acknowledging caregivers' struggles, we create a more compassionate environment that values their vital contribution.

As we walk alongside caregivers, let's extend support to those they care for and the caregivers themselves. With understanding and resources, caregivers can find balance and derive meaning from the love that guides them.

Getting Help

There are many resources available to help caregivers, such as:

Support Groups: Joining a caregiver support group can provide emotional solace and practical advice. Sharing experiences with those in similar situations can lessen feelings of isolation and provide coping strategies.

Respite Care: Respite services offer temporary relief to caregivers, allowing them time to rest and attend to personal matters. This can range from a few hours to several days, provided either in-home or in a facility.

Home Healthcare Services: These services can include medical care, therapy, and assistance with daily activities provided at home by healthcare professionals.

Financial Assistance: Various programs and organizations offer financial support to caregivers. This can include reimbursement for certain expenses, tax credits, and access to affordable medical supplies and medications.

Professional Advice: If the stress of caregiving becomes overwhelming, consulting with a doctor or mental health professional is vital. They can provide coping strategies, mental health support, and sometimes medication to manage stress and depression.

Additionally, exploring local and national caregiver organizations can provide access to a wealth of resources, including educational materials, legal advice, and advocacy. Websites and hotlines dedicated to caregiver support can also offer guidance and information tailored to specific conditions or situations.

Communicating With Your Loved One

Communicating with a loved one about their care needs is a delicate balance that requires empathy, respect, and a keen understanding of their individuality. It's not just about the practical aspects of caregiving but about engaging in a dialogue that honors their life experiences, preferences, and dignity. This journey of communication should be underpinned by a person-centered approach, emphasizing the individual's humanity over their condition and ensuring they remain an active participant in decisions regarding their care.

In conversations about care, it's beneficial to shift the narrative around aging from one of decline to a period rich with potential. Such a perspective encourages a focus on the strengths and capabilities of your loved one, fostering an environment where they feel valued and respected.

This approach not only empowers them but also reinforces the idea that aging is a natural, respected phase of life, full of opportunities for growth and connection.

Effective communication with a loved one, especially one facing cognitive decline, demands clarity, patience, and an open heart. The language we use should be straightforward and devoid of medical jargon, making it accessible and easy to grasp. Listening plays a crucial role here, requiring us to be fully present and attentive to both spoken words and the silent messages conveyed through body language and expressions. This level of engagement shows our loved ones that we genuinely value their thoughts and feelings.

Patience is particularly vital, as it allows our loved ones the time they need to articulate their thoughts and preferences, no matter how long it takes. In doing so, we affirm their autonomy and their right to have a say in their care. The choices we present should aim to enhance their sense of control and self-respect, even in small, everyday decisions.

The tone of our conversations can also significantly impact their well-being. By framing discussions positively and emphasizing adaptability and resilience, we can help our loved ones maintain a hopeful, engaged outlook on life. This positive framing extends to non-verbal communication as well; our gestures, facial expressions, and even our presence can offer comfort and reassurance.

Incorporating humor and lightness into our interactions can bring moments of joy and relief, reminding both of us that, despite the challenges, there is still room for laughter and happiness. This approach does not diminish the seriousness of caregiving but adds a layer of human connection and warmth, making the journey more bearable and fulfilling for both parties.

In essence, navigating the conversation about care with a loved one is an art that combines respect, empathy, and genuine dialogue. By adopting a person-centered approach, emphasizing the positive aspects of aging, and engaging in effective, compassionate communication, we can foster a supportive and understanding environment. This not only aids in the practical aspects of caregiving but also strengthens the emotional bond between caregiver and recipient, enriching the caregiving experience with dignity, love, and mutual respect.

Self-Care

Why Self-Care

Caregivers often pour so much energy into scheduling, planning, and caring for their loved ones that they sometimes forget a vital piece of advice: to take care of themselves first. This is similar to the guidance given during airplane safety briefings, where you're told to secure your own oxygen mask before helping others. This principle is crucial in caregiving too. If you don't look after your own health, you might find yourself unable to care for your loved one.

While caregivers excel at providing top-notch care for others, practicing self-care for themselves isn't always as straightforward. True self-care goes beyond enjoying a hot bath or treating yourself to extra desert. Self-care involves participating in activities that improve your life and support your physical and mental health.

Self-Care Tips

Here are some domains of self-care you should pay attention to:

Prioritize Your Health

Regular Check-ups: Keeping up with your medical appointments, screenings, and check-ups is crucial. It's the foundation that supports your ability to care for others.

Eat Well: While fast food may be convenient, a balanced diet rich in fruits, vegetables, lean proteins, and whole grains is essential for maintaining your energy and health.

Stay Active: Regular physical activity, even if it's just short walks, can boost your mood and energy levels, helping you provide the best care possible.

Mental and Emotional Wellbeing

Take Breaks: Regular short breaks can help reduce stress and rejuvenate you, making you more prepared for caregiving tasks.

Seek Support: Joining a caregiver support group, whether face-to-face or virtually, is like joining a convoy of fellow travelers on the caregiving journey. Get advice and backing from people who understand the terrain you're navigating.

Mindfulness and Relaxation: Practices like meditation, deep breathing, or yoga can calm your mind and reduce stress, helping you maintain emotional balance.

Time Management

Set Realistic Goals: Breaking down tasks into smaller, manageable steps and prioritizing them can help you manage your caregiving responsibilities more effectively.

Seek Help When Needed: Don't hesitate to ask for help from family, friends, or professional services. Sharing the load can make caregiving more manageable.

Engage in Activities You Enjoy

Hobbies and Interests: Making time for hobbies and activities that bring you joy is crucial for your well-being, acting as a necessary break from caregiving duties.

Stay Connected

Maintain Social Connections: Maintain connections with friends and family, much like a train staying on course through constant communication with the control station. These interactions are like stops along your journey where you can refuel with positive energy, ensuring your caregiving duties are carried out with a lighter heart and a stronger spirit.

Professional Counseling: If navigating the caregiving journey becomes particularly challenging, consider consulting a mental health professional. They can provide you with the tools and strategies to manage stress, depression, or anxiety, ensuring you can continue caregiving with better tools to handle the ups and downs.

Remember, taking care of yourself isn’t a luxury - it’s an essential part of being an effective caregiver. By implementing these self-care strategies, you can help ensure that you remain strong, healthy, and resilient on your caregiving journey.

The Caregiver Dictionary

A

Acute Condition: A sudden and severe health condition that requires immediate attention but typically is short-lived.

Activities of Daily Living (ADLs): Actions that a person must do by themselves to engage independently in everyday life, which include bathing, eating, dressing, mobility, transferring from bed to chair, and using the bathroom.

Administration on Aging (AOA): The federal agency that provides leadership and expertise on programs, advocacy, and initiatives affecting older adults and their caregivers and families.

Advance Directive: Prepared ahead of time, an advanced directive is a written document that outlines a person's preferences in situations where they are unable to make decisions themselves.

Adult Day Care: Community-based centers that provide companionship and assistance to older adults who need supervision during the day.

Adult Protective Services (APS): Services aimed at ensuring the safety and well-being of elders and adults with disabilities who are at risk of abuse, neglect, or exploitation.

Aging in Place: The ability to live in one's own home and community safely, independently, and comfortably, regardless of age, income, or ability level.

Alzheimer's Disease: A form of dementia that causes the brain to shrink (atrophy) and brain cells to die, leading to a continuous decline in thinking, behavioral and social skills.

Ambulatory: Able to walk; not bedridden or unable to walk.

Analgesic: A class of drugs designed to relieve pain without causing the loss of consciousness.

Area Agency on Aging (AAA) or Aging and Disability Resource Center (ADRC): An agency designated by the state with the responsibility for planning and coordinating services for older people or for older people and adults with disabilities within a specific geographical area. Both agencies provide information, resources, assistance and links to community services.

Assistive Technology Devices: Tools, equipment, and devices that assist individuals in performing functions that might otherwise be difficult or impossible. Low-tech assistive devices include canes and pill organizers; high-tech items include electric wheelchairs, hearing aids and smartphones.

Assisted Living Facility (ALF): Housing for those who may need help living independently but do not need skilled nursing care. The level of assistance varies among residences and may include help with bathing, dressing, meals and housekeeping.

B

Beneficiary: A person designated to receive benefits from a policy or plan.

Bereavement Support: Assistance and support provided to individuals experiencing grief following the death of a loved one.

Burnout: A state of physical, emotional, and mental exhaustion experienced by some caregivers, caused by prolonged stress.

C

Cardiologist: A doctor specialized in diagnosing and treating diseases of the heart and blood vessels.

Care Plan: A detailed plan developed to address the specific care needs of an individual.

Care Recipient: An individual who receives care from a caregiver.

Caregiver: A family member or paid helper who regularly looks after a child or a sick, elderly, or disabled person.

Chronic Condition: A condition that lasts one year or more and either requires ongoing medical attention or limits a person's ability to bathe, care for themselves, dress, eat or walk.

Cognitive Decline: Deterioration in memory, thinking, and understanding abilities.

Cohousing: A small planned community in which single-family homes, townhouses or rental units are clustered around amenities such as a community kitchen and dining room, common areas for sitting, craft and meeting rooms, gardens and potentially adult and child day care. The goal is to design a neighborhood where people of all ages and family statuses can rely on the informal, mutual support of neighbors to help out.

Comorbidity: The presence, or coexistence, of more than one disorder in the same person. They can occur at the same time or one after another. Interactions between diseases can worsen the course of both.

Competence: A person's ability to understand information, make a choice based on that information and communicate that decision in an understandable way.

Conservatorship: A person whom a court appoints to handle someone's affairs when that person cannot do the job. Usually, a conservator handles only finances.

Consumer-Directed Personal Assistance Program: A Medicaid program available in several states that permits chronically ill and physically disabled people to choose, train and supervise workers who help them with activities of daily living such as bathing, light housework and meal preparation so they can remain in their homes. Some relatives and friends of participants can qualify to be paid through this program.

Continuing Care Retirement Community (CCRC): A retirement community that offers a broad range of services and levels of care based on what each resident needs over time. Sometimes called "life care," it can range from independent living in an apartment to assisted living to full-time care in a nursing home.

Community Meal Program: Programs that provide meals to seniors in a communal setting.

Continence: The ability to maintain control of bowel and bladder function. Or, when unable to maintain control of these functions, the ability to perform associated personal hygiene (including caring for catheter or colostomy bag).

Copayment: The specified portion that Medicare, health insurance, or a service program may require a person to pay toward his or her medical bills or services.

Custodial Care: Non medical care that helps individuals with bathing, dressing and other basic care that most people do themselves, such as using eye drops. It can occur in a range of environments including adult day care, assisted living centers and residential care facilities.

D

Delirium: Short-term or sudden confused thinking and disrupted attention usually accompanied by disordered speech and hallucinations.

Dementia: An umbrella term for a decline in mental ability severe enough to interfere with daily life. Memory loss is an example. Alzheimer's disease is the most common cause of dementia, but not all dementia comes from Alzheimer's.

Dermatologist: A medical doctor who specializes in treating skin, hair, nail, and mucous membrane disorders.

Discharge Planner: A professional who assists patients and their families in developing a method of care for a patient following a hospital or nursing home stay.

Do Not Resuscitate Order (DNR): A type of advance directive in which a person states that health care providers should not attempt to restart the heart through CPR if they stop breathing or their heart stops beating.

Durable Medical Equipment (DME): Equipment and supplies ordered by a health care provider for everyday or extended use, including walkers, wheelchairs, and hospital beds.

Durable Power of Attorney: A legal document that gives someone you choose the authority to act financially, legally and medically in your place if you become incapacitated and unable to handle matters on your own. It remains in effect until the person who grants it either cancels it or dies.

E

Employee Assistance Program (EAP): Work-based intervention programs designed to identify and assist employees in resolving personal problems (e.g., marital, financial, or emotional problems; family issues; substance/alcohol abuse) that may affect their work performance.

End-of-Life Care: Care to patients approaching the end of life that is focused on comfort, respect for decisions, support for the family, and treatments to help psychological and spiritual concerns.

End-of-Life Doula: An individual who provides nonmedical comfort and support to a dying person and their family. This may include education and guidance and emotional, spiritual or practical care.

Endocrinologist: A physician specializing in hormonal and metabolic disorders, including diabetes.

Entitlement: A government program guaranteeing access to benefits by members of a specific group and based on established rights or by legislation.

Estate Planning: The process of arranging who will receive your assets and handle your responsibilities after your death or incapacitation.

F

Family Medical Leave Act (FMLA): A federal labor law that provides certain employees with up to 12 weeks per year of unpaid, job-protected leave to accommodate some family and medical situations. The law also requires that employees' group health benefits be maintained during the leave.

Family or Informal Caregiver: Any relative, partner, friend or neighbor who has a significant personal relationship with and provides a broad range of assistance for an adult with a chronic or disabling condition.

Febrile: Pertaining to or characterized by an elevated body temperature or fever.

Financial Power of Attorney: A legal document granting someone authority to act on another's behalf in financial affairs.

G

Gastroenterologist: A physician specializing in indigestion.

Geriatric Care Manager: A specialist who assesses a person's mental, physical, environmental and financial conditions to create a care plan to assist in arranging housing, medical, social and other services.

Geriatrician: A medical doctor who has completed a residency in either family medicine or internal medicine and focuses on older adults.

Gerontologist: A professional who studies the aging process and the problems older people might face.

Guardianship: A legal process by which a court appoints an individual to make decisions for someone who is unable to make decisions for themselves due to mental or physical incapacity.

H

Health Care Power of Attorney (HCPA Health Care Proxy): A type of durable power of attorney in which people appoint another person to make healthcare decisions for them if they become unable to do so.

Health Insurance Portability and Accountability Act (HIPAA): A federal law that provides privacy standards to protect patients' medical records and other health information provided to health plans, doctors, hospitals, and other health care providers.

Hematologist: A medical specialist who focuses on researching, diagnosing, treating, and preventing diseases related to the blood.

Home Health Agency: A company or nonprofit, often certified by Medicare, that provides health-related services such as nursing, personal care, social work, or occupational, physical or speech therapy in a client's home.

Home Health Aide (HHA): A trained and certified health care worker who assists a patient in the home. Duties typically include help with hygiene and exercise, light household work such as meal preparation, and monitoring the patient's condition.

Homemaker Services: Support services in a patient's home, such as cleaning, cooking, and running errands, to help maintain an independent living environment.

Hospice Care: A treatment regime for people who have an advanced, life-limiting, often incurable illness. Considered a type of palliative care, hospice focuses on the patient's psychological well-being and on managing symptoms of a disease rather than the disease itself, so they can spend their last days with dignity and quality, surrounded by loved ones.

Hypertension: A condition where blood pressure in the arteries is persistently elevated, often leading to serious health problems.

I

Incontinence: Inability of a person's body to control bowel or bladder functions.

Independent Living: An age-restricted option for a house, condominium or apartment — sometimes offered as part of a continuing care retirement community — that has few services as part of the basic rate. Those that are included are more often related to convenience, such as grass cutting or a clubhouse.

Informed Consent: The process of making decisions about medical care or medical experimentation based on open and honest communication among the health care provider, the patient and the patient's family.

Instrumental Activities of Daily Living (IADLs): Activities related to independent living, including preparing meals, managing money, shopping for groceries or personal items, performing light or heavy housework, and managing medication.

International Units (IU): A unit of measurement for the amount of a substance, based on measured biological activity or effect.

L

Licensed Practical Nurse (LPN): A person who has completed nursing or vocational training and obtained a state license that authorizes the person to take care of basic duties in settings such as hospitals, nursing homes and long-term care facilities.

Living Will: A legal document in which the signer requests to be allowed to die rather than be kept alive by artificial means if disabled beyond a reasonable expectation of recovery.

Long-Term Care Insurance: Insurance policies designed to cover the cost of long-term care services, including services in your home, in the community, or in assisted living or nursing home facilities.

Long-Term Care Ombudsman: An advocate for residents of nursing homes, board and care homes, assisted living facilities, and similar adult care facilities who works to resolve problems between residents and the facilities.

M

Meals on Wheels: A service that delivers daily hot meals to the homes of elderly or disabled people.

Medicaid: Government-provided health care coverage for eligible low-income adults, children, pregnant women, elderly adults and people with disabilities. States and the U.S. government share the cost of Medicaid, with states administering the program according to federal requirements.

Medical Doctor: A health care professional who has graduated from an approved medical school, received additional training in a hospital, passed a federal medical licensing exam and qualified for a state license. Specialists must complete an additional three to nine years of postgraduate work in their practice area.

Medicare: A federal government program that provides medical insurance if you are 65 or older, under 65 and receiving Social Security Disability Insurance, or under 65 and diagnosed with end-stage renal disease (ESRD). Medicare Part A is hospital insurance, and Medicare Part B covers certain doctors' services, outpatient care, medical supplies and preventive services.

Medicare Advantage (Part C): A type of Medicare health plan offered by a private company that contracts with Medicare to provide all your Part A and Part B benefits.

Medicare Savings Program: A federally funded, state-administered program that helps people with limited income and resources pay some or all of their Medicare premiums, deductibles, copayments and coinsurance. Four types of MSP are available:

1. Qualified Medicare Beneficiary (QMB) for people also enrolled in Medicaid.
2. Specified Low-Income Medicare Beneficiary (SLMB), which helps pay for Part B premiums only.
3. Qualifying Individual programs (QI and QI-1), which have slightly higher income limits but still help pay for Part B only,
4. Qualified Disabled & Working Individuals (QDWI), which helps pay for Part A premiums.

Medicare Telehealth Services: Medicare covered visits that allow patients to interact with healthcare providers via telecommunication technologies for healthcare services, consultation, or information.

Medigap: Medicare Supplement Insurance that helps fill "gaps" in Original Medicare and is sold by private companies.

Memory Cafe: A gathering place that provides a safe and supportive environment where individuals with dementia or other brain disorders and their caregivers can socialize, provide mutual support and exchange information.

Memory Care Communities: Separate facilities or specialized units of an assisted living center that focus on helping people with Alzheimer's disease and other forms of dementia, where the staff is specifically trained to deal with recall problems and other impairments.

N

Nephrologist: A physician who specializes in the diagnosis and treatment of kidney diseases.

Neurologist: A physician specializing in the diagnosis and treatment of nervous system disorders, including diseases of the brain, spinal cord, nerves, and muscles.

Nursing Home: A public or private residential facility providing a high level of long-term personal or medical care for chronically ill, disabled and older people who are unable to care for themselves properly.

O

Oncologist: A physician who specializes in diagnosing and treating cancer.

Ophthalmology: The branch of medicine that deals with the anatomy, physiology, and diseases of the eyeball and orbit.

Orthopedic Surgeon: A physician specializing in bone and connective tissue disorders.

Osteopath (DO): A doctor who has completed four years of medical school and has had 300 to 500 additional hours in the study of hands-on manual medicine and the body's musculoskeletal system. These doctors are state licensed and may have completed a two- to six-year residency and passed state examinations to become board certified.

Otolaryngologist: A physician specializing in ear, nose and throat (ENT) problems.

Outpatient Care: Also called ambulatory care. Health care procedures and treatment that do not require overnight hospitalization.

P

Palliative Care: Specialized medical care that focuses on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family. Unlike hospice care, which is typically given to people with terminal conditions who are nearing the end of life, palliative care can coincide with treatments to arrest or cure a disease.

Patient Advocate: A professional who can resolve concerns about someone's health care experience, particularly problems that cannot be taken care of immediately.

Personal Care Services (PCS): A broad term used to refer to help with personal hygiene and other self-care, such as bathing, dressing, eating, going to the bathroom, maintaining personal appearance and walking, provided by in-home personal care aides (PCAs). Some PCAs also help with meal preparation, grocery shopping and money management.

Personal Emergency Response System (PERS): Also known as a medical alert system. An alarm system that lets someone experiencing a medical or personal emergency such as a fall summon help. Traditional systems are triggered by the user pressing a button on a wearable device like a bracelet, sending a radio signal to a console connected to a phone, which calls an emergency response center. In recent years, some smartphones and other connected devices like smartwatches have incorporated medical alert functions.

Physician Assistant (PA): A licensed healthcare professional who practices medicine under the supervision of physicians and surgeons, capable of diagnosing and treating patients.

Podiatrist (DPM): A medical doctor specializing in diagnosing and treating conditions of the foot, ankle, and related structures of the leg.

Preferred Provider Organization (PPO): A type of health plan that contracts with medical providers, such as hospitals and doctors, to create a network of participating providers. You pay less if you use providers that belong to the plan’s network.

Primary Care Physician (PCP): The doctor that you see first for checkups and health problems. Sometimes these health care professionals have family practices for all ages; others specialize in internal medicine for adults or pediatrics for children.

Prognosis: A prediction of the probable course of a disease in an individual and the chances of recovery.

Psychiatrist: A physician specializing in emotional and mental disorders.

Psychologist: A specialist, but not a medical doctor, who can talk with patients and their families about emotional and personal matters and can help them make decisions.

R

Radiologist: A medical doctor who specializes in X-rays and related procedures such as computed tomography (CT) scans, magnetic resonance imaging (MRI) and ultrasound tests.

Registered Nurse (RN): A health professional who has graduated from a nursing program, passed a state board examination and has a state license.

Rehabilitation Hospital: A specialized hospital dedicated to the rehabilitation of patients with various neurological, musculoskeletal, orthopedic, and other medical conditions following stabilization of their acute medical issues.

Remote Patient Monitoring (RPM): The use of digital technologies to monitor and capture medical and other health data from patients in one location and electronically transmit that information securely to health care providers in a different location for assessment and recommendations.

Respite Care: Short-term or temporary care of a sick, disabled or older person for a few hours, days or weeks, designed to provide relief to the regular caregiver.

Rheumatologist: A medical doctor who specializes in pain and other symptoms related to joints and other parts of the musculoskeletal system, such as bones, cartilage, ligaments, muscles and tendons.

S

Senior Center: A community facility dedicated to providing a variety of services and activities geared towards older adults, designed to encourage engagement and socialization.

Senility: Popularized layman's term used by doctors and the public alike to categorize the mental deterioration that may occur with aging.

Sentinel Event: A Patient Safety Event that results in death, permanent harm, or severe temporary harm and intervention required to sustain life.

Self Care: Activities and practices that individuals engage in on their own to maintain health and well-being.

Skilled Care: Nursing or rehabilitation services that a doctor orders and that licensed health professionals such as nurses and physical therapists provide.

Social Security: The U.S. government's social insurance program, providing monthly benefit payments to retired workers age 62 and older; their spouses (or ex-spouses), children and survivors; and people with disabilities that prevent them from working for an extended period. The system is funded by payroll tax contributions workers make throughout their careers, with monthly benefit amounts determined primarily by their lifetime earnings history.

Social Security Disability Insurance (SSDI): Monthly benefit payments to people below retirement age with a significant illness or impairment that prevents them from working for at least a year or is expected to result in death. Eligibility is based on past work in which the person paid Social Security taxes and is reviewed periodically to make sure the disability continues to restrict them from working.

Sundowning: A state of confusion that occurs later in the afternoon and into the night. It is most often found in patients who have dementia or Alzheimer's disease and includes a range of behaviors such as increased confusion, anxiety, agitation and sleeplessness.

Supplemental Security Income (SSI): A program the Social Security Administration oversees that pays monthly benefits to people with limited income and resources who are disabled, blind, or age 65 or older.

Support Group: A group of people with common experiences or concerns who provide each other with encouragement, comfort, and advice.

Surrogate: An individual appointed to act in place of another.

Spend Down: The process of reducing personal assets to qualify for Medicaid.

T

Terminal: A disease or condition that is expected to cause death.

Third Party Payment: Payment for care that is made by someone other than the patient or his/her family (for example, Medicare or a private insurance company).

U

Urologist: A physician specializing in disorders of the male reproductive system and the male and female urinary tract.

V

Vertigo: A condition marked by dizziness and a feeling that either the individual or the surroundings are spinning.

Vital Signs: Clinical measurements, specifically pulse rate, temperature, respiration rate, and blood pressure, that indicate the state of a patient's essential body functions.

References

Caregiver's Glossary for Commonly Used Caregiving Terms. (n.d.). AARP. https://www.aarp.org/caregiving/basics/info-2019/caregiver-glossary.html

Governor's Office of Elderly Affairs. Commonly Used Caregiving Terms. (n.d.). https://www.goea.louisiana.gov/resources/caregiver-resources/commonly-used-caregiving-terms/

AARP Guide to Caregiving. AARP Family Caregiving Guide. (n.d.). https://www.aarp.org/content/dam/aarp/home-and-family/caregiving/2013-02/AARP%20Guide%20to%20Caregiving.pdf

Resources

Service Network Resource Guide

For many, the caregiving journey represents one of the most challenging yet intrinsically rewarding experiences of their lives, one only truly understood by those who have walked the path themselves. Stepping into a caregiving role for the first time might feel like an overwhelming mix of new responsibilities and emotions, leaving you unsure of where to start. Know you are not alone. No matter where you are in your caregiving journey—just starting, taking care of someone at home or from afar, or dealing with end-of-life care—finding the right help can make things easier.

The Senior Alliance has developed this Resource Guide to offer family and informal caregivers a starting point for discovering the help and services available to simplify the caregiving role. whether you're just beginning or looking to enhance your current experience, ensuring a smoother journey ahead. For more resources, please visit The Senior Alliance Resource Directory online at https://thesenioralliance.org/resources/

Contact TSA for additional information about network services and other community programs.

Contact Information

The Senior Alliance, Area Agency on Aging 1-C
5454 Venoy Road, Wayne, Michigan 48184

Website: www.thesenioralliance.org
Phone: 800-815-1112
Fax: 734-722-2830
Email: info@thesenioralliance.org

Advocacy & Information

Elder Abuse Services: This service provides public education, outreach, and referrals with respect to the prevention of abuse, neglect, and exploitation of older adults.

Neighborhood Legal Services-Elder Law & Advocacy Center
313-937-8291

Legal Assistance: Provides free legal advice and counseling on issues such as guardianship, power of attorney, age discrimination, entitlements, etc. to individuals age 60 and older, their caregivers, and those aged 55 and over who are kinship caregivers for a child no more than 18 years old. No fee generating or criminal cases are handled.

Neighborhood Legal Services-Elder Law & Advocacy Center
313-937-8291

Long Term Care Ombudsman: Provides assistance and advocacy for families and residents of nursing homes, homes for the aged and adult foster care homes. The Long Term Care Ombudsman assists residents in understanding rights, resolving concerns, and provides community education regarding long term care issues.

Statewide Phone Number
313-937-8291

Medicare/Medicaid: The Medicare Assistance Program (MMAP) is Michigan's State Health Insurance Assistance Program (SHIP). MMAP volunteer counselors are trained and certified in Medicare and Medicaid Insurance Programs. Counselors provide education and free unbiased personalized health benefit information. Our counselors meet face to face, on the telephone and virtually with Medicare beneficiaries in the community. Call our office to schedule an appointment or to find out where they will be in the community this month.

MMAP Hotline
800-803-7174

Health & Wellness

Evidence Based Disease Prevention: Evidence-Based Disease Prevention Programs help individuals age 60 and older to increase their activity levels. The courses offered have demonstrated proven results for participants. Programs have the same content regardless of location.

Arthritis Exercise Program: This program offers low-impact exercises, that can be done either sitting or standing, to help relieve stiffness/pain and to build strength/stamina. The class was developed by physical therapists specifically for individuals with arthritis or related conditions.

Garden City Senior Adult Services
734-793-1856

Sumpter Township Senior Center
734-461-9373

Van Buren Township Senior Center
734-699-8918

Arthritis Tai Chi Program: This program brings the gentle, graceful, flowing power of sunstyle tai chi to the community. This joint-friendly exercise program will both relax and increase mental and physical energy.

Garden City Senior Adult Services
734-793-1856

Redford Township Senior Services
313-387-2788

Van Buren Township Senior Center
734-699-8918

Enhance Fitness Program: Enhance Fitness Program focuses on stretching, flexibility, balance, low impact aerobics, and strength training exercises.

National Kidney Foundation of Michigan
800-482-1455

National Diabetes Prevention Program: A program designed to show participants how lifestyle changes can reduce their risk for type 2 diabetes. Participants work with a lifestyle coach in a group setting over a period of 12 months.

Beaumont Health
800-633-7377

PATH (Personal Action Toward Health) Chronic Disease Self-Management Classes: Designed to help individuals manage their chronic conditions. The class is held over a six-week period, and each session lasts 2½ hours. The workshop has a wide range of activities and skill building exercises that help the participant learn to communicate with their medical provider, make better food choices and become more active.

National Kidney Foundation of Michigan
800-482-1455

Diabetes PATH Classes: Learn skills needed in day-to-day management of diabetes and to maintain and/or increase life's activities.

National Kidney Foundation of Michigan
800-482-1455

Friendly Reassurance: This program offers regular telephone contacts with homebound individuals age 60 and older to assure their well-being, safety and provide social interaction.

734-722-2830

Programs & Services

Adult Day Care: Adult Day Programs provide care and supervision for functionally impaired individuals age 60 and older in a secure community setting. Services may include social and recreational activities and assistance with daily living skills.

Woodhaven Retirement Community
734-261-9000

Engaging Adults in Interaction Adult Day Services
313-291-2713

Caregiver Education, Support and Training: Dementia specific education workshops, caregiver support groups, information and referral services, and care consultation service for dementia caregivers. Focus on serving Arab American communities along with other persons in need. Services can be provided virtually or in person. Goal is to help participants seek dementia diagnosis, access interventions early on, and better plan for the future.

Alzheimer's Association Michigan Chapter
800-272-3900

Caregiver Support: Offers free legal assistance to caregivers of individuals age 60 and older.

Neighborhood Legal Services-Elder Law & Advocacy Center Caregiver Legal Assistance
313-937-8291

Care Management: Care Management is designed to provide support and link services to individuals age 60 and older who have complex needs and are at risk of nursing home placement. The program includes an in-home assessment by a registered nurse and social worker, followed by arrangements for service delivery.

734-722-2830

Case Coordination and Support: The Case Coordination and Support program assesses an individual's needs and provides linkage and supports for community resources for individuals age 60 and older.

734-722-2830

Congregate Meals: Individuals age 60 and older can get a hot lunch during the week at any of the 41 community lunch sites. The meals provide at least one-third of the Recommended Dietary Allowance (RDA). Reservations must be made.

Call TSA or Wayne County Senior Services for a nearby site.

Wayne County Senior Services
800-851-1454

Home Delivered Meals: Homebound individuals age 60 and older can receive a hot meal delivered to them Monday-Friday. The meals provide one-third of the Recommended Daily Allowance (RDA). Liquid meals are also available.

Wayne County Senior Services
800-851-1454

Halal Home Delivered Meals: Homebound Muslim individuals age 60 and older can receive a hot meal delivered to them Monday-Friday. An Arabic speaking specialist is available to answer questions.

Wayne County Senior Services
800-851-1454

Holiday Meals: This program provides a hot meal to homebound individuals age 60 and older and adults with disabilities on Thanksgiving, Christmas Day and Easter. The Holiday Meals Program is supported primarily through private donations. Meals are delivered by volunteers.

734-722-2830

Hearken: Hearken is a program that combats social isolation among older adults age 60 and over by building sustainable connections. A holistic approach is used to evaluate needs and address barriers in order to provide person-centered resources and interventions that allow for improved physical, mental and emotional health.

734-516-1767

Information & Assistance: Information and Assistance (I&A) is the first point of contact for individuals calling TSA. Information Specialists provide information and referrals to assist older adults, caregivers and individuals with disabilities with their questions and concerns. Referrals include, but are not limited to:

Transportation	Legal Assistance
Home Healthcare Services	Caregiver Support
Nutrition Programs	Health Promotion Programs
Housing Options	Long Term Care Options

734-722-2830

MI Choice Waiver Program: MI Choice Waiver is a Medicaid home and community-based long-term care program for individuals age 18 and older who meet the following eligibility requirements: financial, medical, and the need for supports coordination and at least one other ongoing MI Choice Waiver service.

Available services include personal care, respite care, homemaking, private duty nursing and many other services to support people in staying in their own homes.

The 2024 individual income limit is $2,829* per month and countable assets of $2,000 or less. Spousal impoverishment rules apply when only one spouse is applying for the program. *Income eligibility changes annually and is calculated at 300% of SSI

To make a referral for yourself or on the behalf of someone else, please, call 800-815-1112, or complete the online MI Choice Medicaid Waiver Referral Form located at: https://theseniorallliance.org/waiver

Program is funded by Michigan Department of Health and Human Services

Nursing Facility Transition: Nursing Facility Transition Services are available to residents of nursing facilities, who meet functional and financial guidelines, and would like to return to their own home, move in with family members, find an apartment, or choose another community based housing option.

Available services include, Support Coordination, establishing or re-establishing housing, and addressing any other barriers that will lead to a successful transition to the community.

An individual must be eligible for Medicaid while in the nursing facility to be eligible for this program.

To make a referral for yourself or on the behalf of someone else, please call **734-722-2830**

Senior Community Service Employment Program: Offers subsidized part-time training opportunities for low-income individuals aged 55 and older to help them become job ready. Participants in the program are placed at different community sites and work/train an average of 18 hours a week. The Senior Community Service Employment Program (SCSEP) is funded by a grant from the Department of Labor. The Department of Labor is not responsible for the program description in this booklet.

800-815-1112

Transportation Services: Most communities have some form of public transportation for seniors and individuals with disabilities. Services are limited to the residents of each community. Contact TSA for additional community specific transportation options.

This program offers limited transportation for individuals age 60 and older who live in the TSA service area, and also for their caregivers. The Senior Alliance cannot provide transportation on a continuous basis but will fill urgent needs when no other options are available. There is no charge for the service, though donations are accepted.

734-722-2830

TSA Planning & Service Area Information: Funding for agency services is provided by the Aging and Adult Services Agency, Michigan Department of Health and Human Services, Veterans Administration, foundations and fundraising.

The agency is governed by a Board of Directors which receives recommendations on senior issues from an Advisory Council. Each Area Agency on Aging (AAA) can offer information and assistance to older adults and individuals with disabilities specific to their region.

Information about AAA services nationwide can be obtained by calling the Eldercare Locator at **1-800-677-1116** or by visiting their website at https://eldercare.acl.gov.