

The Caregivers

“There are only four kinds of people in this world:
Those who have been caregivers;
Those who are currently caregivers.
Those who will be caregivers; and
Those who will need caregivers.”

Rosalynn Carter
Former First Lady





Unpaid family caregiving is an activity that knows no bounds, it cuts across all ages, genders, race/ethnicities, and types of relationships.



Who is a Caregiver?

- While some in need of caregiving receive care from paid (or formal) caregivers, most rely on unpaid assistance from family, friends and neighbors.
- Caregivers, whether paid or unpaid, manage a wide range of responsibilities.
- Caregivers may be full or part-time.
- Caregivers may live with their loved one or provide care from a distance.

Characteristics of a Caregiver

PCERPAT



Characteristics of a Caregiver

PASSION. Caregivers must be passionate about providing the best compassionate care for their patient. There is usually an intense desire and strong love involved in informal caregiving.




Characteristics of a Caregiver

PATIENCE. Being patient means that the person understands that there may be changes in plans, things may not go as quickly as planned, and there may be a little hesitation at times on the part of the person receiving care.



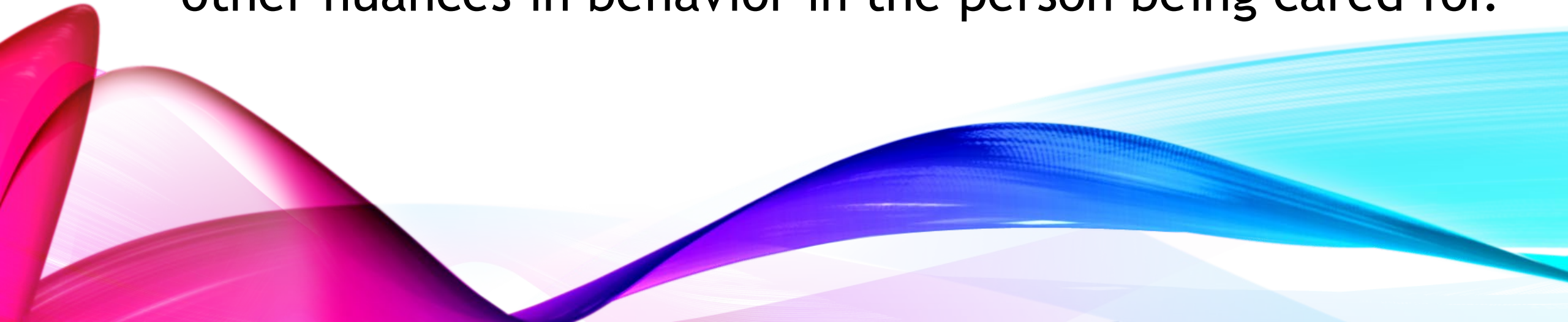
Characteristics of a Caregiver

EMPATHY. When someone has empathy for another person they have an understanding of what the person is going through. They may not identify with the situation, but certainly with their feelings.



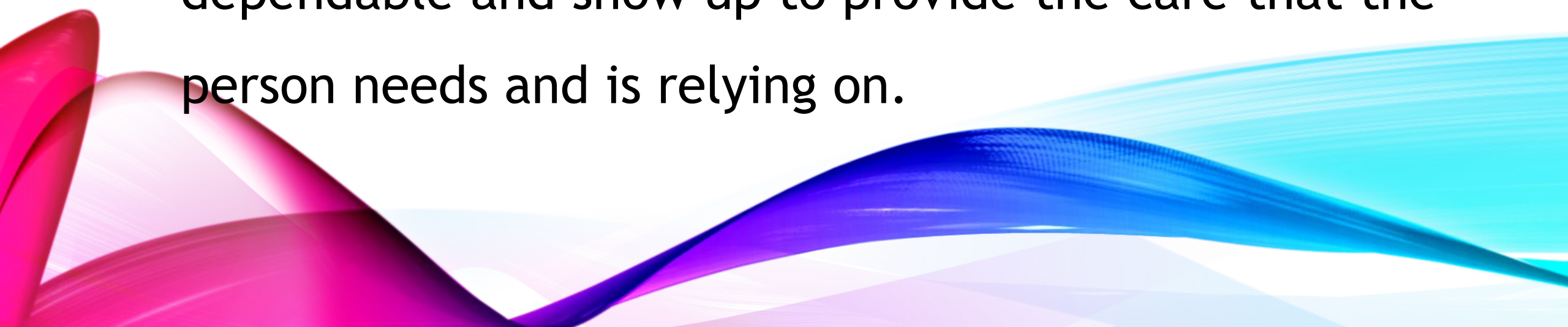
Characteristics of a Caregiver

ATTENTIVENESS. Caregivers must be attentive to the needs and changes that are taking place by noticing when there are emotional or physical changes and other nuances in behavior in the person being cared for.



Characteristics of a Caregiver

RELIABILITY. Those who need home care don't usually just need it sporadically. Rather it is ongoing a regular basis, so it is imperative that a caregiver be dependable and show up to provide the care that the person needs and is relying on.



Characteristics of a Caregiver

TRUSTWORTHINESS. It is crucial that the caregiver be honest and trustworthy and must not breach that trust by taking advantage of the person her or she is caring for.



Who is a Caregiver?

- **Formal**
- **Informal**
- **Long Distance**



Who is an *Informal* Caregiver?

Informal caregiving is the *privilege* of providing *unpaid* assistance and support to individuals who have physical, psychological, or developmental needs.

Caring for others generally takes on three forms: *instrumental*, *emotional*, and *informational* caring. Most informal caregivers finds themselves in this role with a lack of training and support.

(Drentea, 2007)

Instrumental caregiving helps includes activities such as shopping for someone who is disabled or cleaning for an elderly person.

Caregiving also involves a great deal of *emotional* support, which may include listening, counseling, and companionship



Today's Caregivers

- 29% of the U.S. population provide care for a chronically ill, disabled, or aged family member or friend
- 22% of caregivers are caring for someone with Alzheimer's or other dementia
- Caregivers often report that they had “no choice” in taking on the caregiving role.

1 National Alliance for Caregiving in collaboration with AARP; November 2009

2 Evercare Survey of the Economic Downturn and Its Impact on Family Caregiving; National Alliance for Caregiving and Evercare. March 2009

3 ALZHEIMER'S ASSOCIATION 2015 FACT SHEET alz.org

Today's Caregivers

- The typical caregiver is a 49 year-old female caring for a 69 year-old relative.
- The value of the “free” services of family caregivers is estimated to be \$375 billion/year
- More than 15.9 million family and friends provided 18.1 billion hours of unpaid care in 2015 to those with Alzheimer's and other dementias



In Utah, nearly half (46.7%) of all adults provide unpaid care to loved ones with Alzheimer's or related dementias and have been doing so for two or more years. More than three-quarters of caregivers (77.4%) manage household care such as cleaning or cooking and 61% manage personal care such as feeding or bathing.

152,000

Number of Caregivers

173,000,000

Total Hours of
Unpaid Care

\$2,180,000,000

Total Value of
Unpaid Care

\$79,000,000

Higher Health
Costs of Caregivers

Caregiving Statistics in Utah

Three in five care recipients have a long-term physical condition. (59%)

More than a third have a short-term physical condition. (35%)

A quarter have a memory problem. (26%)

Most care recipients have more than one ongoing problem or illness. (37%)

Caregiver Statistics



Family caregivers are increasingly performing tasks that nurses typically perform known now as “medical/nursing tasks,” these skilled activities include injections, tube feedings, catheter and colostomy care, and many other complex care responsibilities.

About 6 in 10 caregivers assist with medical/nursing tasks. (57%)

Higher-hour caregivers are more often performing these tasks.

Caregiver Statistics



Impact of Caregiving



- ▶ Impacts home life
- ▶ Impacts work life
- ▶ Impacts social life
- ▶ Impacts health
- ▶ Impacts relationships
 - ▶ With parents
 - ▶ With spouses
 - ▶ With siblings
 - ▶ With friends

Caregiver Burden

38 percent of caregivers consider their situation is highly stressful.

Furthermore, nearly half of this high-stress group provides more than 20 hours of care each week.

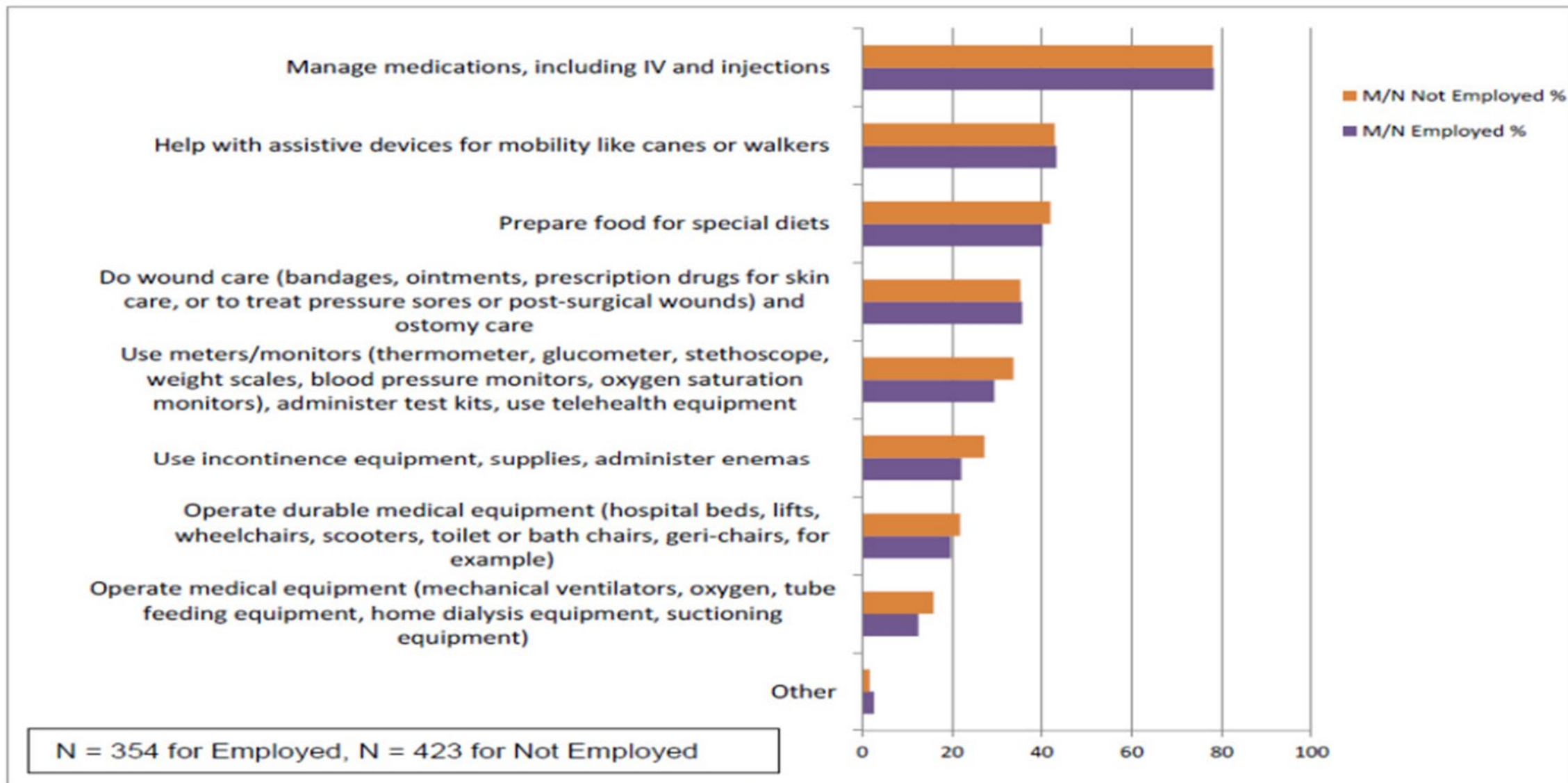


Experiencing physical strain (32%) and emotional stress (46%) is more common among higher-hour caregivers.

Those who feel they had no choice in taking on their caregiving role report high levels of emotional stress. (53%)

One out of every two caregivers of someone with a mental health issue (53%), Alzheimer's or dementia (50%), or a long-term physical condition (45%) reports feeling emotional stress

Percent of Family Caregivers Performing Medical/Nursing Tasks



10 Signs of Caregiver Stress

1. Depression
2. Anxiety
3. Withdrawal
4. Anger
5. Loss of concentration



10 Signs of Caregiver Stress

6. Denial
7. Changes in eating habits
8. Drinking or smoking
9. Insomnia
10. Health problems

Financial Stress

- Reduction of work hours and increase in leave time taken
- Loss of income
- Loss of promotional opportunities
- Loss of retirement income
- Out of pocket costs to help with expenses
- Loss of income of the care recipient

47% of working caregivers indicate an increase in caregiving expenses has caused them to use up ALL or MOST of their savings.



The MetLife Study of Caregiving Costs to Working Caregivers: Double Jeopardy for Baby Boomers Caring for their Parents.
June 2011

Benefits of Caregiving

- Sense of Purpose
- Fulfillment
- Opportunity to give back
- Closer or stronger relationship



Caregiving Roles-Decision-making

1. The importance of shared decision-making
2. Decisions to make upon leaving the hospital
3. Long-term care options

What is Shared Decision-Making?

Shared Decision-Making: Persons living with dementia, partners, involved neighbors, caregivers, family members, and their health care team make health care decisions together, taking into account the evidence available, as well as the desires of the persons living with dementia.

What is Shared Decision-Making?

- Focus on values, goals, and preferences.
- Have persons living with dementia participate.
- Respect differences in opinions.
- Seek an advocate or mediator.

Proactive Planning

- ▶ Proactive vs Reactive
- ▶ Talk to professionals about disease trajectory
- ▶ Discuss known pitfalls
- ▶ Make a plan B, plan C...

**IF
PLAN **A**
FAILS,
REMEMBER
THERE ARE
25
MORE LETTERS.**

Hospital Discharge Process

1. **Doctor:** writes a discharge order
2. **Discharge planner:** arranges hospital release; contacts family
3. **Patient and/or Caregiver:** receives discharge instructions/plan (The discharge plan will include information on care needed after leaving the hospital, medications, warning signs, follow-up care, etc.)
4. **Care manager:** consider hiring to help talk to the discharge planner

Hospital Discharges

- Prepare to make decisions quickly.
- The health of the person discharged may change following a hospital stay.
- Work with the hospital discharge planner and medical team.
- Make decisions about required, available, and affordable care.
- Determine which provider you will use.

Discharge Considerations

- Should you provide more, or different care following the hospital stay?
- What are the care options? Are they affordable?
- Which care facilities have openings?
- Which are covered by patient insurance?
- Should you choose another facility while you are on the waiting list for your first choice?

Care Options

- Home health care
- Home and community-based services
- Rehabilitation unit
- Assisted living
- Nursing homes
- Palliative Care
- Hospice care

Questions for Home Care Providers

- What kind of therapists and professionals are available?
- Is there weekend care?
- Can the special needs of the person living with dementia be met?
- What does it cost? Is it covered by insurance?

Personal Care

- **Definition:** Minimally trained workers provide assistance with basic care needs at home.
- Nurses may supervise personal care providers.
- Medicare does not cover this care, however Medicaid may cover it for certain people home.

Range of Caregiving



In-Home Care



Professional caregivers hired through an in-home care agency provide companionship and assistance with activities of daily living (bathing and dressing, housekeeping, meal preparation, etc.) in the patient's own home.

Home Health Care

- **Definition:** a Medicare service supervised by registered nurses, which provides active nursing care.
- Staff may also include physical, occupational, and speech therapists, and social workers.
- Home health **aides** provide the bulk of the care.
- Focus is on regaining strength, and learning tasks which allow patients to live safely at home.

Assisted Living



Assisted living facilities can provide both short-term respite and long-term services for seniors who require an increased level of supervision and assistance with daily tasks, but do not need skilled nursing care.

Memory Care



Memory care is a type of assisted living that is specifically designed for individuals with Alzheimer's disease and other types of dementia. These communities employ staff who have been trained in dementia care and feature added security measures to ensure the residents' safety.

Independent Living



Independent living communities are ideal for active seniors who are able to live alone safely and maintain their own personal care. Most provide housekeeping services and chef-prepared meals so residents can focus on enjoying a wide range of social events, amenities and recreational activities.

Adult Day Care



Adult day services are a great option for family caregivers who are still working or need a break from providing care. Most adult day care centers offer the opportunity for socialization, engaging activities and nutritious meals. Some centers may provide transportation and basic health care services as well.

Adult Day Health Center

- **Definition:** Care provided outside the home in special centers.
- Care may be mostly social, or may include services like physical therapy.
- Care typically includes a meal.
- Care may provide transportation to, and from, a patient's home.
- This care provides socialization for the patients, and relief to their caregivers.

Rehabilitation



A senior may require short-term in-patient care at a rehabilitation center following a serious injury or illness. These facilities provide 24/7 medical care and supervision as well as various therapy programs in a residential setting to help patients focus on regaining their maximum functional potential.

Rehabilitation Units

- **Definition:** licensed facilities that provide rehabilitation.
- Nurses, physical and occupational therapists, provide most of the care to patients.
- To be covered by Medicare, patients must receive at least 3 hours of therapy each day.

Palliative Care

Definition: Palliative care is specialized medical care for people with serious illness.

This type of care is focused 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.

Hospice

“What is hospice?” A special type of care focusing on providing physical, emotional and spiritual support to patients who are in the final stage of life. This care benefits the patient and their loved ones by providing symptom management as needed and allowing the entire family to focus on enjoying quality time together.



Hospice Care

Definition: care that lessens pain and symptoms of people close to death and gives emotional and spiritual support. Most often provided at home.

For people expected to live less than 6 months.

A Medicare and Medicaid benefit that may be appropriate for many persons living with dementia.

Skilled Nursing Facility (SNF)

Definition: residential care for those recently discharged from the hospital, as well as longer term care.

Nursing homes are required to provide nursing staff capable of caring for frail residents.

Some include special care units for persons living with dementia.

Medicare pays for some length of nursing home stays. Also private insurance and out of pocket.







