

# **AGING IN AMERICA AND THE ROLE OF THE FAMILY CAREGIVER**

**How to meet an individual's  
clinical and social needs and goals  
in today's world.**

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# Agenda

- Aging in America (and New York)
  - What it looks like and what people want
- Who is caring for the elderly and what does it cost
- How to plan and why an interdisciplinary approach works
- Legal issues, benefits, resources, and solutions to best protect assets and pay for the care you need
  - To achieve the best possible quality of life
  - To meet individualized needs and goals
- Who are America's Caregivers and what do they do
  - Am I still a caregiver even if I have help or my loved one is in a facility?
  - How to building a caregiver team and who is on it?

# Aging in America



- In 1985, older adults accounted for 11 percent of the U.S. population
- By 2010, they were 13%
  - With more than 40 million Americans age 65+
- By 2030, as the last Baby Boomers turn 65, older adults are expected to reach 20 percent of the population
  - After that, the proportion is expected to level off, but the absolute number of individuals age 65+ will keep growing

# According to the U.S. Census Bureau (2018 update...2016 actual data / others projected)

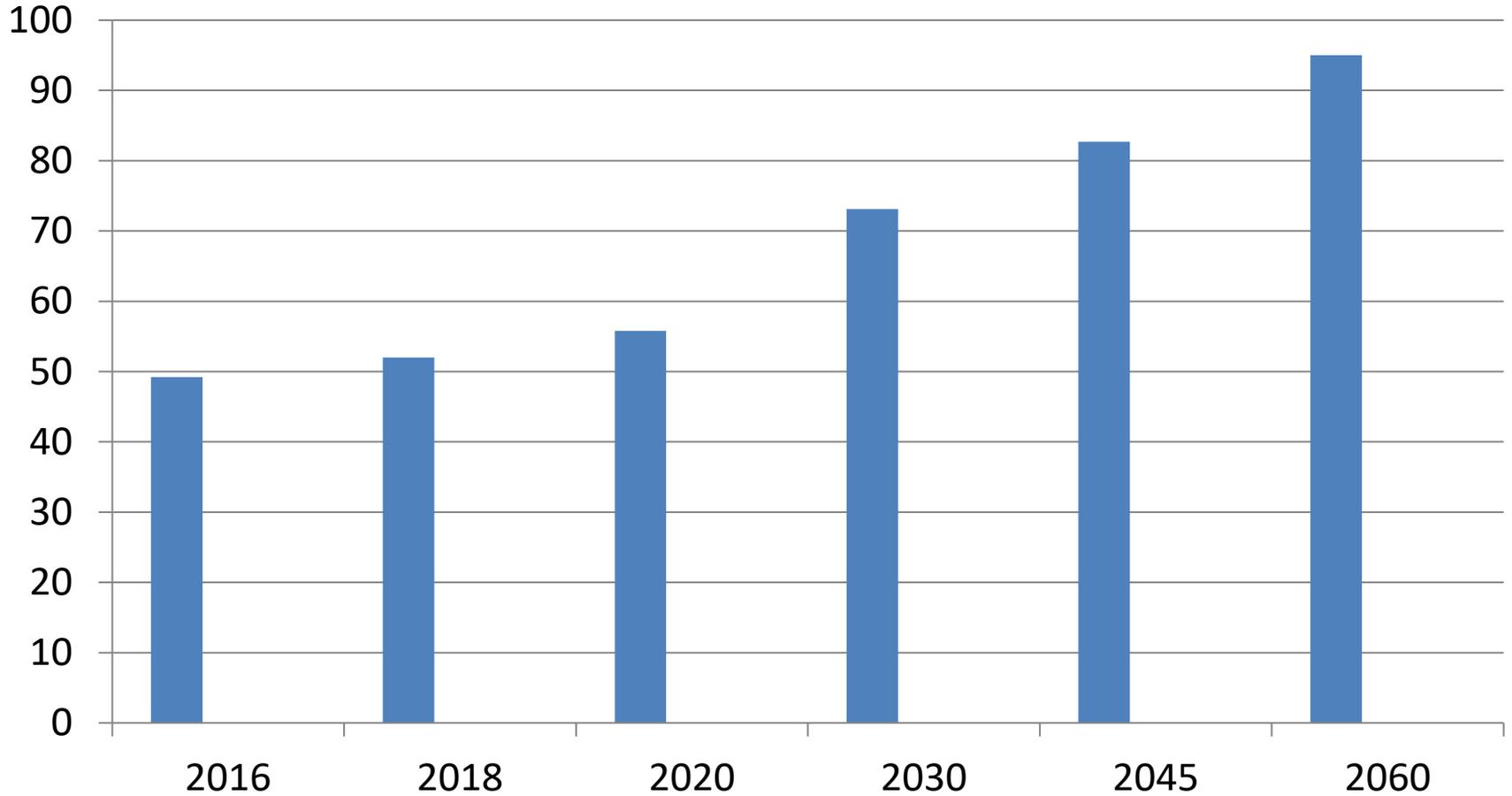
	2016	2020	2025	2030	2035	2040	2045	2050	2055	2060
<b>Total</b>	<b>323,128</b>	<b>332,639</b>	<b>344,234</b>	<b>355,101</b>	<b>364,862</b>	<b>373,528</b>	<b>381,390</b>	<b>388,922</b>	<b>396,557</b>	<b>404,483</b>
Median age (years)	37.91	38.52	39.26	40.08	40.95	41.50	41.93	42.31	42.59	42.88
Under 5 years	19,927	20,439	20,868	20,976	20,993	21,106	21,319	21,610	21,914	22,144
5 to 9 years	20,430	20,200	20,721	21,163	21,283	21,311	21,432	21,653	21,951	22,261
10 to 14 years	20,618	20,770	20,489	21,019	21,471	21,599	21,634	21,761	21,986	22,288
15 to 19 years	21,130	21,038	21,221	20,960	21,507	21,974	22,114	22,159	22,294	22,527
20 to 24 years	22,381	21,899	21,910	22,146	21,929	22,510	23,005	23,168	23,231	23,384
25 to 29 years	22,891	23,512	22,792	22,863	23,152	22,978	23,593	24,115	24,301	24,387
30 to 34 years	21,786	22,979	24,147	23,480	23,593	23,919	23,775	24,412	24,952	25,155
35 to 39 years	20,774	21,922	23,326	24,527	23,899	24,041	24,391	24,268	24,917	25,470
40 to 44 years	19,696	20,430	22,063	23,501	24,725	24,129	24,294	24,664	24,558	25,218
45 to 49 years	20,948	20,105	20,412	22,061	23,519	24,760	24,196	24,382	24,770	24,680
50 to 54 years	21,839	20,510	19,855	20,197	21,858	23,336	24,590	24,064	24,273	24,681
55 to 59 years	21,980	21,772	20,100	19,506	19,891	21,562	23,057	24,327	23,847	24,087
60 to 64 years	19,483	21,011	21,105	19,565	19,046	19,478	21,154	22,664	23,948	23,525
65 to 69 years	16,820	18,030	19,978	20,144	18,753	18,312	18,792	20,460	21,977	23,269
70 to 74 years	11,810	14,759	16,662	18,542	18,779	17,567	17,217	17,744	19,379	20,884
75 to 79 years	8,368	10,053	13,001	14,768	16,526	16,827	15,837	15,592	16,163	17,725
80 to 84 years	5,866	6,508	8,136	10,609	12,147	13,690	14,035	13,317	13,183	13,779
85 to 89 years	3,885	3,943	4,496	5,695	7,518	8,707	9,911	10,252	9,836	9,808
90 to 94 years	1,883	2,017	2,105	2,455	3,173	4,269	5,033	5,817	6,102	5,957
95 to 99 years	530	649	729	784	945	1,257	1,740	2,106	2,490	2,666
100 years and over	82	92	120	140	156	196	270	386	486	589

# So what does this mean.....

In less than two decades, the graying of America will be inescapable: Older adults are projected to outnumber kids for the first time in U.S. history.

The middle-aged already outnumber children, but the country will reach a new milestone in 2034 when the U.S. Census Bureau projects that older adults will edge out children in population size: People age 65 and over are expected to number 77.0 million while children under age 18 will number 76.5 million.

# 65+ Population Growth (in Millions)



# The Aging of New York



- One in six New Yorkers is over 65
  - This represents over 16% of the population (more than any other age group)
  - This population grew 26% over the past decade compared to an overall population that grew 3%
    - This means that this group is growing 8 times faster than the state’s total population
    - This population outpaced overall population growth in all of the state’s largest cities and counties

# Health issues are also changing

- As the population's age increases so does their medical, social, and economic issues.
- Chronic illness has replaced acute illness as the major health problem of older adults—and increasingly so as medicine evolves.
  - In 1984, more than 80 percent of older adults had one or more chronic health conditions.
  - By 2005, that percentage had increased to 91 percent.
  - By 2016, 60-75% of those aged 65+ suffer from two or more chronic health conditions.
- As of 2010, 99% of Medicare and 80% of Medicaid spending went toward the treatment of chronic diseases

# Who is caring for the elderly?

- 65% of older adults with long-term care needs rely exclusively on family and friends to provide assistance
  - Another 30% supplement family care with paid assistance
- Care provided by family and friends can determine whether an older person can remain at home.
  - 50% of the elderly who have a long-term care need but no family available to care for them are in nursing homes
  - 7% who have a family caregiver are in institutional settings
- As more people live long enough to experience multiple health issues and dependency, more relatives will be facing this responsibility.
- 30 million American households are providing care for adults over 50 years old
  - That number is expected to double over the next 25 years



# What Americans Want as they age



Staying at home and receiving the necessary support is something that both older Americans and professional cite as important and agree that this cannot be achieved without the following considerations and improvements:

- Community Infrastructure / Transportation
- Community Connections / Support Services
- Home modifications, upgrades, and repairs to promote independence



\*2015 U.S.  
Aging Survey



# Aging in place has become a priority for many older adults

According to a 2018 AARP survey:

- 3 out of 4 Americans over the age of 50 hope to remain in their current home as long as possible
- Some may want to age in place due to:
  - An emotional connection to their home or community
  - A desire to keep their independence
  - A financial necessity (to age in place rather than move to a residential senior community)



# Who Pays for Care?



- Medicare
  - Acute, Sub-Acute, Transitional
  - MDs, Tests, Medications
  - Must qualify (age)
- Medicaid
  - Chronic, Custodial
  - Must qualify and apply (income and clinical need)
- Private Funds (what happens when it's gone)
- Long Term Care Insurance (varied coverage)
- Veterans Benefits (supplements other



# Cost of Care



- Between 1977 and 2009, the percentage of household income that people age 65+ spent out of pocket for health care increased among the poor and near poor from 12% to 22%.
- Caregivers report an average of \$550K in wage wealth loss due to unanticipated caregiver responsibilities
- Medicaid spending on long-term care has increased significantly: from \$3.4 billion in 1973 to \$13.2 billion in 1982 to \$126 billion in 2010.

\*Institute of Aging (IOA)

# Why an Interdisciplinary Approach?

The pandemic affected individuals medically, socially, legally, and financially). Having a team that can address all of these needs as well as guide and coordinate with the family would have alleviated many of the problems that were faced.

How are we expected to meet an individual's needs and goals if we don't also help them and their families to find the resources and the funding so they can get what they want?

- What care transition advice, recommendations and support can we give without crossing the line?
  - Educate Validate Support
- Are all attorneys, financial planners, clinical navigators equal?
  - You don't go to an orthopedic surgeon for cardiac problems!
- What level of care provides what and how is each paid for?
  - Knowledge is power!



# How and Why Things Changed so Quickly

- The country and the world was confronted by a pandemic that changed our way of life within days.
- Social and financial considerations took a back seat to health and medical concerns.
  - Sick individuals were left at emergency rooms without family
  - There was often no ability to communicate with family
    - Patients were too ill / intubated and unable to speak
    - No communication devices available
    - Not enough staff to assist

THOSE WITHOUT PLANS WERE NOW UNABLE TO PLAN

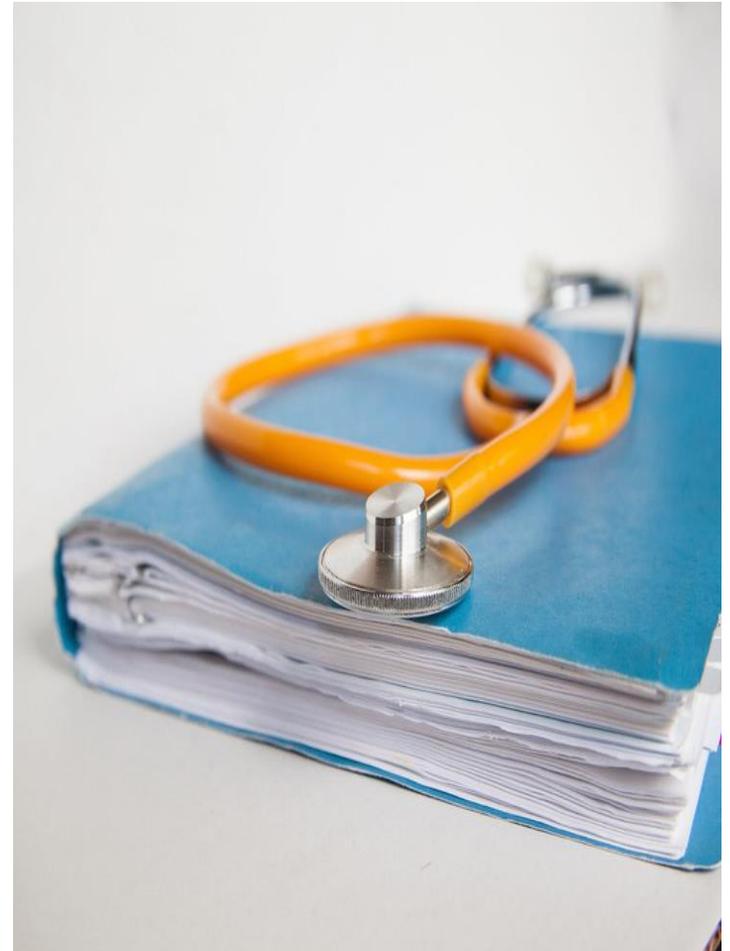
# What Would Have Helped

Even listening to the medical experts didn't help for the 4 to 6 weeks because they all had it wrong, but there were things we could have done.

- Have planned for the future.
- Have documents readily available (to transport to the hospital).
- Know what your loved one wanted.
- Have an interdisciplinary team working for you.

# Four Essential Estate Planning Documents

- Power of Attorney (POA)
- Health Care Proxy (HCP)
- Living Will
- Last Will and Testament



# Power of Attorney

The Power of Attorney is an important document and should always be completed by an attorney to ensure that it is done correctly and complies with all applicable laws. As the “principal,” you give the person whom you choose (your “agent”) authority to spend your money and sell or dispose of your property during your lifetime once you become unable to do so due to incapacitation. You should choose someone you trust and who you believe will execute this responsibility with integrity. Without a Power of Attorney, your assets cannot be protected and financial wishes carried out until there is a court appointed guardian. You do not lose your authority to act even though you have given your agent similar authority.

# POA Facts

- When your agent exercises this authority, he or she must act according to any instructions you have provided or, where there are no specific instructions, in your best interest.
- Your agent can act on your behalf only after signing the Power of Attorney before a notary public.
- You can request information from your agent at any time.
- You can revoke or terminate your Power of Attorney at any time for any reason as long as you are of sound mind. If you are no longer of sound mind, a court can remove an agent for acting improperly.
- Your agent cannot make health care decisions for you. You may execute a “Health Care Proxy” to do this.

# Health Care Proxy

Health care providers often look to family members for guidance.

They may express what they think your wishes are regarding treatment options

There can be a conflict between family members regarding this

The New York Health Care Proxy Law

Allows you to appoint someone you trust (your agent) to make health care decisions for you

Allows you to control your medical treatment even as your condition changes

If you become unable, even temporarily, to make health care decisions, someone else must decide for you.

Your agent will start making health care decisions for you when your doctor determines that you are not able to make these decisions for yourself.

In the absence of a Health Care Proxy someone will be appointed to make decisions for you based on the Family Health Care Decisions Act (FHCDA)

FHCDA establishes the authority of a patient's family member or close friend (in a priority order) to make medical treatment decisions for the patient

- in the event the patient lacks capacity to make such decisions personally
- and did not previously make such decisions or appoint a health care agent

# HCP Facts

- Appointing a health care agent is voluntary. No one can require you to appoint one.
- You may give the person you select as your health care agent as little or as much authority as you want, including specific instructions.
- Before appointing someone as your agent, discuss it with them to make sure they are willing to do this, and then discuss your health care wishes.
- Hospitals, doctors and other health care providers must follow your agent's decisions as if they were your own.
- This form can also be used to document your wishes or instructions with regard to organ and/or tissue donation.
- You may cancel the authority given to your agent by telling him or her or your health care provider orally or in writing.

# Living Will

- A Living Will (also known as a healthcare directive) is a document that expresses a person's desires and preferences about medical treatment in case he or she becomes unable to communicate these instructions during terminal illness or permanent unconsciousness.
- Decisions relating to health care and incapacity should be carefully considered, because once problems arise there may not be an opportunity to fix mistakes or provide clarification.
- For this reason a Living Will like a Health Care Proxy should be completed by an estate planning attorney that will ensure that your wishes are understood and enforced if you become unable to communicate them for yourself.
- Although once only used to communicate the desire not to have extraordinary means to prolong life, these documents can now contain specifics on other treatment options, and when they should be used.

# Living Will Facts

- A Living Will is not accepted at medical facilities (hospitals, SNFs ) as “final” written documentation of a patient’s wishes or carried out as such

BUT

- This document can provide clear and convincing evidence if an individual has not named an agent in a Health Care Proxy and decisions are made by an individual as determined in the Family Health Care Decision Act (FHCDA).
- When admitted to a hospital or SNF (nursing home / rehab facility), even if you have a Living Will, you (or your health care agent) will be asked to complete another form that clearly expresses your wishes.
  - In some cases it will be a (simple) Do Not Resuscitate (DNR) form
  - In most cases it will be a MOLST (Medical Orders for Life Sustaining Treatment)

# MOLST

## Medical Orders for Life Sustaining Treatment

Honoring patient preferences is a critical element in providing quality end-of-life care.

To help physicians and other health care providers discuss and convey a patient's wishes regarding cardiopulmonary resuscitation (CPR) and other life-sustaining treatment, the New York State Department of Health has approved an order form (DOH-5003) which can be used statewide by health care practitioners and facilities.

Although the conversation(s) may be initiated by any qualified and trained health care professional, a licensed physician or nurse practitioner must always confer with the patient and/or decision-maker about the patient's diagnosis, prognosis, goals for care, treatment preferences and sign the orders based on that.

# Last Will and Testament

- A will is a legally-binding document that lets you determine how you would like your estate to be handled upon your death.
- Having a will, speeds up the probate process and informs the court how you'd like your estate divided.
- Executors make sure all your affairs are in order, including paying off bills, canceling your credit cards, and notifying the bank and other business establishments

# Caregiver Demographics and Value

- 75% of all Caregivers are female
  - Average age is 49.2 years
- 65% of all Care Recipients are female
  - Average age is 69.4 years
- 85% care for a relative or loved one
- 75% live within 20 minutes of the recipient
- Average Duration of a Caregiver's role is 4 years
  - 25% care for more than 5 years, 15% for 10+ years
  - Dementia caregivers provide care for 1-4 years more than other chronic disease caregivers
- Value of informal caregiver services has increased steadily over the last decade
  - 2013 economic value of \$470 Billion
    - Exceeds the value of paid home care and total Medicaid spending combined
    - Increased from \$375 Billion in 2007



# Caregiver Tasks



- On average, time spent is as follows:
  - 13 days a month on shopping, food preparation, housekeeping, laundry, and med administration
  - 6 days a month on ADLs (dressing, feeding, ambulation, bathing, and toileting)
- Of family caregivers who provide complex chronic care
  - 46% perform medical and nursing tasks
    - Medication Management (including administration according to vital signs and titration)
    - Wound Care and Dressings
    - Tube Irrigation and Changes
    - Enteral Feedings
    - IV Therapy



# Building a Caregiver Team

- Why do you need to build a team
  - Despite employment status, unpaid caregivers report that their own positive activities are reduced by almost 30% due to their caregiving activities
  - To minimize the burden, stress, and feeling of being overwhelmed that an individual caregiver faces
- How do you start
  - List all individuals who can join and contribute (think outside of the box)
  - Plan a family meeting to evaluate the situation and discuss concerns
  - Consider family dynamics and comfort level of all involved
  - Consult professionals and seek support and skills from outside the family

CAREGIVING NEEDS	WHO CAN HELP / NAME	PHONE NUMBER(S)
HOME		
Maintenance and light repairs		
Laundry and shopping for supplies		
Groceries and meal planning		
House cleaning		
Yard work, cut grass, snow removal		
Pet care and vet appointments		
Home safety (advice and work)		
DAILY LIVING		
Bathing and grooming		
Meal preparation		
Transportation for appointments		
Socialization and companionship		
HEALTH CARE		
Making doctor / provider appts.		
Communication with providers		
Education of care recipient		
Medication (order, pick up, monitor)		
Exercise and ambulation		
FINANCIAL		
Accessing benefits		
Paying bills and taxes		
Planning and managing investments		
Banking		
Sale of property, belongings		
LEGAL		
Organizing documents		
Preparing Power of Attorney		
Preparing Will		
Advice regarding insurance eligibility		
Preparing Health Care Proxy		

# Who Can Join and Contribute to the Team

- Family members, including children
- Physicians
- Pharmacists
- Medical professionals
- Clergy/Church members
- Neighbors/Friends
- Volunteers
- Caregiver consultant/Social worker
- Counselors/Therapists
- Adult day program staff
- Home Care Providers
- Medical organizations



# *You are the center of the care team*

- With those closest to you with you
- You will expand your inner circle as you tell others about the diagnosis
- You will add the additional circles of medical professionals and community resources with time





# 10 TIPS FOR FAMILY CAREGIVERS



Seek support from other caregivers. You are not alone!



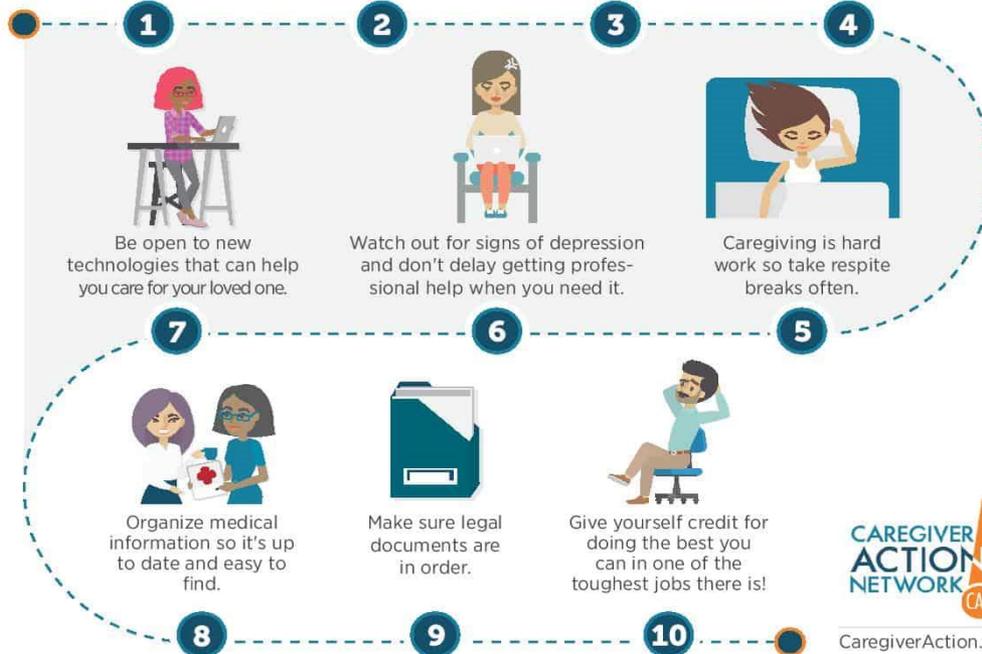
Take care of your own health so that you can be strong enough to take care of your loved one.



Accept offers of help and suggest specific things people can do to help you.



Learn how to communicate effectively with doctors.



# Tips to Develop Your Team

- Identify which friends, family and neighbors may be willing to help you.
- Discuss the help you may need.
  - Have a conversation with each person who may be willing and able to assist. y
- Be specific.
  - State clearly what help is needed or may be needed in the future.
- Ask if you could do things together.
  - Examples include shopping or preparing meals.
- When asking for help, seek those who are willing to listen and who care.
  - Avoid people who seem judgmental, critical, or blaming.
- If someone isn't able to help you, don't blame yourself.
  - It probably has to do with what's going on with the other person.
- Say thank you!
  - Everyone likes to feel appreciated, and thanking people makes it more likely that they will help again.





# Contact Information

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