More than 5 million Americans are living with Alzheimer’s disease, a type of dementia that starts when plaque deposits in the brain stop nerve cells from working. It’s a devastating condition for the person who has it and their loved ones, as people begin losing their memory and cognitive ability, and family members bear the burden of their care.

Some mild forgetfulness is normal with age, but severe memory loss or other symptoms could be signs of Alzheimer’s or other types of dementia. Alzheimer’s is the most common form of dementia, but there are many types of dementia and other medical conditions that can contribute to dementia-like depression, memory issues or other cognitive symptoms in the elderly. Depending on the diagnosis or cause of the symptoms, treatment, the likely course of the disease and outcomes may vary.

“It’s of the utmost importance to get good information from suspicion to diagnosis and post-diagnosis in Alzheimer’s disease,” said Dr. Sharon D. Allison-Ottey, a physician trained in internal medicine and geriatric medicine and a member of HealthyWomen’s Women’s Health Advisory Council.

“When a patient is diagnosed with Alzheimer’s, there’s more than one patient — their caregiver, family and friends also will be affected by the disease,” Allison-Ottey explained. “Knowing what to potentially expect and understanding the many layers with this disease is very important throughout the course of Alzheimer’s.”

Allison-Ottey said individuals should seek medical attention for themselves or loved ones at the first signs of memory loss, difficulty finding things, mixing up words or repeating themselves. These symptoms don’t automatically mean Alzheimer’s disease is present, because many contributing factors and illnesses can cause this behavior. But early detection is key, as with most medical conditions.

“Don’t delay, and if there is hesitancy with a loved one, work with their physician and other family members to push for evaluation and action,” she said.
Questions to ask your healthcare provider (HCP) before you have been diagnosed.

Am I at risk for Alzheimer's disease?

Why this question is important:
According to the National Institute on Aging and other reputable organizations, physicians and scientists do not yet fully understand what causes Alzheimer's disease. There probably isn't one single cause, and changes in the brain can begin years before the first symptoms appear. There are, however, risk factors that your HCP can discuss with you.

- Age is the best-known risk factor. Most people with Alzheimer's are 65 years and older, and risk increases with age. The number of people with Alzheimer's disease doubles about every five years beyond age 65.

About one-third of all people age 85 and older may have Alzheimer's disease. But age is only one risk factor — many people live into their 90s and beyond without ever developing dementia.

- Gender is another risk factor for developing Alzheimer's disease. Worldwide, women with dementia outnumber men 2 to 1, and a woman's estimated lifetime risk of developing Alzheimer's at age 65 is 1 in 5. The incidence of the disease is higher in women than in men and is not related to women living longer.

- Researchers believe that genetics may play a role in developing Alzheimer's disease, although there isn't 100% certainty if you have a loved one who has dementia that you will get the disease.

- Scientists are finding more evidence that some of the risk factors for heart disease and stroke, such as high blood pressure and high cholesterol, may also increase the risk of Alzheimer's.

- Researchers are studying whether education, diet and environment play a role in developing Alzheimer's disease.

- There is growing evidence that physical, mental and social activities may help reduce the risk of developing Alzheimer's.

Questions to ask your HCP once you (or a loved one) have been diagnosed.

What stage am I in? What should I expect next? What planning should I do now?

Why these questions are important:
Your HCP should explain how far the disease has progressed and ways different symptoms can appear. Every patient is different and the course of the disease is different, but getting a good understanding of the disease and what stage you or your loved one is at the time of diagnosis is important in long-term planning, managing expectations and understanding the possible course of the disease.

Who will lead my treatment? Will it be the primary care physician, a geriatrician or a neurologist or another healthcare professional? Who else will be on my team? How will communication be handled?

Why these questions are important:
You should be comfortable with the care plan presented. If not, seek a second opinion and request a consultation with a specialist if you want to explore other options. Alzheimer's is a disease that gets worse as time goes on, and it's not the same in everyone; getting other opinions and expertise helps the patient and loved ones understand the process and navigate the best possible care.
What treatment options, both medications and behavioral, are available? Are there new treatments? Are medications effective and what are the side effects?

**Why these questions are important:**
These questions give a realistic view on what to expect on the journey through Alzheimer’s and what proactive measures can be taken. It’s always essential to understand medications, their purpose and the possible side effects; this is especially true with a patient that may or may not be able to effectively communicate. It’s also important to understand what lifestyle and behavioral factors can help slow progression and maintain quality of life as long as possible.

What can family or friends do to be supportive and protective of me (or my loved one)? What resources do you recommend?

**Why these questions are important:**
Alzheimer’s is a disease that affects the patient and their families. Understanding each stage of the disease and what to expect helps all to recognize what they can and cannot do to support the patient without robbing the patient prematurely of their independence. This question should be revisited with the healthcare team as the disease progresses. The need for support networks and resources may increase for the patient and family on this journey.

What should those living with, coping with or caring for individuals with Alzheimer’s know about the caregiving process?

**Why these questions are important:**
The mental, physical and social toll on taking care of a loved one with a chronic condition like Alzheimer’s cannot be overstated. Informal or unpaid caregivers (family members or friends) are the backbone of long-term care provided in people’s homes. While some aspects of caregiving may be rewarding, caregivers have an increased risk for negative health consequences including stress and depression. Maintaining a healthy lifestyle and getting regular checkups can also be a struggle for caregivers. Over half (53%) of caregivers indicate that a decline in their health compromises their ability to provide care.

Caregivers and their families often experience many challenging decisions around care, while experiencing emotional hardship and stress along with economic hardships through lost wages and additional medical expenses. For this reason, caregivers need to see their healthcare providers, discuss how the illness is impacting them, keep up with sleep, receive regular checkups and pay attention to their own health/well-being.

Caregivers should also work to have a comprehensive understanding of potential costs (lost wages, transportation, etc.) and put together a financial plan that takes these into account.

The patient living with Alzheimer’s must be in a safe environment and regularly evaluated by their medical team — whether they live independently, with family or in a facility. This can help combat untoward outcomes and other medical complications from Alzheimer’s and aging like fall prevention, motor vehicle safety, monitoring of activities and potential wandering.

This is why it’s important to have an early diagnosis, ask questions, understand what you may expect and build a network of support.