

CAREGIVER'S FACT SHEET

THE ROLE OF A CAREGIVER



Caregivers for those diagnosed and living with cognitive and other brain health illness play a major role in managing the disease and their overall well-being.

Whether your loved one suffered a stroke or has Alzheimer's, understanding how to support both them and yourself is key.

Caregiver Roles During Stages of Illness/Disease:

➤ **During Early Stages of Illness** – During the early stages of most cognitive and brain health illnesses caregivers serve more as a partner

than an actual caregiver, as most people can still perform everyday activities with little help or assistance. During the early stages of an illness or disease caregivers can help their family members with the following:

- ✓ Keeping their medical appointments
- ✓ Providing support to manage finances and medical bills
- ✓ Remembering to take medications
- ✓ Help them with planning and organizing their schedules, home, and work if necessary
- ✓ Support to understand and cope with their new diagnosis

➤ **During Middle Stages of Illness** – As cognitive and other neurological diseases progress our loved ones often require more care as they become unable to normal task like driving or even feeding themselves. Caregivers during the later stages of a disease have to balance caring for the individual but also for themselves and their family. This can be a stressful time for caregivers. To help prevent burnout and help maintain balance in your role as a caregiver the list below provides some helpful tips and recommendations:

- ✓ Find local support groups and trainings for caregivers in your area
- ✓ Start to plan ahead for the next stages of the disease and have a plan in place for things like finances and advanced medical directives
- ✓ Educate yourself on the possible changes in your loved ones behavior and recognize when additional help and support may be needed

➤ **Late or Final Stages of Illness** – During the more advanced and severe stages of brain health diseases, caregivers are under a tremendous amount of both physical and emotional stress. It is often during this phase of the disease that decisions have to be made regarding end of life choices and how to provide the level of care now required by our loved ones. These issues can result in family conflict and struggle and can be a challenging time for caregivers. During this stage of Alzheimer's or other diseases that affect the brain, it is important for caregivers to consider the following:

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- ✓ Identify mental health and psychological support for themselves and other family members to help reduce and resolve conflicts
- ✓ Discuss options for inpatient and/or hospice level care for your loved one, this includes availability and cost of these types of care
- ✓ Spend quality time with your loved one doing things that comfort them such as listening to music, reading their favorite book, or just laying with them
- ✓ Be patient and understanding with your loved one as they are unable to control body functions and even their emotions as their disease progresses

Burden for African-American Caregivers

African-Americans are twice as likely to have some form of dementia, including Alzheimer's disease. This means that there is a disproportionate number of African-Americans being impacted by these illnesses as well. There is little research available that has measured or studied the burden of African-American caregivers, however published literature suggests that there are many barriers and challenges regarding:

- ❖ The level and quality of healthcare being provided
- ❖ Lack of awareness about available services and support for both the caregiver and their loved ones
- ❖ Need for more cultural competence of healthcare professionals including clerical and administrative staff on how to provide care and support services to African-American diagnosed with cognitive health illnesses and their caregivers

HOW TO TAKE CARE OF YOURSELF AS A CAREGIVER?

When not equipped with good information and support the health of the caregiver can begin to suffer. It is important for caregivers to understand that the best thing they can do for both themselves and those they care for is to take make their own health a priority.

To help maintain a healthy lifestyle and the strength needed to be a good caregiver remember to P.R.A.Y:

- Be **Prepared**
- Take time to **Relax**
- Stay **Active**
- Remember **YOU** are not alone!



RESOURCES/ADDITIONAL INFORMATION

The Alzheimer's Association – www.alz.org/care

The National Institute on Aging - <https://www.nia.nih.gov/health/featured/caregiving>