

Our Mission

The mission of CaringKind is to create, deliver, and promote comprehensive and compassionate care and support services for individuals and families affected by Alzheimer's disease and related dementias, and to eliminate Alzheimer's disease through the advancement of research. We achieve our mission by providing programs and services for individuals with dementia, their family and professional caregivers; increasing public awareness; collaborating with research centers; and informing public policy through advocacy.

CaringKind Helpline
646-744-2900
www.caringkindnyc.org



caringkind *The Heart of
Alzheimer's Caregiving*

Making Home Care Work For You

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Other Considerations

- Consider setting up a daily communication log. Both you and the Home Care Worker (HCW) can report any changes in the person with dementia. If a special need arises it is good to have a place to write it down so that it is not forgotten. This is also a great place to record activities and events of importance.
- Many times people with dementia experience heightened paranoia and can become overly suspicious as a result of the disease. Some families find that the person with dementia will misplace a possession and might blame the HCW for its disappearance. It is helpful to remove or secure your family member's most valuable possessions when transitioning to home care.
- There are some legal limitations to the types of assistance a HCW can provide. For instance, it is helpful to know that a HCW employed by Medicare, Medicaid, or a home care agency is not trained to administer medication.

This means the HCW is able to prompt the person with dementia to take medication, bring the medication to them, and assist them in opening the bottle. The HCW is not legally able to place the medication in the person with dementia's mouth. Sometimes family members make alternate arrangements for medication administration based on the needs of the person with dementia.

- Maintaining a positive relationship with a HCW requires effort from both the caregiver and the HCW. This can be a very stressful and tiring experience. Remember to take care of yourself. In order to provide care for others, you must first care for yourself.

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How Do I Know it's Time for Home Care?

It is often difficult to know when a person with dementia is transitioning from being fairly independent to requiring assistance with Activities of Daily Living such as eating, bathing, and grooming. Start by asking these questions.

- How is the person spending his or her time?
- What are her days like?
- Is he shopping and cooking for himself?
- Is she getting adequate nutrition?
- Is he managing his finances? Paying his bills on time?
- Is she paying attention to personal hygiene?
- Is the house clean?
- Has anyone found the stove left on or the water running?

Home care can provide assistance to the person with dementia with daily household chores, personal care, meal times, shopping, accompaniment to appointments and engagement in activities.



Maintaining a Positive Relationship with a Home Care Worker

Open and respectful communication, clear expectations, and explicit instructions surrounding the care of a person with dementia often lead to the most effective caregiving. If there are any problems with a Home Care Worker (HCW), it is best to first communicate with the HCW directly. If necessary, you may then contact the case coordinator to further discuss the issue.

Despite the amount that you or Medicaid is paying an agency, HCWs contracted through home care agencies are generally paid minimum wage. Everyone likes to feel appreciated. You might choose to give a HCW an appropriate bonus or gift on special occasions such as holidays or birthdays. HCWs generally welcome positive feedback and acknowledgement of a job well done. It is beneficial to discuss holidays, vacation, and sick time with a HCW. If a HCW is contracted through an agency, you can typically refer to the agency's official policy to learn more about replacement HCWs in the instance of an absence. If you have hired a HCW privately or through CDPAP, it is best to create a written agreement and plan in the event of an absence.

Remember to set realistic expectations. Nobody can care for the person with dementia in the way that you would. The transition to home care can be challenging for both you and the person with dementia. However, over time, a positive relationship usually develops. Know that you can always call our Caringkind Helpline at 646-744-2900, for information and support throughout this process.

- Tell the person with dementia the HCW is a visiting family friend.
- Be creative! Remember you know the person with dementia best. Tailor these suggestions to best fit your situation.

Sometimes HCWs, private pay or Medicaid, have not had formal dementia care training. In all cases it is helpful to provide a written daily plan posted in an easy-to-find place such as on the refrigerator. This plan should also include emergency instructions such as first contact, physician contact information, location of critical documents, and medication list.

HCWs are welcome to attend the Dementia Care Training for Professional Caregivers and the Monthly Education Meetings held at the CaringKind office. For more information and to register, please call the CaringKind Helpline at 646-744-2900.

Maintaining a positive relationship with a HCW is one key to ensuring the person with dementia stays safe in the community. A HCW should be able to evaluate the person with dementia's situation on a day-to-day basis and keep you informed accordingly.

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How to Pay for Home Care

Medicare

Medicare is a health insurance program for the aged and the disabled, administered by the US Department of Health and Human Services. In-home nursing and home care are covered only when the person with dementia has a “skilled nursing need” (e.g., wound care), such as after a hospitalization or when a bedsore develops. Medicare does **not** pay for long-term “custodial” care required by a person with dementia as the illness advances. It is most often time-limited and temporary.



Medicaid

Medicaid is a joint federal and local program designed to meet the health care needs of people who have little savings and income, or have exhausted their savings. Medicaid requires extensive documentation to establish eligibility. For those who meet financial and medical eligibility criteria, Medicaid in NYC covers the cost of many services needed by a person with dementia as that person's illness advances. People with dementia who live at home may need Medicaid-funded home care or adult day care in order to remain safe, or to provide respite for caregivers. These services are covered under Community Medicaid.

CaringKind offers Legal and Financial Seminars conducted by volunteer elder law attorneys. These meetings are a good way to be introduced to Medicaid eligibility and other important legal and financial issues. CaringKind also conducts a Medicaid Home Care Seminar to guide

caregivers through the Medicaid application process. All sessions are free of charge but registration is required. To register, please call our CaringKind Helpline at 646-744-2900

Long Term Care Insurance

Some Long Term Care Insurance programs will cover home care services. If you already have Long Term Care Insurance, be sure to call your provider to inquire about coverage requirements and limitations as most require that you contract with a specific home care agency.

Veteran's Benefits

Veteran's benefits are administered through the Department of Veteran's Affairs. For most benefits, the claimant must be a veteran or a veteran's spouse, widow or widower, child, or parent. There are a number of medical benefits available to qualified veterans and certain dependents and survivors including adult day care, home care, prescriptions, outpatient care, hospital care, and nursing home care. Call New York State Division of Veterans Affairs at 888-838-7697 to learn more.

Private Pay Home Care

Families can choose to hire a **Home Care Worker (HCW)** through an agency or through informal means. For more information, please call our CaringKind Helpline at 646-744-2900.

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Introducing the Home Care Worker to the Person with Dementia



Introducing a Home Care Worker (HCW) to the person with dementia may take some time as the person may still consider him or herself to be quite independent. This time is an adjustment period for both you and the person with dementia. Although your choice to seek home care might be met with resistance, it is important to remember that the person with dementia does need help to remain safe in the community.

Creativity is the key to planning a successful introduction. Here are several suggestions for introducing a HCW to the person with dementia:

- Tell the person with dementia the HCW is there to help you.
- See if the person with dementia's physician would be willing to write a "prescription" for home care.
- Appeal to the person with dementia's interests –
 - If they enjoy gardening, have the HCW present the person with dementia with a book about flowers that you have purchased in advance.

The Interview Process

When Meeting a Home Care Worker Assigned by Medicaid

Although you do not have the ability to interview potential Home Care Workers (HCWs) when receiving services through Medicaid, it is important to spend some time with a HCW prior to introducing them to the person with dementia. This time will give you the opportunity to get to know the HCW and provide them with specific information about the person with dementia, including the person's preferences, culture and routine. At this time, the HCW and caregiver can exchange important information such as emergency contacts and the name and phone number of the appropriate case coordinator.

When Interviewing a Privately Paid Home Care Worker

It is a good idea to conduct the initial interview with potential employees privately before you introduce them to the person with dementia. You may want to conduct the interview outside the home. This is a good opportunity to provide a potential HCW with information about the particular needs and behaviors of the person with dementia as well as for you to see if the two might be compatible. During this time you can ask the interviewee about his or her past training, experience, and personal and professional references. You may want to ask the interviewee specific questions that relate to your caregiving situation. For instance, "How have you handled a situation in which the person you were caring for was angry?" If the interviewee has participated in training, make sure you inquire about the length and content of the training. Does the interviewee have dementia care training? Has he or she been trained in transfers (e.g., moving a person from a bed to a chair)? If so, by whom?

How Do I Get Help in My Home?



Medicaid Home Care

Medicaid is a government sponsored health insurance program designed to meet the health care needs of people who have little savings and income, or have exhausted their savings. It is Medicaid, not Medicare, that will pay for long term care services.

In past years, New York State Medicaid has transitioned from a fee-for-service model (AKA "straight" Medicaid) to a care coordination model (AKA "managed" care). Care coordination entails a separate health insurance plan or health care system coordinating the provision, quality and cost of care for its enrolled members. In New York State the plans are paid a capitated amount to administer all of an enrollee's care. As a result of this transition, a separate Managed Long Term Care (MLTC) plan is now the way in which Medicaid recipients must access long-term care services including home care, adult day care and respite care.

New applicants are required to join a plan if they:

- are 21 or older;
- have both Medicare *and* Medicaid;
- need home care, adult day health care, or other long term care for more than 120 days (4 months).

If a person has Medicaid without Medicare, a managed plan is still required for long term care unless a special waiver is granted. In this position, Medicaid-only recipients can choose between the below-mentioned MTC plan and what is simply called a Managed Medicaid Plan. The principle difference between these options is that an MLTC plan covers both medical and social adult day programs and a Managed Medicaid Plan only covers medical adult day programs.

Types of MLTC Plans:

- Managed Long Term Care (MLTC) Plans
- Programs of All-Inclusive Care for the Elderly (PACE)
- Medicaid Advantage Plus (MAP)

There are important differences between each type of plan.

MLTC plans only affect a recipient's Medicaid benefits such as home care or personal care services, adult day care, specialty services and nursing home services. Medicare benefits are not affected.

MAP plans administer a recipient's Medicare *and* Medicaid benefits, which means enrolling in a MAP plan will affect both Medicaid and Medicare services. All service providers must be within the plan's network. In addition to the services covered under MLTC plans (listed above), MAP plans also include Medicare benefits such as doctor services, Part D drug benefits, hospital stays and radiology. *Altering your Medicare benefit may mean you will have to select new doctors.*

PACE plans administer a recipient's Medicare *and* Medicaid benefits out of one central location. Under the PACE program all medical care and social adult day services are provided at the PACE center. PACE participants are required to use the providers within the center.

Fully Integrated Dual Eligible (FIDA) Plans

FIDA plans are similar to MAP in that they administer both a recipient's Medicare and Medicaid benefits. FIDA plans offer the advantages of receiving benefits with no extra deductibles, premiums or copayments (with the exception of a Medicaid "spend-down" or SNT), and providing an interdisciplinary team to consult around care including the member and representatives of a medical team.

Local Newsletters/Newspapers/Online

Read the "Employment Wanted" ads or place a notice advertising the opening. Be aware that ads often generate many responses. You will likely have to be available to do extensive screening and interviewing. Be clear in your ad that the job requires caring for someone suffering from memory loss and confusion.

Health Care Professionals - Doctors, Nurses, Social Workers

Occasionally health care professionals might be able to suggest a HCW familiar to them personally or professionally.



Hiring Outside an Agency

Sources for Potential Employees

When looking for a HCW privately, it is helpful to put the word out to as many people as possible. Here are some suggested places to begin your search.

Together We Care™

This resource was created to bridge the gap between aides who have completed the *CaringKind Dementia Care Training for Professional Caregivers* and families seeking to hire trained aides to provide care. Aides who have completed CaringKind's training are afforded the opportunity to create a profile and families are able to view, search profiles, and post a job ad. For more information, or to create a profile, visit www.togetherwecare.com.

Ask Fellow Support Group Members

Fellow caregivers may be able to direct you to someone they have employed or a friend or relative of the person they currently employ.

Colleges and Universities

Students looking for experience in the human services field may need a source of income to help them through college. Colleges often provide employment services for students. If you wish to post a job opening with a college, ask for the career placement or job development center.

Word of Mouth

Friends, neighbors, shopkeepers, etc. may be good resources. Let them know you are looking for a HCW.

Adult Day Care Centers, Senior Centers and Nursing Homes

Ask the administration or staff if they know anyone who might be interested in a job and if you can post a job announcement.

Local Churches and Synagogues

Your local clergy may know of potential sources that have spiritual commitments to nurturing and caring for the elderly and sick.

Prior to Joining a Plan

Before joining a plan and after being approved for Medicaid (or while Medicaid approval is pending), an evaluation must be conducted by the Conflict-Free Evaluation and Enrollment Center (CFEEC). This evaluation will determine whether a person has sufficient needs to qualify for the long term care services that are provided by an MLTC plan. CFEEC can be reached at: 1-800-505-5678. You have the right to be evaluated in the language you prefer. It is recommended that a caregiver be present during all evaluations so that the needs of the person with dementia are accurately described.



When Considering a Plan

You may want to consider exploring more than one plan to ascertain which plan can best meet your needs.

Things to Consider:

- Check with your current health care providers and homecare agency to see which MLTC plans they are affiliated with.
- Ensure the plan has adult day programs convenient to your location.
- Inquire about temporary and permanent nursing home services offered.

Plans are required to conduct a home visit and assess an applicant's needs. One outcome of this assessment will be your Plan of Care, which will include the number of home care hours the plan is willing to provide you with. This information can be most helpful as you compare plans, because the services covered by MLTC plans may vary.

Before joining any MLTC plan be sure the plan is able and willing to meet all of your health care needs.

Joining a Plan

To begin the process of enrolling in a Managed Long Term Care plan, you should contact a participating plan in your area. For a current list of participating plans, you can contact CaringKind's Helpline at 646-744-2900.

New York Medicaid Choice can also assist you by looking up which plans work with the home care agency and other providers you are currently using, or want to use as a plan member. New York Medicaid Choice can be reached at 888-401-6582.

After You Join a Plan

After you enroll in a plan, you will receive a confirmation letter that tells you the date your new plan takes effect. You will also receive a member handbook and plan identification card. You will also be assigned a Care Manager, an employee of the plan you have selected, who will work with you and anyone else you want to involve.

Transitional Care

During the first 60 days in a plan, the plan is required to maintain the same services you had in place prior to joining the plan. After the initial 60 days, the plan will conduct a re-assessment and your services, including authorized home care hours, may change depending upon your needs and the plan's assessment of your needs.

While enrolled in a plan, every six months the plan is required to conduct a re-assessment to evaluate the member's changing health care needs. Based on that, a new service plan will be issued in writing including any changes in home care hours or adult day services. If you do not agree with the new service plan, a member may request a fair hearing, during which time the plan may not change from the previous service plan, known as "aid continuing." This request must

happen within ten days of receiving the written notice regarding service plan changes. For more information about this process, please contact CaringKind's Helpline at 646-744-2900 and speak to a social worker.

When Working with Medicaid Home Care Agency

Sometimes family members can feel disappointed by their lack of choice over the Home Care Worker (HCW) assigned to their case. A relationship takes time to develop between a HCW and a person with dementia. Surprisingly, most HCWs do not receive training in dementia care. It is important to acclimate the HCW to the person with dementia's needs and routine. If after a trial period you find that a different HCW might be more appropriate for the person with dementia, it is recommended that you contact the case coordinator at the contracted agency. Remember, it is important to develop a positive relationship with the staff, particularly the case coordinator, at the contracted agency. These are the people responsible for sending help into your home. If you are dissatisfied with the response of the agency assigned to you, you are able to request a change of agency with the MLTC plan.



Consumer Directed Personal Assistance Program (CDPAP)

CDPAP may be used by families who already have a Home Care Worker (HCW) in mind, or wish to employ a family member (not a spouse) as the HCW. Under CDPAP, families must hire, train and supervise private HCWs who are paid by Medicaid. If during the initial assessment process, the applicant is found to be eligible for home care services, the MLTC must provide the individual with the option of choosing CDPAP.