

WHAT YOU NEED TO KNOW ABOUT LONG TERM CARE



Long Term Care Community Coalition

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WHAT IS LONG TERM CARE?

What happens as you get older?

Have you ever thought about the changes that will occur in your life as you grow older? If you are working, you will probably retire; you will probably spend more time with your family and friends. You may learn and enjoy new activities. However, you also need to think about the fact that as you grow older your body will also change. You may fall sick or you may no longer be able to do things on your own that you are doing today, you may not remember things, and you may even need help with walking, eating and bathing.

What is Long Term Care?

Long term care is not care that will cure you of an illness. It is care that continues over time for such things as:

- Help with activities such as cooking, laundry or housekeeping.
- Help with activities of daily living such as bathing or dressing.
- Help with an illness such as checking your blood-pressure or monitoring your diabetes as your illness continues.
- Helping you recover from your illness such as an operation.

Should you plan for Long Term Care?

Yes. Studies have shown that 70% of all people over the age of 65 will need long term care at some point in their life. So, it is very possible that you or your loved one may one day need such care. The possibility that you will need long term care only increases as you get older. You and your loved ones need to be ready so that you don't have to make a quick decision in times of an emergency. You need to plan now if you want to have some choice in where and how you get your care.

Start by answering these questions and check them off as you make some decisions:

- ☐ **What** are or might be your care needs?
- ☐ **Where** do you want to get your care?
- ☐ **How** do you want your care given?
- ☐ **How** can you pay for your care?
- ☐ **What** are your rights?
- ☐ **Which** care programs are available to you?

Read through all of the information before looking at the chart at the end to see all the information on the many different choices you may have. Take care to look at these issues together and as a whole.

Where you get your care may depend on your care needs and/or whether you have the money to pay or whether you will need help from the government. Some of the choices may not be available to you because they are open only to people who meet certain criteria. By doing this, by planning, you will be more in control of whatever happens.

ASK YOURSELF:

What Are Your Care Needs?

Do you need help with Support Activities? Check all you need help with.

- ☐ Housekeeping
- ☐ Laundry/Linen services
- ☐ Cooking
- ☐ Transportation
- ☐ Reminder and help to take daily medicines
- ☐ Activities / Meeting other people
- ☐ Shopping

Do you need help with your Personal Care or with your Activities of daily living? Check all you need help with.

- ☐ Bathing
- ☐ Dressing

- ☐ Walking
- ☐ Going to the bathroom
- ☐ Eating

Do you need Medical or Nursing Services? Check all you need help with.

- ☐ Therapy (physical, occupational, speech, respiratory)
- ☐ Recovery from an injury or illness
- ☐ IV drug therapy
- ☐ Tube feeding and tube care
- ☐ Wound care
- ☐ Blood sugar and Blood-pressure supervision
- ☐ Supervision of daily activities to keep you safe because you have become forgetful

Where Do You Want To Get Your Care?

Home?

You may want to stay at home because you are used to it, it is comfortable and you have the freedom to live as you want. Above all it is “your home.” However, if you do not have any family or friends to help you or if you are all alone, you may feel isolated and lonely.

Care at home can be provided through various programs (see “location” column on the chart below). Some services are provided outside the home to help you remain at home (see adult day care in the chart below.) Sometimes you can stay at home because informal caregivers like relatives and friends may be providing you with the care you need. However, caring for someone round the clock can be tiring physically as well as mentally. You may be able to continue getting care from your family or friends if they could get a little help. To help the caregivers cope with this situation, there are a number of programs (see the “Services to Meet Your Care Needs” column of the chart) that offer support to these caregivers, by providing temporary relief, such as Caregiver Support Services or Respite Care. These programs may also provide information about available services, assistance with obtaining services, provide support groups and may help with making decisions. This support can refresh your family and friends so that they can take better care of you.

Residential Community?

You may want to stay in a place with other people so you can have a number of different activities and chances to meet other people. By moving to a building that houses a number of people needing care (see the “Location” column in the chart), you may be able to have your privacy and independence. However, you may have to follow some community rules such as when to eat or when visitors can come to visit and you will have less freedom than you would at home. The residential community is different from a nursing home in a number of ways. It does not provide medical and nursing services and it places more importance on your privacy and autonomy.

Sometimes communities organize to develop more support for seniors and develop a Naturally Occurring Retirement Community (NORC). It is a community which is not built for the purpose of long term care. It is a community where people have lived all their lives and now have grown older. As they got older, they may have gotten more physically weak. Seniors have taken it upon themselves to bring in services to help them stay in their own apartments. The community can receive state funding if more than 50 percent of its households are headed by a person aged 60 and older or it has more than 2500 individuals aged 60 and older. There may be younger individuals living in the community as well - it is not restricted to seniors. If you want you might be able to move into a NORC or you can organize a NORC in your own community (see resources section to get more information).

Nursing Home?

You may want to receive your care in a nursing home as it has a skilled nursing staff that gives care and supervision on a 24-hour basis. It too offers activities and a chance to meet others. You can get all the care you may need under one roof. However, currently, many nursing homes are run in a way that may limit your freedom such as when to eat, when to bathe or whether you can go for a walk.

Once you decide where you want your care, look at the chart below for the different choices and look at the list of resources for more help.

How Do You Want Your Care Given?

You may want your care given at a program or place that focuses on the needs and desires of the Chinese community. Some agencies do in fact do this. For example, some programs have people who speak Cantonese, Mandarin and other Chinese dialects. Others understand Chinese diets and practices and family relationships. Some have special Chinese programs where only Chinese people give the care. When you think you are ready to choose a program, use the resources to help you find one that will meet these needs.

How Can You Pay for Your Care?

There are a number of ways that long term care services are paid for, depending upon the type of services needed and your financial resources. Services can be paid for through government programs or privately, either through funds available to you or private insurance. Following is a discussion of these different payment options. **Once you know how you will pay, look at the “Payment Options Accepted by the Program” column of the chart below for more information.**

Can you pay with your own money or do you have insurance?

- Private Pay:

This means that you pay for the services with your own money. One of the services (Expanded In-home Service for the Elderly Program) will allow you to pay on a sliding scale basis. This means that the more money you have, the higher the amount you will be asked to pay.

- Private Insurance:

You can also buy private long term care insurance to help you pay for these services. Long term care insurance is similar to other insurance such as car insurance, which may cover you for any car accidents. You pay a certain amount each month and if you need long term care, your insurance will cover some or all of the costs. If you are interested in long term care insurance, it is important that you look at the policies very carefully to find out what each covers and how much each pays out. Some are very expensive and may not cover the type of care you will want or need at the place you want. You may not have many insurance options if you are over 70 years, are retired or have any current illness. See the Resource section below for more help.

Do you need the Government to help pay for your care?

Long term care services can be very expensive. If you do not have the money to pay for such care, the government has a number of programs to help. Many people receive services this way. There is nothing wrong in turning to the government for help if you need it. That is why the government offers such help. In fact, if you need care and do not get it, you may get worse and end up costing the government even more.

- Medicaid:

Most of the public money spent on long term care is through Medicaid, which pays for a large portion of the services that people in New York need. However, since this program is only for people who cannot afford to pay with their own funds, you will need to fill out an application

form to find out if you qualify to receive Medicaid. See the Resource section for more help. It is important to know that Medicaid may limit your choice of where you want to get your care because some service programs may not accept Medicaid as payment.

- Medicare:

Although many people think that Medicare pays for most of long term care, it does not. Medicare, the federal health system for people over 65 years of age, is very limited in terms of its coverage for long term care. It may sometimes cover therapy and skilled nursing services for up to 100 days after a hospital stay of 3 or more days, paying for 20 days of a nursing home at full cost and a percentage of the full cost for another 80 days. Private Medicare supplemental insurance, if you have it, may add to this coverage.

However, Medicare will not pay for any help you need with support activities or help with activities of daily living unless it involves therapy that it approves.

- Supplemental Security Income (SSI):

SSI is another option if you cannot afford to pay with your private funds. SSI pays for a few of the services, but not all. It does not cover any medical expenses; it does cover some housing expenses in residential community places. However, providers are allowed to refuse to accept SSI and some will only accept those who can pay privately. You will need to contact each provider separately to find out if they accept SSI or not. Here too, to qualify for SSI, you need to fill out an application form.

Being eligible for Medicaid, Medicare or SSI does not guarantee that you will receive the services that you may want and need. Once you are found to be eligible for Medicaid, Medicare or SSI, you need to find out if the government will approve and pay for your services. **Look at the list of resources for more help.**

What are your rights?

Knowing your rights is another step to getting what you want and need. Sometimes you or your loved one may have to advocate for these rights to get what you need and want.

- You have the right to be treated with respect and dignity.
- You have a right to care and treatment without being treated unfairly.
- You have a right to privacy.
- You have a right to take a part in planning your care and you have the right to refuse any treatment or medication.
- You have a right to complain.
- Even if the government covers your long term care costs, you have the right to live and get services in a place that has the least restrictions according to your wishes. If you do not want to go to a nursing home, you do not have to. There are other choices, but some are limited. You may have to fight for them.

NOTE TO THE FAMILY: HELP IS AVAILABLE, JUST ASK FOR IT

You and other family members may be working or attending school and therefore may not have the time or even the necessary knowledge to take care of your loved ones. So, go ahead and ask for help, if you need it.

Remember--- even if you have outside help you can still be involved in your loved one's care. You can help them answer the questions above and help them make choices. The resources and contact information below will help you make the decision that is right for you and your loved one. (See resources section). And you can certainly keep an eye on the care they receive and help them make sure that their rights and wishes are honored.

Resources For More Help

Information on Available Services

1. Dial 311 on your phone. Ask for long term care. An operator is available 24 hours a day, 7 days a week. Ask for someone who can speak your language. 311 has begun an on-line directory of organizations that provide health services in New York City. Go to: www.nyc.gov/311.

2. Human Resources Administration – call – 1-877-472-8411 or go on the web to:
<http://www.ci.nyc.ny.us/html/hra/html/home/home.shtml>

3. Public Advocate's Office – call – 1-212-669-7250 or go on the web:
www.pubadvocate.nyc.gov/services/senior_services.html.

4. Asian American Federation – call – 1-212-344-5878 or go on the web: <http://www.aafny.org/>

Support for Caregivers

Find a caregiver resource center by going to the internet:
<http://www.nyc.gov/html/caregiver> or call 311.

Information on Finding a Program Focusing on Needs of the Chinese Community

1. FRIA – call 1-212-732-4455.

2. Dial 311.

Information on Long Term Care Insurance

New York State Department of Insurance – call - 1-800-342-3736 or 1-212-480-6400 or go on the web to -
<http://www.ins.state.ny.us/lntmcare.htm>.

Information on Medicaid

Human Resources Administration - call –1-718-557-1399 or toll free at 1-877-472-8411. Go to the web at:
http://www.health.state.ny.us/health_care/medicaid/

Information on Medicare

1. Social Security – call – 1-800-772-1213 or go to the web to: <http://www.medicare.gov/MedicareEligibility/home.asp?version=default&browser=IE%7C7%7CWinXP&language=English>

2. Medicare Rights Center – call – 1-212-869-3850 or go to the web: www.medicarerights.org

Information on SSI

Social Security Administration – call – 1-800-772-1213 or go to the web: <http://www.ssa.gov/ssi/text-eligibility-ussi.htm>

Information on NORCs

1. Call 311 or go to the web: <http://www.nyc.gov/html/dfta/html/about/about.shtml>. Click on the right: Select a Service.

2. NORC Blueprint - call at 1-212-494-0700 or go to the web: <http://www.norcblueprint.org/>

Getting General Help

1. Public Advocate's Office – call – 1-212-669-7250 or go on the web: www.pubadvocate.nyc.gov/services/senior_services.html

2. Call 311 and ask for help with case management.

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Programs	Average Cost Per Month (2007-8)*	Services to meet your care needs	Location	Eligibility	Payment options accepted by the program
Home Attendant Program	\$2058 (At \$19/hour for 5 hours a day for 5 days a week) \$1300-\$2000 (For care 7 days a week for 24 hours a day – the attendant must be provided with room and board.)	Housekeeping, cooking, bathing, care for your personal appearance, helping you to go to the bathroom.	Home	Your illness must be able to be cared for by a local doctor or hospital in your community. You must be willing and able to deal with and supervise the attendants who care for you.	Medicaid Private Pay Private Insurance
Long Term Home Health Care Program (Lombardi Program)	Only Medicaid covers	Delivers meals to your home, helps you move if necessary, helps with your diet, provides temporary relief to your family if they are taking care of you (respite care), provides transportation to social activities, helps in planning your treatment, provides therapy and rehabilitation, helps you with your medication and also provides nursing care.	Home	You must qualify for Medicaid and need the care of a nursing home. The program is trying to keep you out of the nursing home. Your care cannot cost more than 75% of what it would cost if you were in a nursing home.	Medicaid
Expanded In-home Service for the Elderly Program (EISEP)	\$1500	Housekeeping, temporary relief to your family if they are taking care of you (respite care), personal care and help with planning your treatment, delivers meals to your home and provides transportation if you need medical care or go out for social activities.	Home	You must be over 60 years of age to receive the services of this program. To qualify for this program, you cannot be on Medicaid.	Private pay on a sliding scale based on your income. At \$15/hour for 5 hours a day for 5 days a week: One person household with annual income below \$12,763-No fee; \$12,763 to \$25,525-you pay some amount; over \$25,525-you pay full amount.
Meals on Wheels	\$100 (2 meals a day for 5 days a week. Special arrangements for the weekends are required.)	Delivers meals to your home.	Home	You must be over 60 years of age and you must be unable to shop for or cook food due to your illness or a disability.	Private Pay No fee if you cannot afford to pay

Programs	Average Cost Per Month (2007-8)*	Services to meet your care needs	Location	Eligibility	Payment options accepted by the program
Supportive Senior Housing	\$1500 to \$2500	Housing, meals/dining program, housekeeping, transportation, activities, laundry/linen services and a person to help you get other services and programs from community based agencies.	Residential Community	You must be over 60 years of age.	Private Pay
Adult Home	\$1200 to \$3000	Housing (private or shared rooms), meals, housekeeping, laundry/linen services, transportation, social activities, help with your personal care and 24 hour supervision.	Residential Community Some may be in large buildings that look like an institution.	You should be able to move around on your own in the home and be able to move from a bed to a chair. You must be able to think clearly and be aware of where you are. You cannot be incontinent-that is you must be able to go to the bathroom on your own.	Private Pay Supplemental Security Income (SSI)
Enriched Housing	\$3500 to \$6500 (Depending on size of apartment)	Same as an adult home but more home-like location-an apartment setting.	Residential Community	You must be over 65 years of age.	Private Pay Supplemental Security Income (SSI)
Assisted Living Residence	\$3000 to \$6000**** (Depending on size of room or apartment) \$7000 to \$9000 (Help with memory)	Housing, personal care services like bathing, dressing, feeding, helping you take your medication, helping you go to the bathroom and to walk, housekeeping and activities. Medical and nursing services may not be included.***	Residential Community	You cannot need 24 hour skilled nursing care.	Private Pay Supplemental Security Income (SSI)**
Adult Day Care Social Model	\$1500 to \$2000 (\$90 per day for 5 days a week)	Provides services only during the day. Social activities and meals.	Residential Community	You should be able to live alone during the night without needing anybody's help or supervision.	Private Pay Private Insurance
Adult Day Care Medical Model	\$2000 to \$3400 (\$100 to \$170 per day for 5 days a week)	Provides services only during the day. Social activities, meals and medical services like therapy, rehabilitation, nursing services, dental services through an on-site nurse and doctor.	Residential Community	You should be able to live alone during the night without needing anybody's help or supervision.	Medicaid Private Pay Private Insurance

Programs	Average Cost Per Month (2007-8)*	Services to meet your care needs	Location	Eligibility	Payment options accepted by the program
Consumer Directed Personal Assistance Program (CDPAP)	\$1500 to \$2000 (\$15 to \$20 per hour for 5 hours a day for 5 days a week)	Housekeeping, cooking, bathing, help you with going to the bathroom, help with your personal appearance and skilled nursing services.	Home	You or someone you choose, must be able and willing to look for and hire the people who will care for you, be able to deal with them and supervise them. You should be able and willing to arrange for someone else to care for you if the person who usually comes is unable to come, as well as maintain their payroll records.	Medicaid
Assisted Living Program (ALP)	\$3000 to \$5000	At this time ALP programs are offered only in adult homes or enriched housing programs. They offer: meals, housekeeping, laundry, shopping, transportation, social activities, speech therapy, occupational therapy, physical therapy, assistance with planning your care by nurses and aides and bathing, helping to take you to the bathroom and helping you with your personal appearance.	Residential Community	You must need services that a nursing home gives, but can be safely taken care of in the adult home or enriched housing program. You must be able to move around the home on your own.	Private Pay Medicaid Supplemental Security Income (SSI)
Skilled Nursing Facility	\$10,000 (semi-private room)	A nursing home offers all the care you need 24 hours a day. Also offers short term rehabilitation and specialty care for individuals with physical and neurological disabilities. Nurses are on duty 24 hours a day.	Institution	You must need 24 hours of skilled nursing care. This can include all of the services offered in the other programs as well as specialty care such as head injuries, ventilator care or Alzheimer's Disease.	Medicaid Medicare (limited) Private Insurance Private Pay

*The numbers are for private pay only. For 2010, these costs will go up. Please check the latest costs. These numbers give you a good idea of the costs of the different programs.

**A number of programs will only accept private pay. Please ask if they accept SSI.

***A number of programs are not applying for a license to operate an assisted living residence. Make sure that the residence you choose is licensed.

****Certain residences may charge more depending on the size of the room or apartment.

PLEASE NOTE THAT THE INFORMATION ON THIS CHART IS SUBJECT TO CHANGE.

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