

How to Choose a Nursing Home in the State of Illinois

A Step By Step Guide

ILLINOIS CITIZENS FOR BETTER CARE is the Illinois nursing home residents' advocacy and service organization. Since 1978, ICBC has worked to improve the care and quality of the life of Illinois nursing home residents.

ICBC's primary focus is helping individual residents, families and resident and family councils. Every year we help hundreds of families choose a nursing home, shorten nursing home stays or avoid nursing home placement altogether by helping them find alternative care, improve poor or abusive nursing home care, and cope with Medicaid and Medicare. We charge nothing for any of our services, and get no government grants to support our work.

Making the decision to move a loved one in a nursing home is a daunting task. We understand that this can be overwhelming. You are choosing a place to be someone's new home, at least for a short while, and maybe for the rest of her life. You want to find a nursing home that meets her needs.

We hope the following guide will walk you through each step, making this process easier for you and your family.

PART 1: NARROWING DOWN YOUR CHOICES

Step 1: Are you really looking for a nursing home?

Depending on what your family member needs, you may really be looking for a nursing home, or you may actually be more satisfied with a different kind of long-term care.

If you are looking for intensive daily therapy for somebody who is in the hospital, you almost certainly are looking for a nursing home. But if the doctor says "she needs to be in a nursing home," you need to understand why she is saying that. "Needing a nursing home" is not a medical diagnosis, it is a judgment that a person needs and wants care and services that cannot be provided at home. A person who needs just occasional medical help, and mostly needs help with everyday living tasks (cooking food, eating, doing laundry,) mental stimulation and companionship, or just somebody to check on them make sure they are doing well, may have other, preferable, choices.

Some services will allow people to remain in their own homes, while getting the care and support they need. These include:

- Home health care
- Outpatient physical and other therapies
- Chore and housekeeping services
- Home-delivered meals
- Adult day care
- Friendly visitor programs
- Telephone reassurance
- Emergency call and support
- Hospice

The Illinois Department of Public Health has helpful descriptions of these services on its website: http://www.idph.state.il.us/webapp/LTCApp/ltc.jsp

Illinois will pay for some of these services for eligible persons. Unfortunately, the state's financial situation is so bad that it almost certainly will be paying for much less care for many fewer people beginning in the summer of 2012.

If you are interested in finding services that will help somebody stay at home, you can call the Illinois Department on Aging: 1-800-252-8966.

People who cannot stay in their current home, may want to consider other residential settings besides a nursing home. For example, Illinois licenses "assisted living" facilities. These typically are a small studio or one-bedroom apartment with a kitchen, although most residents eat most meals in a common dining room. Services include meals, laundry, and housekeeping, as well as help with such personal care as dressing and bathing, and some scheduled activities. Assisted living facilities do not provide nursing care, but there will be home health care agency staff available part-time to provide some help with medication and possibly other health care services. Some assisted living facilities have special Alzheimer's care units.

Assisted living facilities are built to look less "institutional" and "medical" than nursing homes. The state has some requirements, but each assisted living facility has its own standards for when a resident becomes too sick or disabled to stay. While nursing homes are required to meet minimum staffing standards, Illinois does not have minimum staffing requirements for assisted living. Assisted living tends to cost as much or more than nursing home care.

You can find a list of licensed assisted living facilities in Illinois at https://data.illinois.gov/Public-Health/IDPH-Assisted-Living-and-Shared-Housing-Licensed-E/992y-d4p5?

Illinois also has "supportive living" facilities. Supportive living is basically the same as assisted living, except that it is not regulated by the Department of Public Health. While the state does not pay for assisted living, it does pay for supportive living for people who would otherwise qualify for nursing home care. Supportive living is usually less expensive than assisted living.

You can find a list of supportive living facilities in Illinois at http://www.slfillinois.com/operational.html

Step 2: Consider your needs and preferences

There are more than 700 nursing homes in Illinois. There are more than 300 in Cook County. Only some are in the Medicare or Medicaid programs. Only some accept new residents on Medicaid. Some house only people with a serious mental illness. Most accept new residents with Alzheimer's disease, but only some have separate Alzheimer's units. Some have a particular religious or ethnic affiliation.

You aren't interested in all nursing homes, and couldn't visit or learn about all of them even if you were. So the first thing you need to do is narrow down your choices.

- Think about what are your financial requirements. Do you need a home that is covered by Medicare, Medicaid or a particular private insurance plan?
- Where should the home be located? Do you prefer a particular city or county?
 In deciding this, you should consider not just where your loved one lives now, but how close the nursing home should be to the people who are most likely to visit and to be responsible for making decisions about her care.
- What type of care are you looking for? Are you looking for a facility that does intensive physical rehabilitation? That does dialysis? Are you looking for a longterm placement for a person with Alzheimer's disease? For somebody with a chronic mental illness?
- Does the doctor have recommendations? Are these recommendations based on personal observations about the quality of care in a particular home? Is the doctor willing to keep treating the person if she goes to a particular nursing home?
- Are there language issues? It is very difficult for a person to live in a nursing home without any staff with whom they can speak. If this cannot be avoided, the home will have to be able to make accommodations that do not make your loved one feel isolated.

Step 3: Make a list of what are your minimum requirements, and what other things you would like to see in the nursing home you choose.

Your list should include, first, the absolute minimum requirements. A person on Medicare who is leaving the hospital for intensive daily therapy after a stroke, is going to need a nursing home with available beds in its Medicare unit. For that person, the Medicare unit should specialize in, or at least do a great deal of work with, people who need rehabilitation. (Medicare units may also care for people who need intensive nursing care because, for example, they are on oxygen, or need dressings changed after surgery.)

Medicare will pay for no more than part or all of 100 days of skilled nursing home care. Few people have private long-term-care insurance to pay for more than that. People without substantial financial resources will need a nursing home that will allow them to switch to Medicaid to pay for their care once their Medicare and any private savings have run out (Alternatively, they may want to get Medicare rehab services in one nursing home, and then move to another after Medicare runs out.)

Someone who needs in-patient dialysis, will need one of the few nursing homes in Illinois capable of doing this.

Someone with a strong religious background may find any home that does not have appropriate religious services, and cannot otherwise accommodate her religious beliefs, unacceptable. Or, if the nursing home stay is just for short-term rehabilitation, religious services may be less important.

Someone with a beloved pet may be devastated by being separated from her friend. She may need a home that will accommodate animal visits, either in the resident's room or in a common living area.

A person who is social may need to be around other residents who are her intellectual equal.

In addition to these minimum requirements, consider what other aspects of daily living would make your loved one's life better. You may want to be within easy travelling distance of particular relatives or friends. You may want a home with a garden or other accessible green outdoors. There may be a preference for vegetarian meals.

PART 2: FINDING NURSING HOMES THAT MEET YOUR NEEDS

Step 4: Starting your internet research

Once you have decided what you are looking for in a nursing home, it is time to create a list of possible choices. To do this, you will need a computer with internet access.

The federal government has a **Nursing Home Compare** website that gives you information about every nursing home in the Medicare and Medicaid programs.

To get to the website, go to

http://www.medicare.gov/NursingHomeCompare/search.aspx?bhcp=1

You can do a Google (or other internet) search for "Nursing Home Compare" to get to the Medicare website.

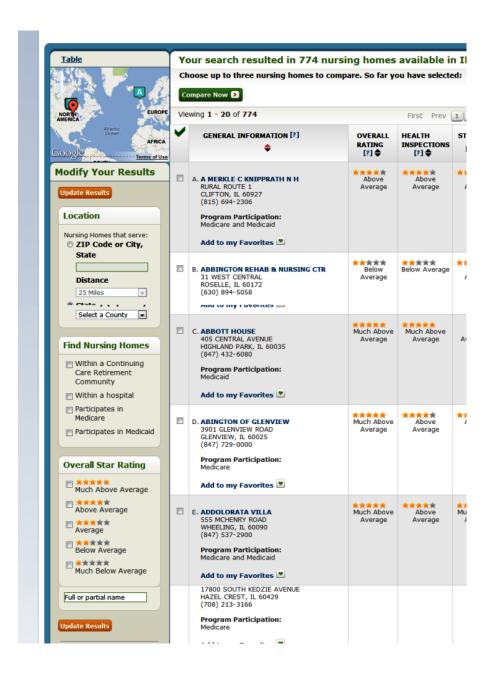
The Medicare website looks like this.



3HomeCompare/search.aspx?bhcp=1

You should start your search for a nursing home by writing in the city and state you are interested in. (Choosing a zip code does not seem to give complete answers.) After clicking on "Show Nursing Homes," you will see a list of nursing homes in the city you chose and nearby.

Unless you are absolutely certain of the spelling, do not write in the name of a particular nursing home. Instead, look for it in the list of nursing homes in the city you choose.



The left side of the new page lets you "Modify Your Results." If you are looking for a nursing home in Chicago, go to the choice "Distance." The Medicare website automatically sets the "distance" at 10 miles from downtown Chicago. Because Chicago is so big, if you want all Chicago nursing homes, you must change the "Distance" by clicking on the arrow next to "10 Miles," and changing it to "25 Miles." 10 miles is the distance the website automatically uses for **all** searches. You can change the "distance" to get more or fewer nursing homes, if your first search is unsatisfactory.

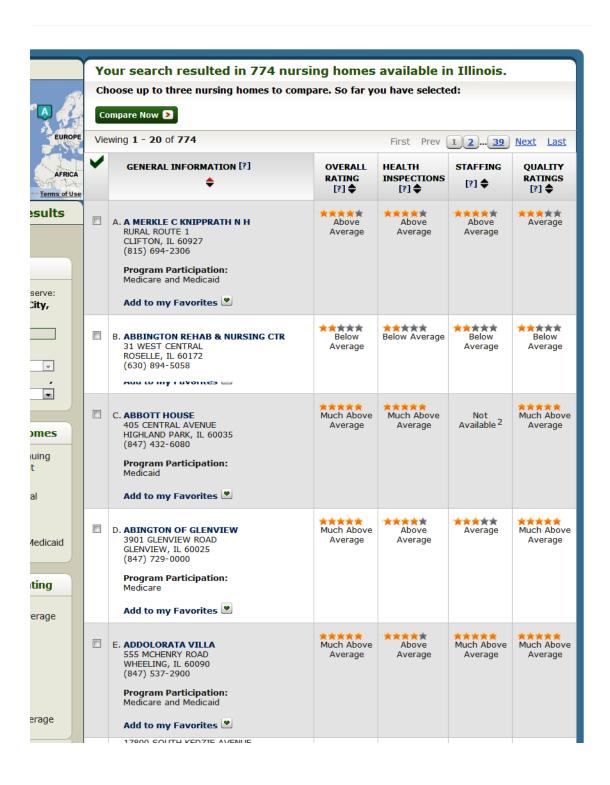
If there are more than 20 nursing homes in the area you choose, you will only see the 20 nearest. Sometimes the page will let you click on "Next" at the top or bottom of the list to see more homes; other times you will have to click on "View Table" (this is on top of the map) to be able to see more homes.

If you live in an area with only a few nursing homes, the easiest way to find all of them is to click on the \circ next to "State" and choose Illinois. Right below that, you can click on the \circ next to "County," to see all the nursing homes in any county in the state.

You can also use "Modify Results" to find only nursing homes that are in the Medicaid or Medicare programs, or have a rating of 3 or more stars. (More about this below.)

If you have changed your search with "Modify Results," click on "Update Results" to get a new list.

Depending on your search criteria, the results of your search may be dozens of nursing homes, or just one. Here is what the result of your search will look like.



You will see that every nursing home has columns with a set of stars next to it. The columns, in order, are an "overall" rating, and then ratings for "health inspections," "staffing," and "quality."

The "**Overall Rating**" is a combination of the other three ratings. The number of stars shows how the home rates compared to other Illinois nursing homes.

"Health Inspections" are a summary of inspections done by state nursing home inspectors over the past three years. The number of stars shows how the home rates compared to other Illinois nursing homes.

"Nursing Home Staffing" rates the amount of time registered nurses are available to care for each resident. The number of stars shows how the home rates compared to the staffing recommended by the federal government.

"Quality Measures" are statistics reported by the nursing home. The number of stars shows how the home rates compared to other Illinois nursing homes.

A nursing home can get up to five stars in each category. More is better. The fewest in each category is one. **There are no zero star nursing homes.**

A few nursing homes with especially bad violation histories show this symbol 4 after the name. Be very, very careful about choosing such a nursing home.

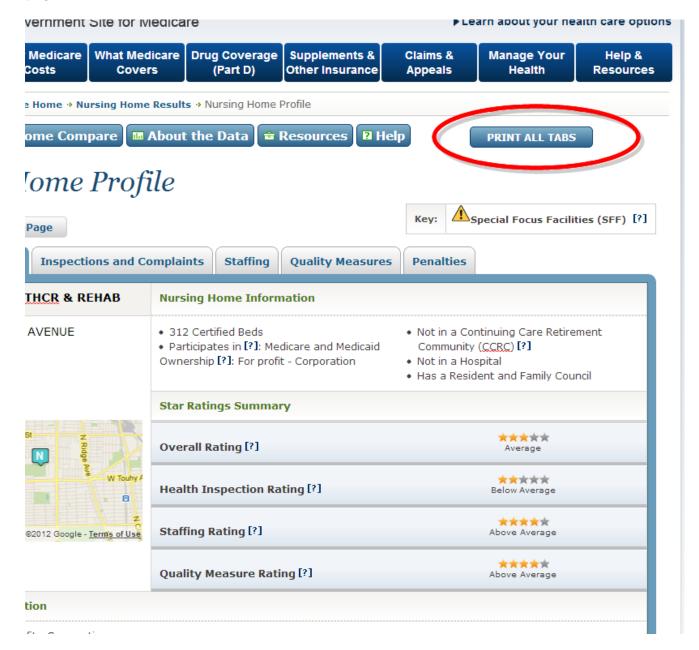
You can choose up to three nursing homes at a time to learn more about. You should consider the number of stars for each category except "quality measures" in deciding which homes to learn more about. ("Quality measures" sound important, but the information is not reliable.) You can go back to your search page to choose more homes afterward.

Click up to three boxes next to the homes you want to learn more about, and then click on CCCCompare Nowwww

If you are collecting information about nursing homes from this website, you may want to keep it all together. To do this, you can click on "Add to my Favorites" below the nursing home name, or once you get to the set of information about the individual home. This will open a page to set up a free "account" where you can save information. You will need to know your Medicare number, and be willing to use it, in order to save the information just by clicking on it.

If you don't want to set up the free account, you will need to either copy the information to a different computer program, or write down or print information about homes you may be interested in. So, if necessary, get a pen and paper before you go any further.

Once you have picked a nursing home to learn more about, you will see something like this.



Click on "Print All Tabs" to see all the information about the nursing home. (Click on this even if you are not going to print anything.) (If your screen shows separate tabs for "Inspections and Complaints," "Staffing," and so forth, you can look at each one separately.)

Step 5: Understanding the details

The first part of this page is the same rating information you have already seen.

Additional information you will see includes

- 1. Participation: Does the nursing home take both Medicare or Medicaid, or just one?
- 2. Number of certified beds: how many beds are in the Medicare and Medicaid programs.
- 3. Is the nursing home part of a continuing care community? This usually means there is an entrance fee in addition to a monthly payment, and that there are independent apartments, and sometimes assisted living, as well as the nursing home.
- 4. Is the nursing home part of a hospital? If yes, the person will be admitted only for short-term rehabilitation and therapy.
- 5. Does the nursing home have a resident and family council. All nursing homes are required to have a resident council. A family council is an organized, self led, democratic group of family and friends of nursing home residents. Unfortunately, many nursing homes that say on this website that they have a family council, do not. Visit the ICBC website (illinoiscares.org) to learn more about family councils and how you can start one.
- 6. Ownership: Is the home for-profit or not-for-profit? Not-for-profit homes tend to have more staff and fewer violations.
- 7. "Penalties and Denials of Payment Against the Nursing Home." This means the amount of fines the home has been told to pay because of poor care (in the past 3 years,) and the number of times the home was told it would get no Medicare or Medicaid money for new residents because of poor care. These are unusual penalties, and reflect especially bad violations.
- 8. "Complaints and Incidents." This data is misleading. It really means the number of investigations about complaints and incidents (a problem reported by nursing home staff.) Because the state often investigates multiple complaints during one visit, the number of complaints is often much larger than shown on this website.

Step 6: More about the star rating system

Of course, the overall rating is important. Knowing how the rating was decided is at least as important.

Here are the things we think are the important parts of the overall rating:

1. **Health Inspections**. When you click on "Health Inspections," you will be able to see a summary of up to three years of inspections. The most recent inspections are listed first. You will be able to see both how many violations (the website calls them "deficiencies") a home had during each inspection, how serious the violation was and what kind of violation it was (a nursing violation, for example, or something about sanitation.)

If you want to know more about what actually happened, you can click on "View Full Report" next to the date of the inspection you are interested in. Reading the survey reports is the only way to know why the nursing home was actually cited for a particular violation. You can decide for yourself how serious the violation was, and if it matters to you. We find that many people think many violations are more serious than the government does.

Nursing home inspectors are required to visit each nursing home only once a year, or in response to a complaint. When they do visit, they do not spend time with every resident, or check every resident's records. This means the health inspections may reflect the quality of the home, but they are not a complete picture of what is going in the home.

Because the process is the same for all nursing homes, it is fair to assume that a home with many violations really does, on the whole, provide worse care to its residents than does a home with few or no violations. (The exception to this is homes that house many people with a serious mental illness (not Alzheimer's or another dementia.) The evaluation system was not designed to measure the quality of care in these homes.)

A nursing home with an average number of violations for Illinois will have three stars. You need to decide if you are willing to consider nursing homes that are average or below average, or only homes that are above average.

2. **Staffing**. Homes with more registered nurses tend to have better care and fewer violations. By looking at "staffing," you can see how the staffing for a particular nursing home compares to the staffing for the state and the entire country. You can see the registered nurse (RN) staffing time, the other licensed nurse staffing time

(LPN,) and the staff time for the certified nursing assistants (CNA's) who do most of the direct resident care.

Stars for staffing are based on registered nurse staffing. Unlike the other star ratings, which show how the home compares to others in Illinois, stars for staffing are based on how close the home's staffing comes to the federally-suggested minimum nurse staffing. Very few nursing homes in Illinois meet the federal standard. You need to decide if you are willing to consider nursing homes that are below, or far below the federal standard.

3, The overall rating is also based on "quality measures." Quality measures are information the nursing home reports about itself, that is supposed to give you some idea about how well the home is taking care of its residents. Because the information is self-reported, and nobody checks to see if it is accurate, you should not rely on the star ratings for "quality measures."

There are some quality measures that you may find helpful because, **if they are accurate**, they are a good indication of how the home is dealing with issues that often hurt residents. So you may want to look at the number of short-term and long-term residents who develop pressure sores, and how these numbers compare to average numbers for Illinois.

Because so many nursing homes allow or encourage the over-medication of their memory-impaired residents with anti-psychotic medication, knowing what percentage of the residents are on these medications is an important measure of quality. You cannot learn this from the Medicare website. You can find it out by going to the database created by the Boston Globe from federal data, and looking up each nursing home you are interested in.

http://www.bostonglobe.com/lifestyle/healthwellness/2012/04/28/database/j8FWvjNHMaP6uo7hQ0mrHO/story.html?p1=News_link s

You may have to pay \$.99 to get access to the database. You can also call ICBC to get this information.

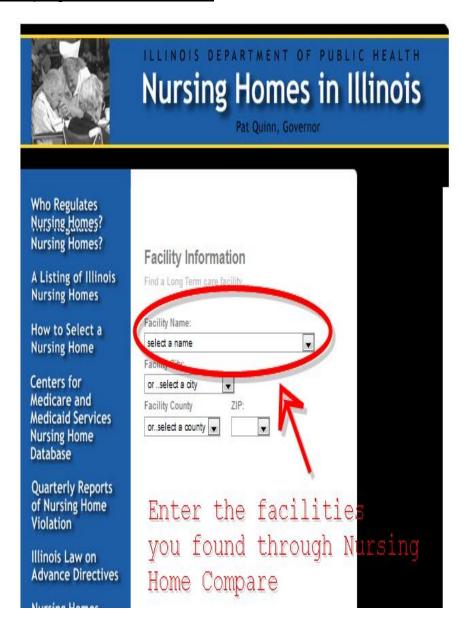
Step 7: Learn more specifics about nursing homes you may be interested in

Once you have your initial list from the Nursing Home Compare website, you can use that list to do some other research on-line.

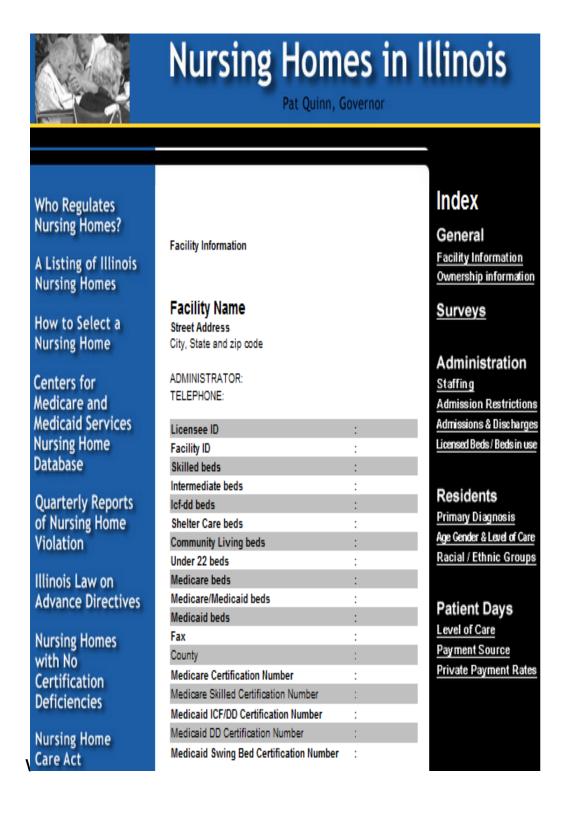
The <u>Illinois Department of Public Health</u> has some basic information about every licensed nursing home in Illinois at its website.

http://www.idph.state.il.us/webapp/LTCApp/ltc.jsp

The Public Health website lets you look up only one nursing home at a time. You cannot save information on the website, so you have to either copy it to another computer program, or write it down.



This is sample page about a nursing home



By clicking on the right-hand column you can see who owns the nursing home, and what other nursing homes they own. You can click on the name of each home to learn more about it, including some information about violations.

You can also find some basic information about the residents, including their primary diagnosis and age. This information will be outdated, but usually gives you a general idea of who is living in the nursing home. Because there have been so many problems with nursing homes that house both residents with a serious mental illness, and residents who have physical illnesses or Alzheimer's disease, you will want to be alerted if a facility you are interested in houses all kinds of residents. You may not want to cross it off your list, but you should be vigilant in making sure that your loved one will be protected and receive good care.

Step 8: Learning more about violations

The right-hand column for each nursing home has a section for "Surveys." Surveys are inspections done by the state. They are the same as the "health inspections" on the Medicare Nursing Home Compare website. The difference between the Medicare website and the Illinois Public Health website is that each may have some inspection reports that are not on the other.

When you click on surveys, you will see a list of dates, and the kind of inspection done on each date. Most of the dates are printed in grey. This means that the report is not available on-line. You can get it only be asking for it from Public Health, or by reading it when you visit the nursing home. Reports that can be read on-line are printed in **bright blue**. What we said about "health inspections" earlier is still true here: reading the survey reports is the only way to know why the nursing home was actually cited for a particular violation. You can decide for yourself how serious the violation was, and if it matters to you. We find that many people think many violations are more serious than the government does.

When you click on "Surveys" for a few different nursing homes, you will probably also see that some of them have only one or two surveys each year. This means that there were few or no violations, and almost no complaints. Others will have dozens of surveys listed; sometimes there will even be several in one month. While some complaints may not be true, you should be concerned about any nursing home with many complaints and many recent surveys.

Step 8: Even more information: What the nursing home reports about itself

The Illinois Department on Aging requires nursing homes to file a Consumer Choice Information Questionnaire every year. You can see what each home reports about itself in the Consumer Choice Information Reports database.

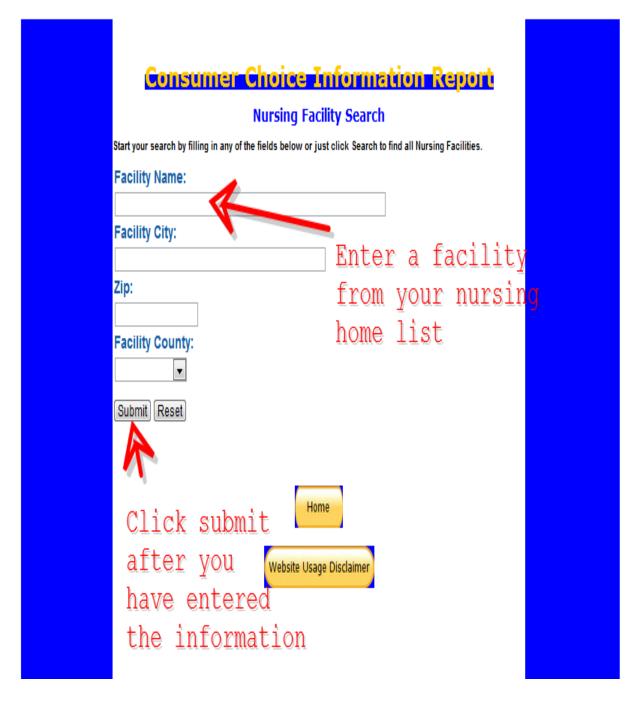
We will walk you through how to use the database. Use your nursing home list to see which homes you want to learn more about.

The Department on Aging website is http://www.aging.state.il.us/ccir/1welcomeintro.htm



When you click on "Search for Nursing Facility," you will see this:





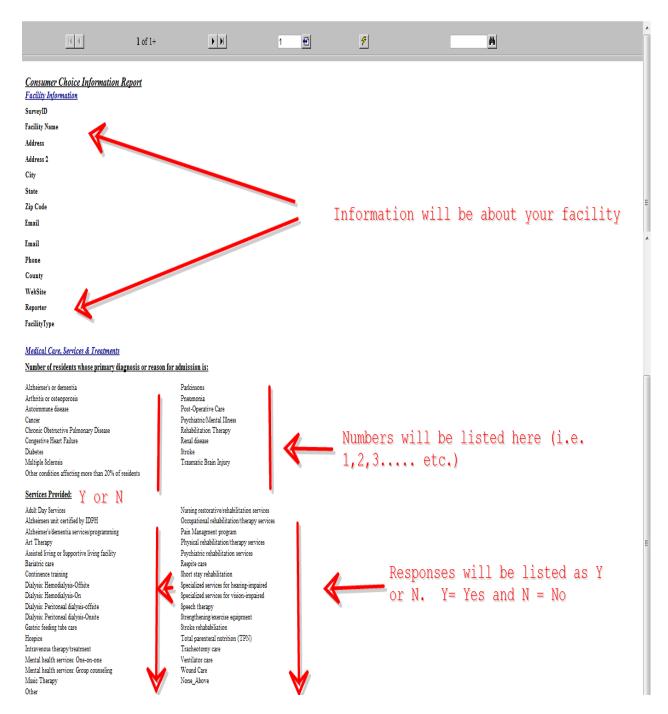
Enter the name of a nursing home on your list. Again, you can get information about only one nursing home at a time. When you click on the name you asked for, you will see the report.

Webpage Screenshot





Here is a sample page of the report. A report has 8 pages. You get to the next page by clicking on the arrow at the top.



If the report is accurate, you will be able to see reasonably current information about the nursing home, including about residents and their diagnoses,, what kinds of services the

nursing home provides, what languages are spoken, how long the staff has been there, and some information about major violations, lawsuits, and criminal prosecutions.

Step 9: And even more online information

There are private websites that offer to recommend nursing homes, based on information you give them about your loved one. Many say that they provide information without any charge. What they mean is that they provide information without charging **you**. In general, they make their money by charging a nursing home for a listing or recommendation. Sometimes they are paid by the nursing home if a person visits or chooses the facility. Be extremely cautious when using such websites.

It may be helpful, however, to try Googling the nursing home name. See if there are newspaper articles or even personal blogs that tell you something you would want to know.

Finally, if you want personalized help in making this decision, and can afford to pay somebody to do it, you can hire a geriatric care manager who is familiar with nursing homes in the area to help you in your search. A good care manager should also be able to help you advocate for your loved one once she enters the home. You can begin to find a geriatric care manager at http://www.caremanager.org/

Step 10: Call ICBC

We have a lot of information that is not online. We can help you understand information that is online. Call 312-663-5120.

Step 11: Make appointments to visit nursing homes you are interested in

It sounds like a great idea to visit a nursing home without warning the staff that you are coming, in order to see how the home actually works when they are not putting on their best face for a prospective new customer. But the first time you visit, you need to be escorted by somebody who knows who the staff are and where everything is. You can't tell how well-equipped the therapy room is, if you can't find it. You can't watch meal time if you can't find the dining room. You can't learn the answers to questions such as whether your loved one's financial resources are enough to get her into a particular nursing home, unless you can meet with the admissions coordinator.

So call the nursing home to make an appointment for a tour. And when you do, confirm any information that is crucial to making a decision, so that you aren't wasting your time. If you need to find a nursing home for rehab in the next two days, a home without available Medicare rehab beds is of no use to you, however good it might look from your research. A home that did dialysis until last month, won't help somebody who needs it next week.

If at all possible, you should not visit alone. Two people visiting means two brains, two sets of eyes, one person to ask a question that the other one forgets. **So try to go with somebody you trust.** Make appointments to visit that are possible for both of you. And try to schedule a visit to coincide with a facility meal time, so you can see what the food is like, what the environment is like, and if the residents are encouraged and helped to eat.

Step 12: Visit the nursing homes on your list

The information you have about the facilities are only a snap shot of the real picture. To get a better sense of what the nursing home is really like, you have to visit. This is your chance to talk to staff, observe the environment, and talk to other family members and to residents.

We have given you a checklist which we suggest you use when you visit. Fill it out while you are touring, or immediately afterward, before you forget what you have seen, or confuse it with the next place you visit.

When you visit a home, try to get there at least half an hour before your scheduled visit. Ask the receptionist to see the Public Health survey reports for at least the past couple of years. (Every Illinois nursing home is required to keep at least the last 5 years of its surveys available to any member of the public who wants to see them.) The thicker the stack of paper you are given, the more concerned you should be. Read as much as you can, starting with the newest survey. Take notes. When you meet the admissions coordinator, be prepared to ask about anything you have read that concerns you. Someone at the nursing home -- maybe the Director of Nursing, maybe the administrator, maybe the social worker -- should be able to tell you what the nursing home has done to fix serious problems and make sure they will not happen again. What they tell you should make sense to you: it should not just be jargon or gobbledygook. You want to know that the nursing home staff are acting responsibly to make sure that serious violations will not happen again.

While you are waiting for your tour, you should also write down the information in the lobby about the nursing home staffing. There should be a notebook or folder with the

number of residents, and of registered and licensed nurses and certified nursing assistants on duty on each shift. You will be able to use this information to compare staffing in different homes.

If you are interested in a particular home, if at all possible go back again. This time you don't need to announce your visit ahead of time. Visit on an evening or weekend, when most nursing homes are less well-staffed. You want to see the place at its worst, not just its best. This doesn't mean you won't choose that home, but you need to know that if there isn't enough staff to help residents eat on Sunday, you will need to make sure that family or friends are there to help your loved one eat. If there are no activities that your loved one would participate in on weekends, she is going to need visitors even more.

When you return, sign in to visit a resident you met on your first visit. Bring that resident something she wants. Then watch what is going on when you are just another visitor, and nobody special.

Step 13: Try Not to Make the Decision Alone

We hope you have some help in choosing the nursing home. Even if other people couldn't visit with you, it may help you to talk over the decision as you make it with people who understand your concerns. If at all possible, this should include the person who will actually be moving into the nursing home.

Step 14: Make the Decision

This is the hardest step. The background work you have done will make the decision easier, but not easy.

No place is perfect. You are not likely to find a place that meets all your needs and wishes. You do the best you can. Nobody should expect more than that from you, including yourself.

If you would like to learn more about nursing homes in Illinois or ICBC, including what to do to make it likely that a person will get better nursing home care in a facility, please feel free to contact us. We are **Illinois Citizens for Better Care**, 401 S. LaSalle St., Suite 1400, Chicago, IL 60605

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Phone: (312) 663-5120